## Contents

Preface ................................................................................................................................. 3  
Introduction .......................................................................................................................... 4  
Rule 1: Accountability ............................................................................................................. 5  
Rule 2: Scope of practice of the profession ............................................................................ 10  
Rule 3: Non-judgemental practice ......................................................................................... 15  
Rule 4: Relationships with patients ...................................................................................... 23  
Rule 5: Decision-making and consent .................................................................................. 28  
Rule 6: Duty to maintain records ......................................................................................... 41  
Rule 7: Confidentiality .......................................................................................................... 46  
Rule 8: Duty to report ........................................................................................................... 59  
Duty 9: Relationships with professional staff and others ...................................................... 65  
Rule 10: Personal and professional standards ....................................................................... 68  
Rule 11: Advertising and financial dealings ....................................................................... 71  
Rule 12: Research ................................................................................................................. 73  

APPENDIX 1  
Principles and values of professional practice .................................................................... 80  

APPENDIX 2  
The Declaration of Geneva ................................................................................................. 81  

APPENDIX 3  
The NHS Constitution: Core Principles ............................................................................. 82  

APPENDIX 4  
Case Law ............................................................................................................................. 83  

APPENDIX 5  
Relevant Statutes .................................................................................................................. 99  

References & Bibliography .................................................................................................. 115
Version History

<table>
<thead>
<tr>
<th>Version</th>
<th>Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

Copyright Statement

Copyright © British and Irish Orthoptic Society 2012. All rights reserved. Unauthorized reproduction in part or in whole and in any form or any medium is strictly forbidden.

If you wish to reproduce any part of this document, contact BIOS on +44 (0)1353 66 55 41.
The British and Irish Orthoptic Society’s Rules of Professional Conduct and Code of Ethics (hereinafter referred to as “the Rules”) are produced by the British and Irish Orthoptic Society (hereinafter referred to as “the Society” for and on behalf of its members. It will be reviewed every five years to assist members of the profession in keeping abreast of changes in legislation and health care policy.

For the UK, the Health Act 1999 bestows the status of profession on Orthoptics and automatically carries the statutory requirement to regulate professional practice for the protection of patients accessing the service. The equivalent is the Health and Social Care Professionals Act 2005 for Orthoptics in the Republic of Ireland.

The title “Orthoptist” is protected by law and can be only used by persons who have successfully completed a course leading to a diploma (DBO) or degree in Orthoptics [BSc (Hons) Orthoptics or BMedSci (Orthoptics) (Hons)] or an equivalent qualification and who are eligible for and hold Health Professions Council registration. A registered Orthoptist holds the status of a professional.

The professional environment is dynamic and practice is driven by evolving policy within all five member countries and the development of evidence-based practice and research.

The Rules have been written in accordance with policy, statute, case law and should be used in conjunction with the Health Professions Council’s current Standards of Conduct, Performance and Ethics and Health and Social Care Professionals Council’s Framework for a Common Code of Professional Conduct and Ethics.

Helen Orton
University of Liverpool

This document has been revised by Helen Orton, experienced lecturer in orthoptics, with a special interest in the ethics of healthcare. The British and Irish Orthoptic Society would like to thank Helen for her work.
Introduction

Rules of professional conduct: ethical, moral, legal and professional considerations for Orthoptists

The Rules sets out for members and student members of the British and Irish Orthoptic Society the relevant ethical, moral, legal and professional considerations that underpin the reasoning of the Rules of Professional Conduct.

The purpose of the Rules is to provide a set of principles that apply to all Orthoptists working in a variety of settings. It is a public statement of the values and principles used in promoting, maintaining and disseminating the highest standards of behaviour expected of Orthoptists and Orthoptists under training as members of the health care profession. Consequently, the good standing and reputation of Orthoptic professionals working within their defined scope of practice will be enhanced.

The Rules are contextualised by the underpinning principles of professionalism, professional responsibility (as summarised in Appendix 1) and accountability.

Any action that is in breach of the purpose and intent of these Rules shall be considered unethical and could result in a formal complaint and a finding of serious professional misconduct.
Rule 1: Accountability

Registered Orthoptists shall be held accountable for their actions to ensure that the public and patients are not harmed by their acts and omissions, and must provide redress for those who have been harmed. They shall ensure that they have appropriate professional liability cover for their practice.

1.1 Purpose of accountability

Orthoptists must recognise accountability as a formal obligation to answer for their actions to a range of higher authorities with whom they have a legal relationship that permits them to demand justification for their actions.

1.2 Society

Orthoptists working in the UK and the Republic of Ireland are subject to the same laws as any other members of society and will be held to account. Orthoptists are not exempt from these laws and if an individual is suspected of committing a crime, they will be called to account for their actions. Within the context of the profession, Orthoptists should be aware of these Acts of Parliament.

1.3 Employer

Contracts

Orthoptists employed by the NHS (England, Scotland and Wales), the Health and Social Care Services in Northern Ireland and the Health Service Executive (HSE) in the Republic of Ireland or other organisations are accountable to their employer through their contract of employment. Typically, contracts are written with reference to expressed terms (hours of work, salary and holiday entitlement) but there exists an implied contract which includes an acceptance from the employee (orthoptist) to employer (NHS Trust) that duties will be performed with due care and diligence.

Insurance

Orthoptists’ employers are vicariously liable for the action of its employees. Thus in the event of an orthoptist committing a civil wrong in the course of their employment, it is the employer who is liable to pay any compensation. However, the level and extent of that vicarious liability should be established at the commencement of employment. Orthoptists should realise that their employer may wish to minimise the likelihood of that liability arising and are entitled under contract law to hold the orthoptist to account through reasonable disciplinary procedures. In addition to being accountable to their employer through reasonable disciplinary procedure, orthoptists owe a duty of contract with their employers. A breach of this duty allows an

action for damages in breach of contract and, in the event of an employing Trust paying compensation they may seek to reclaim that compensation by suing the employee for breach of their contractual duty of care.

The British and Irish Orthoptic Society, through its annual subscriptions, provides its members with professional and clinical negligence insurance and public and product liability insurance. Orthoptists working in private practice can be sued directly.

1.4 Profession

Within the UK, registered orthoptists are accountable to the profession through the provision of the Health Professions Order (2001)\(^2\). The Health Professions Council (HPC) exists to protect the public by establishing standards of education, training and conduct and performance for orthoptists to ensure that these standards are maintained. Registered orthoptists practising in the Republic of Ireland are accountable to the profession through the provision of the Health and Social Care Professionals Act 2005 and the Health and Social Care Professionals Council 2007 regulated by CORU\(^3\) whose purpose is similar to that of the HPC of protecting the public through the promotion of high standards of professional conduct and professional education, training and competence among the registrants of the designated professions\(^4\)\(^5\).

The HPC holds a register and controls entry on to the register of those who meet their standards for their training, professional skills, behaviour and health\(^6\). “Fitness to practice” describes a registrant’s suitability to be on the register without restrictions, the HPC having the power to hold a registered orthoptist to account if it is alleged that their fitness to practice is impaired in a variety of ways. The standards by which orthoptists are judged and which the HPC considers the public are entitled to expect, are set out in the HPC’s Standards of conduct, performance and ethics (July 2008) and the Framework for Common Code of Professional Conduct and Ethics (February 2010). The standards of conduct and competence expected by the HPC and CORU are that of the average orthoptist and not of the highest possible level of practice. This reflects that adopted by civil law when judging a skilled practitioner as in Bolam-Bolitho test. Further reference will be made to the standards within the BIOS rules with which orthoptists should be familiar.

1.5 Patient

1.5.1 Law

Orthoptists are accountable to the individual patients under their care. The tort or civil law system allows a patient to seek redress usually in the form of compensation, if they believe that harm has been caused by a negligent act.

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3 CORU – Regulating Health and Social Professionals. The word originates from the Irish word ‘coir’ meaning fair, just and proper and is not an acronym.

4 See: http://www.coru.ie/ for further information. Please note: CORU operates under the aegis of the Department of Health and is in the process of establishing criteria for registration, codes of professional conduct and ethics and standards of professional performance as a basis for determining fitness to practise.


6 Registration Board for Orthoptists has not yet been established
Negligence

A fundamental principle of health care ethics is that Orthoptists should do no harm, respecting the ethical principle of non-maleficence underpinning the legal expression of negligence. Negligence constitutes a civil wrong or tort and refers to as an actionable harm and an orthoptist needs to be aware that the patient may sue for compensation due to the careless act of the Orthoptist.

Duty of care

Orthoptists need to be aware that they have a common law duty of care to their patients and that the duty automatically arises when an orthoptist offers to give professional advice and assesses and treats a patient. They owe their patients a duty of care and are accountable to the patient if they cause harm by breaching that duty.

Breach of duty

The law imposes a standard of duty as an orthoptist. A breach of duty may be tested as follows:

- “A health care practitioner is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a reasonable body of medical men skilled in that particular art” (Bolam v Friern Hospital Management Committee [1957]).
- The test is of accepted practice and is referred to as the Bolam Test\(^7\)
- The test has been modified in relation to its use on establishing the cause of the breach.
- “A reasonable view pre-supposes that the relative risks and benefits have been weighed by the experts in forming their opinions if it can be demonstrated that the professional opinion is not capable of withstanding logical analysis, the judge is entitled to hold the body of opinion is not reasonable nor reasonable” (Bolitho v Hackney Health Authority [1993]).

Meeting these two statements is a demonstration of Bolam-Bolitho compliance and forms one of the legal tests of acceptable professional practice.

Furthermore, accepted practice requires the obligation to be “reasonable” and be “responsible” which address the need to review evidence in context and to investigate fully even where risk of disastrous consequences is so very minimal\(^9\).

Role of guidelines

Orthoptists must be aware of the role of clinical guidelines in practice, whose principle is to prevent harm to patients. In the event of negligence, clinical guidelines will be disclosed where either there has been a departure from the guidelines or where they are used to exculpate the defendant by demonstrating adherence to the guidelines. However, blind adherence to guidelines and protocols would itself be negligent as it is important for health care professionals to exercise professional judgement based on the needs and circumstances of the individual patient. Guidelines provide some evidence of what constitutes proper treatment for the patient’s condition but practice must be logical and defensible as defined within Bolitho.

\(^7\) Applies to England, Wales, Northern Ireland. The test for negligence for Scotland arises from Hunter v Hanley [1955] and for Republic of Ireland, the test arises from Dunne v National Maternity Hospital [1989].

\(^8\) For further guidance on negligence, refer to Appendix 4.

NICE states: “Health professionals, when exercising their clinical judgement should take its guidance fully into account, but... it does not override their responsibility for making appropriate decisions in the circumstances of the individual patient”.  

**Inexperience**

Orthoptists, including undergraduate orthoptists, will not generally be able to argue that they are not accountable because of lack of experience. It has been argued that although a defendant had done the best that could be expected from a learner driver, she fell short of the reasonably competent and experienced motorist (*Nettleship v Weston [1971]*). Orthoptists must be aware of this in relation to students on placement.

In the majority of negligence cases brought, the defendant is successful by demonstrating that distinguished experts in the relevant field consider the treatment in question to be appropriate.

**Limitation Act 1980**

This law sets out the law within which actions for negligence may be brought. The limitation period for bringing such actions is three years from either the date of the injury or the date at which it was first realised that a person has suffered a significant injury that may be attributable to the negligence. For a minor, defined as below 18 years, the limitation period commences from the attainment of that age until a time when full facts are realised. In the event of a child being born disabled, the Congenital Disabilities (Civil Liability) Act 1976 provides the right of the mother to bring a civil action for damages in respect of the disability.

**1.5.2 Morals and ethics**

Orthoptists may find in practice that their questions cannot always be answered using a legal approach. In these cases, the orthoptist needs to consider whether an intervention is morally acceptable and ethically correct.

Morals refers to a set of beliefs based on culture, experience, upbringing, education and religion which influences behaviour, whilst ethics is the enquiry into moral situations by which a framework is used to guide decision-making. A duty-based approach to ethics dictates that patients have a right to autonomy, information, life and dignity whilst the health care professional has a duty of care, and duties to save lives, to preserve confidences and also to tell the truth. A utilitarian ethical approach focuses on outcomes and the greater good but, in order to attain this, rights and duties are breached. A useful approach to guide decision-making can also is through principlism based on the four principles of ethics which recognise that there is no adamantly right or wrong approach to solving dilemmas but provides a culturally neutral approach which also offers a degree of consistency:

- Respect for autonomy – respect for the right of an individual to decide for themselves, often referred to as self-determination
- Beneficence – acting in ways that promote the wellbeing of others
- Non-maleficence – obligation not to harm

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11 In the Republic of Ireland, the Civil Liability and Courts Act 2004 addresses statutes of limitation (see Appendix 5)

12 Referred to as a deontology

13 Beauchamp and Childress (2009)
Justice – obligation to treat others fairly.

**Respect for autonomy**

The principle of autonomy requires respect for the choice made by an individual and has had a significant impact on the development of a patient-centred approach to health care. Orthoptists must recognise that a patient has a right to decide whether or not to undergo any health intervention, even if by not doing so, will lead to harm. Autonomy must not be compromised through undue influence or interference from others and underpins consent.

**Beneficence and non-maleficence**

Orthoptists have a moral and professional obligation to provide overall benefit to patients with minimum harm i.e. beneficence with non-maleficence. The clinical context of beneficence relates to acting in the patient’s best interest, interpreted from an objective assessment by the health professional.

**Justice**

Orthoptists have a moral and professional obligation to treat patients fairly from the aspects of distributive justice, respect for people’s rights and for morally acceptable laws.

Equality is at the heart of justice and conflicts exist between moral concerns such as providing sufficient health care to meet the standards of all who need it and when this is not possible, distributing in resources in proportion to health care need and enabling orthoptists to give priority to the needs of their patients.

Orthoptists must respect patients’ rights and have no special privilege to create rights for patients or decide which rights should apply.

Orthoptists are encouraged to reflect on these four principles during their practice.

The Hippocratic Oath, although modernised, forms a basis for modern and health care ethics with the underlying principle of duty that health care professionals have to patients and the ways in which that duty should be respected and manifested remaining (see Appendix 2).
Rule 2: Scope of practice of the profession

Registered Orthoptists shall be responsible for their practice and shall only practise to the extent that they have established, maintained and developed their ability to work safely and competently.

2.1 Scope of practice of the profession

Orthoptics is an applied science – the study of the visual system – and includes its development, binocular interaction and ocular motility with an understanding of the neuro-anatomy and physiology that underpin this. It therefore possesses its own knowledge base, its own educational methods and practical application based on that knowledge and supported by best available evidence.

Orthoptic practice is characterised by reflection and systematic clinical reasoning to ensure a problem-solving approach to patient-centred care. Orthoptists should be able to operate as autonomous, independent and innovative practitioners with the ability to respond to a constantly changing health care environment to permit safe, effective and efficient practice and to the advancement of the profession through research. Practice must be sensitive to such changes and thus a definition of the scope of practice must not restrict opportunities and innovation for individuals and the profession by placing fixed limits on the extent of practice. The profession’s scope of practice encompasses those areas for which its members are educated, trained, and competent and insured to perform their activity they provide.

The breadth and scope of orthoptics encompasses:

- The age span of human development from neonate to old age;
- The ability to diagnose and recognise the association between specific defects of binocular vision, ocular motility and visual function to other general and neurological conditions;
- Working with individuals who present with complex and challenging problems resulting from multi-pathology illness;
- Health promotion and early identification of problems in the form of screening;
- Knowledge of the management and treatment of ocular problems associated with abnormal development such as retinopathy of prematurity, amblyopia and strabismus;
- The therapeutic management and treatment of ocular problems associated with recovering conditions such as head injury and stroke;
- Treating ocular complaints caused by deteriorating conditions such as multiple sclerosis;
- The management of individuals with on-going conditions such as diabetes or thyroid problems.

2.2 Scope of practice of orthoptics

Individual orthoptists practice within their own scope of individual scope which may be within both an occupational and professional framework of practice. Such activities should also be linked to emerging
frameworks and be supported by a body of evidence. Furthermore Orthoptists should be mindful of relevant National Service Frameworks relevant to their patient groups\(^\text{14}\).

**Occupational framework**

- Occupational role: clinician, manager, service delivery, educator, researcher and professional adviser.
- Sector provision: public health care (NHS), community and social care (NHS), private health care (e.g. BUPA and AXAPPP or VHI Healthcare in Ireland), education, voluntary/charitable organisation, armed forces, research and academia.
- Environmental: Primary care (community), Secondary care (NHS Trust hospitals, Health Boards or HSE in Republic of Ireland) and schools.

**Professional framework**

- Population groups: new born, babies, children and adult (including those with special needs), the critically ill and other vulnerable groups, older persons, families, groups with identified specific cultural needs and professional peers.
- Speciality areas: specialised paediatrics, childhood vision screening, people with learning difficulties, stroke and rehabilitation, low vision aid groups, glaucoma and cataracts (biometry).

Some specialist groups are represented by a named SIG (Special Interest Group) and allow members with specific interests to develop their own networks which may range from occupational role to population groups and specialty areas. They provide a mechanism to establish contemporaneous practice within comparable groups of the profession.

**Generalised and specialist orthoptist**

An individual may also choose to work as a generalist or specialist Orthoptist. More specifically, a generalist develops a broad base of skills, knowledge and experience in all areas of orthoptic practice enabling them to deal with most patients presenting with straightforward to moderately complex needs whereas a specialist develops finely honed skills and experience in a very specific area of practice, arising from a detailed and particular knowledge base. The main difference in their professional strengths lies in their breadth or depth of their understanding and approach underpinned by clinical reasoning and decision-making.

In exercising autonomy, individual orthoptists need to consider their individual scope of practice in relation to the identified needs of the individual patient or circumstance. Before proceeding, the orthoptist needs to consider whether:

- The decisions made during an assessment can be justified and are evidence-based;
- The appropriate diagnosis based on the extent of the assessment performed can be reached;
- The appropriate treatment can be implemented, all of which are dependent upon the individual’s professional judgement based on a correct balance of skills, knowledge and experience.

By considering these factors, the orthoptist is not only identifying and determining the limits of their competency, but also demonstrating an understanding of the scope of the profession.

\(^{14}\) National Service Frameworks: Older people; Long-term conditions; Child Health (Every Child Matters); Diabetes and Stroke.
The individual is also acknowledging cross-professional boundaries and demonstrating an awareness of other approaches that may be more beneficial to the patient, including referral to another orthoptist or clinical specialist. This approach ensures that every interaction is a learning experience that will not only inform but may also change and develop that individual's scope of practice.

As an orthoptist develops skills in a particular area, there will be an inevitable diminution of skills in another area of professional practice. However, providing that the orthoptist can be certain that the preceding points are realised and addressed, safe and effective practice in the best interest of the patient can be guaranteed.

2.3 Competence

The education and training of members of the British and Irish Orthoptic Society, originally at diploma level and now both undergraduate, as approved by the HPC, and post qualification level, is such that it can deliver a variety of service functions within the occupational and professional practice frameworks.

Individual competence, capability and practice are accountable and determined by:

**Regulation and governance**

The Health Professions Order (2001) of the Health Professions Council sets out as an underpinning principle the need to maintain competence to ensure public confidence in professionals. This includes meeting the required standards of proficiency, the standards of performance and conduct, and undertaking continued professional development. CORU (Health and Social Care Professionals Council for the Republic of Ireland) is in its early stages of establishing its policies and procedures.\(^\text{15}\)

Job descriptions and banding in accordance with the Knowledge and Skills framework guides the level of competency to be expected at certain bands. A competency framework is being established which is being informed by the approach taken by Skills for Health in the UK.\(^\text{16}\)

**Demonstrable evidence of knowledge and skills and competence**

Orthoptists are required to recognise their limits of competency and must practise within them. The qualifications, knowledge and skills that a member uses in their practice should demonstrate that the orthoptist is practising orthoptics within its overall scope. The best available body of evidence should be used to support practice.

Orthoptists must engage with continuing professional development to remain on the Health Professions Council’s register. They must keep up to date and undertake CPD activities that are a mixture of learning activities related to their current and future practice and be such that the CPD enhances the quality of their practice and service delivery and benefits the patients to ensure safe and effective practice is attained.

A record of CPD activities must be kept in their personal portfolio and can be structured around the individual's personal development plan. As a newly qualified Orthoptist, discussions and action points from preceptorship meetings and those related to progression on the Knowledge and Skills framework must also be included to assist in identifying achievements and any particular needs of an individual. No such

\(^{15}\) Registered Orthoptists in the Republic of Ireland are advised to visit CORU website regularly for further developments

equivalent exists in the Republic of Ireland but Orthoptists are encouraged to refer to HSE\textsuperscript{17} and CORU\textsuperscript{18} for further information.

**Inexperience**

An orthoptist must recognise that the law requires them to meet the standard of competence and experience of the band in which they are employed. Therefore, it is imperative that newly qualified orthoptists do not fill the demanding post of a higher band until it can be demonstrated that they have progressed through the necessary gateways. If an orthoptist recognises their lack of experience and calls upon a senior colleague, their duty has been discharged and they cannot be held to account.\textsuperscript{19}

### 2.4 The extended scope of practice

Extended scope implies working outside or beyond the recognised elements of orthoptic practice\textsuperscript{20} using skills and techniques that are not included in the:

- Defined core skills of an orthoptist or
- Qualifying professional educational curriculum for orthoptists

#### 2.4.1 Background and drivers

The enactment of the European Working Time Directive into UK law as the Working Time Regulations in 1998 (as part of the Health and Safety Act 1974) provided an opportunity to modernise the health and social care with the intention to provide improved treatment for patients, a better patient experience and better working environments for staff. To meet this challenge professional groups and individual practitioners have been required to develop beyond their traditional service structures and boundaries. The unique roles of the different professional groups have been acknowledged and there is also a recognition that roles are changing across the pathway of care. Orthoptists must be aware of the dynamic nature of policy and its impact on practice.

#### 2.4.2 Supporting extended scope of practice

The post-registration development of specialist orthoptists and the advancement of knowledge and skills to a higher level may be linked to extended practice but it is also part of the continuing professional development of orthoptists as the profession continues to evolve.

Orthoptists must recognise that the HPC’s Standards of Proficiency clearly state “if you want to move outside your scope of practice you should be certain that you are capable of working lawfully, safety and effectively. This means that you need to exercise personal judgement by undertaking the necessary training and experience”.

Orthoptists in extended roles require support and supervision but this may not be available in their department due to lack of appropriate level of training, knowledge and experience in the extended field and support may be sought from an individual outside the department with the necessary experience.

\textsuperscript{17} http://www.hse.ie/eng/staff/Resources/Performance_Management/

\textsuperscript{18} http://www.coru.ie/ducation-section/cpd/ accessed March 2012

\textsuperscript{19} Wilsher v Essex Area Health Authority [1986] 3 All ER 801

\textsuperscript{20} Quality Assurance Agency for Higher Education (2001). Subject benchmarks for Orthoptics.
2.4.3 Important factors to consider

If an orthoptist is asked or wishes to take on a task, role or responsibility that may be considered to be beyond the recognised scope, they must ensure:

- They have the adequate knowledge, skills and experience to render themselves competent to complete the task
- The task, role or responsibility complies with legislative requirements
- Their employer recognises and formally accepts the inclusion of the task, role or responsibility
- Their employer’s insurance provides adequate liability cover and inform the British and Irish Orthoptic Society to determine whether the professional indemnity insurance will cover the extended roles
- That their increase in responsibility, specialist skills and knowledge are recognised and remunerated by their employer.

2.5 Research

Research is essential for developing the practice of orthoptics and improving health care in the future. Should orthoptists be involved in research they must ensure they:

- Put the participants’ interest first
- Act with honesty and integrity
- Adhere to the approved national research governance guidelines (Research Governance Framework for Health and Social Care)\(^{21}\) \(^{22}\).
Registered Orthoptists shall practise in a non-judgemental manner and must avoid discrimination in the way in which they behave and provide healthcare. They should support social inclusion and respect diversity and beliefs, rights and wishes of patients of all ages, groups and communities.

3.1 Introduction

The National Health Service Act 2006\textsuperscript{23}, section 1 sets out the legal foundations for the NHS including:

- The Secretary of State must continue the promotion in England of a comprehensive health service designed to secure improvement in:
  - The physical and mental health of the people in England, and
  - In the prevention, diagnosis and treatment of illness.
- The Secretary of State must, for that purpose, provide or secure the provision of services in accordance with this Act\textsuperscript{24}.

The NHS Constitution sets out seven core principles, some of which are based upon the availability of services in a non-discriminatory and non-judgemental manner and the promotion of patient-centred health service and, hence, an enabler of patient empowerment\textsuperscript{25}.

The NHS Constitution informs NHS patients of the rights to which they are entitled, some of which are encompassed directly or indirectly into the Human Rights Act 1998 and the right not to be unlawfully discriminated against in the provision of services as addressed within the Equality Act 2010.

Orthoptists must be aware of the associated legal framework of this rule and others, and that patients of the NHS have the right to\textsuperscript{26}:

- Access NHS services. Patients will not be refused access on unreasonable grounds;
- Not to be unlawfully discriminated against in the provision of NHS services including on the grounds of gender, age, race, religion or belief, sexual orientation, disability (including learning disability or mental illness) or age;
- Be treated with a professional standard of care, by appropriately qualified and experienced staff in a properly approved or registered organisation that meets required levels of safety and quality;
- Dignity and respect, in accordance with human rights;

\textsuperscript{23} Members should refer to the Act relevant to their own country for further information. [NHS Reform (Scotland) Act 2004; Provisions for NHS Act 2006 for Wales and Northern Ireland; Health Act 2004 (Republic of Ireland)]


\textsuperscript{25} See Appendix 3

\textsuperscript{26} The legal nature of these rights remains unclear but without doubt some would be capable of enforcement particularly when used in conjunction with other statutes and rules.
Accept or refuse treatment that is offered and not to be given any physical examination or treatment until valid consent has been given. In the event of a patient lacking the necessary capacity, consent must be obtained from a person legally able to do so or the treatment has to be in the best interest of the patient;

Be given information about proposed treatment including any significant risks and alternative treatments and the risks involved of not doing anything;

Privacy and confidentiality and to expect the NHS to keep confidential information safe and secure;

Access health records;

Be involved in discussions regarding health care and to be given information to enable the patient to do this;

Have a complaint about NHS services dealt with efficiently and properly investigated and be informed of the outcome;

Make a claim for a judicial review if a patient has been affected by an unlawful act or decision of an NHS body; and

Compensation in the event of being harmed by negligent treatment.

### 3.2 The legal framework

The legal frameworks of the Human Rights Act 1998 and the Equality Act 2010 aim to address inequalities in the level of health care across the UK and disparities in the general quality of people’s health in different parts of the country and among different social, ethnic and economic groups and the elderly and people with mental health problems and learning disabilities.

According to the Constitution of the World Health Organisation, “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction or race, religion, political belief, economic or social condition.”

#### 3.2.1 The Human Rights Act 1998

The Human Rights Act 1998 makes the rights and freedoms, based on the core principles of respect, equality, dignity, fairness and autonomy, set out in the European Convention of Human Rights (ECHR) permissible, and potentially enforceable, in the UK including Northern Ireland. The obligations created by the Human Rights Act may be positive to ensure that laws and practices are in place to protect citizens and allow them to enjoy these rights and freedoms or negative that requires a state and its public authorities (such as health) to respect rights in their day-to-day dealings with individuals.

The Republic of Ireland has incorporated these principles into its European Conventions on Human Rights Act 2003, similar to the Human Rights Act 1998.

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28 Dignity: right not to be tortured or treated in an inhuman or degrading way; equality: right not to be discriminated against; respect: right to respect for family and private life; fairness: right to a fair trial; autonomy: right to respect for private life.
3.2.2 UN Convention of the Rights of the Child

Furthermore, the UN Convention of the Rights of the Child (UNRC) is a highly ratified human rights instrument in international law and sets out the rights to which all children are entitled and represents a strong international consensus on the treatment of children in all areas of their lives. The UNRC’s provision falls into three main categories, namely, protection, provision and participation. The guiding principles relate to the right to life, survival and development (Article 6); non-discrimination (Article 2); best interests of the child (Article 3) and the right to be heard (Article 12).29

3.2.3 Equality Act 2010

The Equality Act 2010 covers England, Wales and Scotland but not Northern Ireland. The Act consolidates and replaces the previous discrimination legislation for the three countries. However, the provisions of the Act are similar to those in Northern Ireland where a patchwork of anti-discrimination exists rather than a single Act30. The Republic of Ireland has three main statutes addressing equality31.

A close relationship exists between human rights and equality, as indicated within the NHS Constitution, and it is good practice for those exercising public functions, such as health care provision, to consider human rights and equality together32. For example, if a health professional was to discriminate against a patient, this may also amount to a breach of the Human Rights Act if a Convention right is engaged as discrimination in the enjoyment of Convention rights is a breach of the Convention under Article 14. Thus discrimination in the enjoyment of Convention rights is based on a characteristic protected under the Equality Act which could also be a breach of the Equality Act.

3.3 Human Rights and Orthoptic Practice

A fundamental obligation for any health care professional is to respect the rights of their patients. The following provides Orthoptists with an insight into the impact of human rights on practice and ways in which human rights must be respected and the way in which these rights have been challenged within the courts and is, in no way, exhaustive.

**Article 2 (Right to life)**

Under the Human Rights Act, Orthoptists need to respect the right to life (Article 2) which imposes on the estate and its authorities, a positive obligation to protect the right to life and thus preserve life. In *Association X v United Kingdom* [1978], the European Convention on Human Rights highlighted the need to take steps to safeguard life in addition to refraining from taking life intentionally.

Orthoptists may be confronted with patients with serious debilitating and life-threatening conditions who may be wanting to challenge their existence in life and they have to respect human rights whilst at the same time consider the wishes of the patient but must not allow their personal beliefs influence their behaviour and health care owed to the patient.

In *R (Purdy) v DPP* [2009] UKHL, Article 2 was relied upon to state that laws against assisting suicide are needed to ensure that vulnerable people are not pressurised or forced into committing suicide.

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29 See Appendix 5 for further information
30 This has been due to disagreements within power-sharing government of that province.
31 See Appendix 5 for further information.
32 However, for the purpose of this rule, Human Rights and Equality will be considered separately
In R (Pretty) v DPP [2002] and Pretty v UK [2002]\(^{33}\) it was upheld that the right to life in Article 2 does not include the right to die.

**Article 2 in relation to rationing**

Orthoptists must be aware of the impact of rationing on clinical practice and access to health care in light of many legal cases\(^ {34}\).

Orthoptists must be aware that the courts have accepted the rationing decisions need to be made and these may result in some patients not receiving treatment\(^ {35}\).

Orthoptists must be aware that a policy which states that a particular treatment would never be funded is unlikely to be lawful as it will fail to consider each case individually and so cannot be procedurally fair\(^ {36}\).

Orthoptists must ensure that, in the event of a patient being denied treatment, the patient must be informed of the basis of the decision and given an explanation why they have been denied of treatment\(^ {37}\).

Orthoptists should be aware that any guidance from NICE or NHS circulars should be taken into account where appropriate.

**Article 3 (Right to be free from torture, inhuman or degrading treatment or punishment)**

Orthoptists must recognise that Article 3 concerns fundamental issues of respect, dignity and humanity and that this could be used to challenge failure to provide treatment or poor quality treatment. Inhuman and degrading treatment has to attain a minimum level of severity for it to fall within the scope of Article 3. The appalling standards of care reported in Staffordshire Hospital resulting in morbidity and mortality would fall into this Article\(^ {38}\).

Orthoptists should consider the standards of care they may witness with patients who are too ill or incapable to be aware of the degrading treatment themselves. Typically, this applies to patients lacking mental capacity.

In Pretty v UK [2002], Mrs Pretty argued her case that not being able to have assistance in suicide amounted to inhuman or degrading treatment. However, the ECHR (European Court of Human Rights) was not sympathetic to this argument and stated that Article 3 had to be considered with Article 2, so killing someone in breach of Article 2 could not be justified in reference to Article 3.

**Article 8 (Right to respect for private and family life)**

Orthoptists must recognise that Article 8 includes the right to control who touches the person such as during treatment and enables the person to exercise autonomy and not to be treated unless consent has been given.

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\(^{33}\) In order to avoid an undignified death through respiratory failure, Pretty wanted her husband to help her commit suicide and sought an assurance that he would not be prosecuted for his assistance.

\(^{34}\) See Appendix 4 for case law to support principles of rationing (Human Rights)


\(^{36}\) R v NW Lancashire HA ex p A, G and D

\(^{37}\) R(Ross) v West Sussex Primary Care Trust [2008] EWHC 2252 (Admin)

\(^{38}\) “Stafford Health Care So Bad it Denied Human Rights” (2010) Guardian, 10 November.
Orthoptists must recognise that in the context of health, Article 8 includes the protection for private and confidential information\textsuperscript{39, 40}. It is only permissible to interfere with that right if it is deemed necessary in a democratic society and in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder and crime, for the protection of health and morals, or for the protection of the rights and freedoms of others. The term “necessary” is significant in relation to the strength of justification for the interference. Any breach of confidential information must be proportionate to the legitimate state interest\textsuperscript{41}.

Orthoptists must be mindful that the Human Rights Act 1998 does not provide for a straightforward enforcement of the European Court of Human Rights. Claims based on the ECHR may be used to interpret statutes or to shape the development of the common law, such as the law of confidence and under section 7, allows a person to sue a public authority which has infringed their human rights. A claim could be brought against an NHS Trust or similar but not against an individual, which may include a financial claim for damages.

**Article 3 & Article 8 – implications for research**

Orthoptists must be aware that the Human Rights Act could become relevant in the field of research. In the context of civil law, the researcher owes a duty of care and could be liable in the tort of negligence and also in the context of criminal law, if research intentionally or recklessly caused an injury to a participant. Treating participants without their consent would be a breach of both Article 3 and/or Article 8 of the European Convention on Human Rights.

**Article 8**

Orthoptists must be aware of the significance of Gillick competence and Article 8. In R(Axon) v Secretary of State for Health [2006] EWHC 37 (Admin), a mother claimed that the Department of Health guidelines relating to whether an under-16 year-old girl could undergo an abortion without the consent of her parents were unlawful. In particular, they infringed a parent’s right under Article 8 of the ECHR to respect for her family life. The mother’s claim was rejected. Once a child becomes Gillick competent, their parents lose any right under Article 8 to overrule the child’s consent.

**Article 9 (Protection to religious rights)**

Orthoptists must be aware of the need to respect religious beliefs and rights under Article 9. Under the Human Rights Act in Re: T (Adult Refusal of Treatment) [1992]\textsuperscript{42} it could be argued that had the Act been around at that time, the impact of Article 9 and Article 8 may have justified a different conclusion.

\begin{footnotesize}

\begin{tabular}{l}
\textsuperscript{39} \textit{cKennit v Ash} [2006] EWCA Civ 1714. Information given to a doctor was protected by the law of confidentiality as it was given in a relationships where there was an expectation that confidence was kept and because it was private information. \\
\textsuperscript{40} \textit{Z v Finland} [1997] 25EHRR 371 (See Appendix 4) \\
\textsuperscript{41} \textit{MS v Sweden} (Application No: 20837/92) (ECtHR, 27 August 1997) (See Appendix 4) \\
\textsuperscript{42} See Appendix 4
\end{tabular}
\end{footnotesize}
Article 14 (Right not to be discriminated against in relation to any rights of the Convention)

Discrimination occurs when a person is treated less favourably than another person in a similar situation and where this treatment cannot be objectively and reasonably justified. It provides protection from a wide range of discrimination including age, disability, sex, race, colour, language, religion, political or other opinion, association with a minority, property, birth or other status.

Orthoptists must be aware of a potential breach of Article 14 where children of patients for whom English is their second language are asked to interpret for them when medical issues are being discussed. Furthermore, this could be seen as a breach of Article 8 on the basis of sharing information and confidentiality being breached.

Orthoptists must be aware that treatment cannot be denied to older people on the sole basis of their age.

3.4 Equality Act 2010

The Act is a key legal framework that underpins the manner in which the NHS provides its services and supports its staff. It outlaws discrimination against the following protected characteristics: age; disability 43; gender reassignment; marriage and civil partnership; pregnancy and maternity; race (with the possibility of including caste); religion or belief; sex and sexual orientation.

Orthoptists must be aware that under the Act, people are not allowed to discriminate, harass or victimise another person because they have one of the protected characteristics 44. Furthermore, there is also protection against discrimination where someone is perceived to have one of the protected characteristics or where they are associated with someone who has a protected characteristic.

Orthoptists must be mindful of some of the circumstances confronting them in clinical practice.

Age

Orthoptists must recognise that the protected characteristic of age applies specifically to 18 years and above. The Act refers to a person belonging to a particular age group, which could mean people of the same age (e.g. 25 year olds) or ranges of ages (e.g. 18 – 30 year olds, or people over 60).

This characteristic is yet to be expanded upon and is not likely to be enforced until late 2012 or 2013. However, the Government is keen to ensure that positive uses of age in health and social care will continue once the ban on age discrimination comes into effect 45.

However, Orthoptists would be acting unlawfully if they:

- Made assumptions about whether an older person should be referred for treatment based solely on their age, rather than on the individual need and fitness levels;
- Referred/treated certain age groups on the basis of working-age adults;
- Failed to consider the wellbeing or dignity of older people using a service.

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43 See Appendix 5 for definitions of disability
44 See Appendix 5 for definitions of types of discrimination and further information
Disability

The definition of discrimination because of disability differs significantly from that of other protected characteristics and the application of Principle 2 which states that “equal treatment, as an aspect of equality is not equivalent to identical treatment”. The Equality Act has specific definitions of disability which people have to meet in order to be protected under the Act.

Orthoptists must not treat a person unfavourably because of a disability. Orthoptists must be aware that disabled people should not be treated in exactly the same way as those who are not disabled.

Orthoptists would therefore be behaving in a discriminatory manner if, in addition to treating a disabled person unfavourably, it can be shown that the treatment is because of something arising in consequence of the disabled person’s disability and they cannot show that the treatment is a proportionate means of achieving a legitimate claim.

Orthoptists must be mindful that it is unlawful to discriminate in the following ways:

- Refusing to provide or deliberately not providing a service or treatment for any reasons related to the disability;
- Providing a poorer standard of service compared to other patients;
- Providing a service on terms that are worse than those offered to other patients;

Orthoptists must make reasonable adjustments for disabled patients. These could include:

- Providing the disabled person with information in a range of alternative formats such as large print, Easy Read information for people with a learning disability or visual displays in waiting areas for patients with hearing difficulties;
- Providing sufficient physical space to improve access for disabled patients;
- Providing the disabled person with alternative means to communicate if the disability interferes with the person’s ability to communicate.

Race

People from ethnic minority communities tend not to make full use of health services compared to the population as a whole, although some health problems are specific to certain communities.

Orthoptists must be mindful of this and do their utmost to ensure that they must not treat a patient less favourably because of race. Examples of this may include:

- Not assessing ethnic minority patients in an area away from other patients. This amounts to racial segregation and would be regarded as less favourable treatment and represents direct discrimination.
- Not providing patients with information in their native language.

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46 Section 15 and Section 15 (1) (a) of Equality Act 2010
47 See Appendix 5 Equality Act 2010
48 Not using health services may be due to language difficulties, cultural difficulties regarding examinations with male health professionals, cultural beliefs about traditional medicines and therapies, cultural pressures to hide illnesses (particularly mental health). Health problems: Type 2 diabetes (more common in Asians, Caribbeans and Africans than in Caucasians); coronary heart disease and stroke (more common in Indian sub-continent).
- Not arranging for an interpreter to be available at clinic appointments.
- Refusing to treat someone because of the protected characteristic of race
- Depriving them of a normal length of appointment for assessment

**Religion or beliefs**

Orthoptists must recognise that the protected characteristic of religion or belief includes any religion or philosophical belief. For example, Christians are protected against discrimination because of their Christianity and non-Christians are protected against discrimination because they are not Christians. The meaning of religion in the Act is broad but it is consistent with Article 9 of the European Convention of Human Rights which guarantees freedom of thought, conscience and religion. Furthermore, religion under the Equality Act means any religion and includes a lack of religion.

Orthoptists must respect that manifestation of religion or beliefs is demonstrable with patients who follow certain dress codes and asking a patient to remove a burqa (for example) would amount to direct discrimination.

### 3.5 General duty of public bodies (Health Service)

Although Orthoptists must respect human rights and not act in a discriminatory manner, there is a legal duty on the Trusts and Health Boards (and other environments in which Orthoptists are employed) to promote equality within the provision of services. Under the Equality Act 2010, public authorities must in the exercise of its functions for both service users and employees have due regard to the need to:

- Eliminate discrimination, harassment, victimisation and any other conduct prohibited under the Act;
- Advance equality of opportunity between persons who share a relevant protected characteristic and those who do not;
- Foster good relationships between persons who share a relevant protected characteristic and those who do not.

Under Section 75 of the Northern Ireland Act 1998, public authorities have due regard to the need to promote equality of opportunity:

- Between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- Between men and women generally;
- Between persons with a disability and persons without; and
- Between persons with dependents and persons without.

Furthermore, they should also have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group.\(^{49}\)

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\(^{49}\) Equality Commission for Northern Ireland
Rule 4: Relationships with patients

Registered Orthoptists shall at all times recognise that their relationship with patients is based on openness, trust and good communication to ensure they work in partnership with their patients to address their individual needs. They must establish and maintain clear boundaries at all times with all people in their care, their families and their carers.

Orthoptists shall establish the name under which the patient wishes to be known, and they shall also introduce themselves formally to the patient, informing the patient of their job title and the name by which they wish to be known. Registered Orthoptists must establish and maintain clear boundaries at all times with people in their care, their families and their carers and should avoid providing treatment and care to anyone with whom they have a close personal relationship.

4.1 The Orthoptist-patient relationship

Orthoptists must strive to develop relationships and in doing so, must be polite, considerate and honest, respect and uphold their rights and dignity and treat each patient as an individual. Legal frameworks advocate for equality of access to health care services\(^\text{50}\) in addition to policy documents\(^\text{51}\) that promote equal access to health and make reference to the need for alternative mechanisms to be in place to ensure communication is effective.

4.2 Identification

Orthoptists must ensure that they introduce themselves to the patient by name and ranking which is visible on an ID badge to reinforce their role to the patient. They must also check the patient’s ID by asking them, using open-ended questions, for their name, date of birth and address\(^\text{52}\).

4.3 Clear and effective communication

Clear communication is pivotal to the orthoptist-patient relationship and in order to communicate effectively, Orthoptists must:

- Establish the role of the person accompanying the patient, where applicable;
- Explain the need to ask certain questions and the necessity for any examinations and procedures;
- Explain the examination or procedure and ensure that the patients have understood;
- Ensure that the patients are aware that they can communicate any concerns or discomfort during any examination and assessment and that it can be terminated at any time;

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51 National Service Framework for Mental Health; Mental Health Act Code of Practice

52 National Patient Safety Agency (2005)
Listen to their patients, establish and respect their views about their condition, and respond to their concerns and preferences;

Share the information that patients want or need to know about their condition in a comprehensible manner including the possible progression and treatment options available, including any associated risks;

Respond to patients’ concerns and keep them informed of their progress of their care, including treatment;

Ensure that patients are informed about how their information is shared within the healthcare team involved in their diagnosis and treatment.

Ensure that every effort is made, wherever practical that arrangements are made to meet patients’ languages and communication needs.

4.3.1 Special considerations in communication

Orthoptists must be aware that the standard of communication must not be compromised where:

- The patient has limited use of English and there is concern that the patient does not understand clinical information;
- The patient is deaf or has a hearing, speech or cognitive impairment, learning disability or uses sign language.

In these instances, every attempt should be made to select a suitable interpreter with the skills and experience to provide an effective interpretation service\textsuperscript{53, 54} and to provide communication aids and support such as loop systems and pictorial leaflets. Orthoptists must record a patient’s communication needs and preferences at the initial stage of their care and update as and when necessary and ensure that such information is passed on in the event of any referrals to another health care professional within or external to the organisation.

4.3.2 The interpreter

Orthoptists should be aware that the key role of the interpreter is to facilitate communication with the aim to ensure best practice outcome and working towards fostering trust and maintaining confidentiality. Interpreters will be aware of patients’ culture, country of origin and religious beliefs which may assist in the orthoptist-patient interaction.

Orthoptists must not be tempted to rely on carers, family, including children, and friends even though this may be the patient’s preference and should use a trained interpreter due to the potential lack of:

- Accuracy of interpretation (vital information may be omitted);
- Completeness (some words may be omitted which could be vital in an assessment);
- Confidentiality (not understanding the need to maintain confidentiality or failing to disclose issues that may impact);

\textsuperscript{53} Interpretation is the conversation of one spoken language into another and in the clinical setting, should be of a consecutive nature. Translation is an individual’s view of the meaning of what is said.

\textsuperscript{54} It is advisable to record the name of the interpreter in the patient’s notes.
- Impartiality and potential for conflict of interest (a relative may not pass on information with which they do not agree);
- Provision all of the instructions given by the orthoptist.

Orthoptists are advised to check their Trust and the HSE for further guidance on using interpreters.

4.3.3 Children and young children

As Orthoptists, a significant proportion of the caseload is children.

Orthoptists must be mindful of best practice regarding communication with children:
- Provide information in a manner they can understand;
- Treat them with respect and seek their views and take them into account;
- Respond to their questions to the best of your ability;
- Involve the child in treatment decisions as far as possible, bearing in mind their capacity to understand and willingness to be involved;
- Involve the patient’s parents or carers in treatment decisions;
- Listen to children and respond to their questions clearly and truthfully;
- Remember that communication with children is an ongoing process;
- Ensure that the relationship with the child is based on truthfulness, clarity and awareness of the child’s age and maturity;
- Address the child directly during the consultation process by asking them personally about their condition, irrespective of the child’s age but adapt the information according to the child’s age and maturity whilst at the same time addressing the parents;
- Chat with children to make them feel relaxed whilst also respecting professional boundaries;
- Empathise with children, being light-hearted and good humoured where appropriate;
- Create an environment in which they feel comfortable and encourage children to ask questions.

Orthoptists must safeguard and protect the health and welfare of children. See Rule 8 - Duty to report for further information.

4.4 Maintaining trust in the profession

Orthoptists must work with dedication and integrity and be committed to providing the best possible patient care. In addition, they have a duty to ensure the safety and wellbeing of their patients. The relationship between Orthoptists and their patients must be based on mutual respect and trust. Orthoptists must recognise that within the relationship, there may be an imbalance of power as patients are often vulnerable and it is essential that they maintain professional boundaries to protect themselves and their patients.

- Orthoptists must not express to their patients their personal beliefs including moral, political or religious beliefs in ways that may potentially exploit their vulnerability or cause them unnecessary distress.
- Orthoptists must not exploit their professional position to establish financial relationship with the patient or someone close to them.
Orthoptists must not exploit their professional position to pursue a sexual or an improper emotional relationship with the patient or someone close to them. The Council for Healthcare Regulatory Excellence provides detailed guidance on the need and importance for sexual boundaries between healthcare professionals and patients.

4.4.1 Sexual boundaries

Orthoptists must be aware of the boundaries which limit behaviour to ensure that a professional relationship based on trust and respect is maintained at all times.

Orthoptists must be self-aware and recognise behaviours which may be precursors to displaying sexualised behaviour towards patients and their carer. These may include using words or actions of a sexual nature designed to arouse or gratify sexual impulses as defined by the Council of Health Regulatory Excellence. Breaches of sexual boundaries include beginning a personal relationship during or after treatment, discussing and engaging in sexual activity, using sexual humour or repeatedly engaging in prolonged conversation about personal matters unrelated to treatment, arranging to see patients outside the normal pattern of working, communications which are not clinically necessary, accepting social invitations, visiting a patient’s home without warning or prior appointment or revealing intimate details to a patient during an appointment.

It is imperative to maintain an objective and professional relationship but in the event that this is not being maintained and respected, Orthoptists should seek advice from an experienced colleague who should direct them to provide alternative care for the patient without making the patient feel uncomfortable.

In the event of the patient demonstrating sexualised behaviour, Orthoptists should either address the situation constructively with the patient in order to regain the professional relationship or, if this is not possible, transfer the care of the patient to a colleague.

Indulging in such relationships risks impairment of Orthoptists’ professional judgement and objectivity and may result in advantageous or disadvantageous treatment.

4.4.2 Close personal relationships

Orthoptists are strongly advised to avoid treating members of their family or those with whom they have a close relationship. They must recognise that this may result in a lack of objectivity in the clinical decision-making due, in part, to their emotional involvement. It is possible that assessing family member’s conditions and providing treatment outside a standard clinical-practice setting may mean they are deprived of the same standard of care as other patients. Orthoptists’ family members are entitled to confidentiality and may withhold information that could be vital. Family members may be placed in a compromising situation where they feel unable to refuse or seek alternative treatment thus limiting their autonomy.

Further ethical and legal issues may arise including a potential breach of Article 8 of the Human Rights Act which states that everyone has a right for their private and family life to be respected. Orthoptists owe a duty to not harm their patients and this may be compromised in providing care for family members.

4.4.3 Being open and honest in the event of an unexpected incident

Orthoptists must provide a prompt, open, honest and constructive response including an explanation and apology, if appropriate, in the event of a patient complaining about the care or treatment that they have received. It is imperative not to allow a patient’s complaint to affect the care or treatment you provide or arrange.
Orthoptists must act immediately to rectify the matter if possible if a patient has suffered harm or distress. A prompt apology must be offered with an explanation of what has happened and the likely short and long-term effects.

4.5 Reluctance to treat a particular patient and ending the professional relationship with the patient

In exceptional circumstances, if Orthoptists have either conscientious or moral objection to treating a patient, these should be recognised and discussed with an experienced colleague. It is important that Orthoptists acknowledge the obligations within the Hippocratic Oath and recognise that it would be unethical not to treat a patient because of their gender, religion, race or sexual orientation.

In rare circumstances, the trust between the Orthoptists and patient may break down and it may be necessary to end the professional relationship. For example, this may occur if a patient has demonstrated offensive and unacceptable behaviour which may be physical or verbal. Orthoptists are entitled to take reasonable steps to protect themselves and others but must ensure a professional approach. In addition, they should make the patient aware when their behaviour has become unacceptable or potentially harmful to the Orthoptist, to other staff or to other patients.

Before Orthoptists end a professional relationship with a patient, they must be satisfied that the decision has been fair and that they have not been discriminated against unfairly. Preferably, the decision should also be confirmed in writing to the patient.

4.6 Consent

Orthoptists must be satisfied that they have consent prior to performing any investigations, providing treatment or involving patients in teaching and research. Normally, this will involve providing information to patients in a way that they can understand before asking for consent. More guidance on consent can be found within Rule 5 – Decision-making and consent.

4.7 Confidentiality

Patients have a right to respect that any information about them will be kept confidential by their Orthoptist and other members of the health care team. Should Orthoptists wish to consider disclosing information without a patient’s consent, they should familiarise themselves with the principles of confidentiality within Rule 7 – Confidentiality.

4.7.1 Sharing information with a patient’s partner, relatives, carer or friends

Orthoptists should establish with the patient what information they want sharing, with whom and in what circumstances. This will limit any misunderstandings between the orthoptist and the patient.

Orthoptists need to consider whether the patient would feel that sharing any information/ concerns about their health would be a breach of trust. The orthoptist has a duty to make it clear to anyone close to the patient that wishes to discuss their concerns, that whilst it is not a breach of confidentiality to listen to their concerns, the orthoptist cannot guarantee that they will not inform the patient. They must not refuse to listen to the partner, relatives, carers and friends for fear of breaching confidentiality.
Registered Orthoptists shall at all times be satisfied that they have adhered to the decision-making framework from which consent for investigations or treatment is obtained. They must also respect a patient’s decision even though it may not be in their best interest.

5.1 Introduction to decision-making and consent

A fundamental principle of health care law and ethics is for the health professional to gain consent prior to commencing physical investigations or treatment on any patient. This reflects the rights of patients to determine what happens to their own bodies. An orthoptist who fails to respect these principles may be liable both for action by the patient and by the Health Professions Council or the Health and Social Care Professionals Council. Employing bodies may also be liable for the actions of their staff. Within the UK, patients are entitled to complain through the NHS Complaints Procedure, initial contact being made with the Patients’ Advisory Liaison (PALS) Officer at the Trust. Patients in the Republic of Ireland are entitled to complain directly to the Health Service Executive under Part 9 of the Health Act 2004 but can complain initially at a local level to the complaints officer.

Consent has an ethical function relating to the respect for autonomy, rights of patients and protection from harm and is embedded in the Hippocratic Oath, in addition to the legal and clinical functions in which the healthcare practitioners have to secure the patient’s trust and co-operation and which involves far more extensive counselling regarding the implications, risks and potential side-effects of treatment than the laws of trespass and battery require.

There is no real statute setting out the general principles of consent but case (common) law provides the basic legal starting point in that a health professional who intentionally or recklessly touches a patient without their consent is committing a crime (battery) or a tort (trespass to the patient and/ or negligence). Hence, in order to act lawfully in touching a patient a health professional needs a defence or legal “flak jack” which may take the form of the consent of the patient, the consent of another person who is authorised to consent on the patient’s behalf or the defence of necessity. However, it is unlikely that an Orthoptist who intentionally or recklessly touches a patient without their consent would be charged with a crime. However, in the event of an Orthoptist practising following removal from the HPC register, they would most likely be charged with an assault occasioning actual bodily harm.

55 Schoendorff v Society of New York Hospital 105 NE 92 [NY1914]
56 Wilson V Pringle [1986] 2 AER 400
58 Sidaway v Board of Governors of the Bethlem Royal and Maudsley Hospital [1985] 1 All ER 643.
59 Applies to the UK and the Republic of Ireland
60 R v Richardson (1998) 43 BMLR 21
5.2 Informed consent

For consent to be valid and informed, it is necessary to show that the person is:

- Sufficiently informed
- Competent (legal capacity)
- Voluntarily given and not subject to coercion

5.2.1 Freely given consent

Consent is an expression of autonomy and for it to be valid, it must be given voluntarily and freely, without coercion or undue influence being exerted on the person either to accept or refuse treatment. Coercion invalidates consent and thus an orthoptist must ensure that any decisions regarding a particular investigation and treatment are free of coercion from both themselves as a healthcare profession and from family members61.

Every effort must be made to ensure that the decision is truly the patient’s own and that they are given time to reach the decision. Orthoptists should recognise the distinction between providing the person with appropriate reassurance for their treatment and identifying potential benefits of treatments for the patient’s health. Patients have a right to refuse treatment and Orthoptists should make sure that patients know this and are able to refuse treatment if they wish.

5.2.2 Sufficient information

The exchange of information between the health care professional and patient is paramount for good decision-making. The amount of information shared with patients varies depending upon their individual circumstances and ideally, should be tailored for each individual patient according to their needs, wishes and priorities, their knowledge and understanding of the nature of their condition, its prognosis and complexity of the treatment options and of the nature and level of risks associated.

Clinical functions of consent and good practice

Good practice dictates that the following information should be given during the consent process:

- Details of the diagnosis, prognosis and likely prognosis/consequences if the condition is not treated;
- Uncertainties regarding the diagnosis, including options for further investigation prior to treatment;
- Options for treatment or management of the condition, including the option not to treat;
- Purpose of the proposed investigation or treatment (including details of therapies involved, precautions to be taken whilst undergoing treatment, any side-effects);
- For each option, explanations of the likely benefits and probabilities of success (and at appropriate stages in the management process);
- Advice about whether a proposed treatment is experimental or evidence-based;
- How and when the patient’s condition will be monitored;
- Name of the health care professional with overall responsibility for treatment and other members of the team, where applicable;

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61 Re: T (Adult Refusal of Medical Treatment) [1992] 4 All ER 649
• Whether students will be involved and the extent to which students may be involved in their investigation and treatment;

• A reminder that patients can change their minds about a decision at any time and have a reminder to seek a second opinion.

Orthoptists should consider the use of written information as a reminder of key points discussed but are reminded that this is not a substitute for detailed discussion but as an adjunct to and not a replacement. If information leaflets are used as part of the discussion, this should be documented within the patient’s notes.

**The legal function of consent**

The law is clear that part of an orthoptist’s duty is to give advice and information to a patient so that the patient understands the nature of the treatment proposed and can make a rational choice. The Courts do not differentiate between advice given in a therapeutic or non-therapeutic context.

The basis of the duty to give information is derived from two areas of law: the law of trespass and the law of negligence.

**Trespass to the person**
Orthoptists will be liable for trespass to a patient on two accounts:

• If they fail to gain consent to touch the patient and

• if they fail to explain in broad terms the nature of the treatment for the patient. If the orthoptist gives misinformation or false information to a patient, consent will be negated and liability in trespass will result.

**Negligence**
Orthoptists will be liable for negligence if they fail to:

• provide relevant information such as discussing benefits and alternative options and

• explain the risks inherent in any procedure particularly if the patient suffers harm as a consequence.

The courts have been quick to point out that failure to disclose risks does not invalidate a real consent and no action is possible in trespass. The proper cause of action in disclosure of risk constitutes a claim in negligence.

**Breach in the standard**
Orthoptists must be aware of the dynamic and evolving case law of the legal duty to inform the patient.

Orthoptists owe a duty to their patients to take reasonable care not to cause harm. They are required to give advice to the standard of the ordinary orthoptist professing to have that particular skill. This is tested by reference to what information a reasonable body of orthoptists would have given in the same circumstances. As inferred in Rule 2, the orthoptist needs to be mindful that the court can reject a practice if it does not stand

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62 **Hills v Potter** [1984] 1 WLR 641
63 **Gold v Haringey** [1987] 2 All ER 888
64 **Potts v NWRHA** [1983]
65 **Hills v Potter** [1984] 1 WLR 641/ Chatterton v Gerson [1981] 1 All ER 257
66 **Bolam v Friern Hospital Management Committee** [1957] 2 All ER 118
67 **Hunter v Hanley** [1955]/ **Dunne v National Maternity Hospital** [1989] / **Geoghegan v Harris** [2000] 31 IR
up to logical analysis. Furthermore, orthoptists must be aware of the role that clinical guidelines will play in future legal decisions.

Orthoptists must also be aware of the prudent-patient test which recognises the self-determination of the patient and which sets the standard as to what information is required for valid consent according to what the reasonable or prudent patient would wish to know under the circumstances.

Some patients make it clear that they wish to be well informed of risks but the manner of how to inform deserves equal credence as whether to inform. The health care professional must respond honestly to any questions from the patient and answer as far as is possible, as fully as the patient wishes. However, in considering what information to provide, it is advisable to inform the patient of any material or significant risks or unavoidable risks, even if small, in the proposed treatment plus any alternatives and the risks incurred by doing nothing.

It is considered to be the responsibility of the medical practitioner to inform the patient of a significant risk which would affect the judgement of a reasonable patient.

**The unquestioning patient**

The degree of information to be given to a patient about risks is based on the standard of care in Bolam in that sufficient information must be given to enable the patient to make a choice. There exists a two-edged duty:

- To disclose material risks
- To withhold information where a patient would be frightened if told all risks where the likelihood of occurrence was very small.

It was accepted in Sidaway the risk of nerve damage was less than 1% and it was accepted practice not to inform the patient to avoid alarming them.

**The enquiring patient – general risks**

Orthoptists should answer questions by a patient about risks involved in treatment, truthfully and as fully as the question requires. Withholding information is appropriate in these circumstances but lying is not permissible and constitutes a breach of duty. The issue of information was considered in Blyth, where the plaintiff argued that, despite asking questions, she was not informed of the side-effects of the drug that she had been given. The Bolam test was applied in that what a patient should be told in answer to general questions cannot be divorced from the Bolam, any more than when no such enquiry is made. The answer is dependent upon the:

- circumstances
- nature of the enquiry
- nature of the information that is available
- reliability of the information
- relevance and condition of the patient.

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68 Bolitho v City Hackney Health Authority [1998] AC 232
69 Birch v University College Hospital NHS Trust [2008] EWHC 2237
70 Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital [1985] 1 All ER 643
71 Blyth v Bloomsbury Health Authority [1993] 4 Med LR 151
Orthoptists thus need to aware that no patient is entitled to a completely full and honest answer and they only have to answer as fully and honestly as a respected body of professionals would have done in the circumstance.

**The enquiring risks - specific risks**

If an orthoptist is asked specific questions about specific risks inherent in treatment, the orthoptist is required to answer fully and honestly regardless of the likelihood of the risk materialising. In Chester\(^72\) the risk of nerve damage was estimated at less than 1%; but because the patient had asked for this information, he or she was entitled to it and the doctor was found to be negligent in failing to provide it. In an Australian case\(^73\) a doctor was found to be negligent for failing to inform a patient of a 1 in 14000 chance of risk.

Good practice proposed from the judgements in Chester\(^74\) has emphasised that health professionals give information about all significant possible adverse outcomes and record the information given to the patient. If, however, information is offered and declined, it is paramount that this is also recorded: but patients are entitled to this information at a later stage should they change their mind.

**Duty to inform of error**

Orthoptists’ duty of care requires them to inform the patient of any error immediately it occurs\(^75\) \(^76\).

### 5.2.3 Decision-making capacity

Decision-making capacity\(^77\) is the ability to make a decision and is the key to autonomy. Orthoptists must be aware that it is based on the person understanding and using information about investigations and treatment when making a decision. It can vary over time and may be dependent upon the simplicity or complexity of the decision to be made.

**Definition of capacity - Republic of Ireland**

Capacity means the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made\(^78\).

**Definition of capacity - Scotland**

For a definition of capacity and/or incapacity in Scotland, Orthoptists should refer to that within The Adults with Incapacity (Scotland) Act 2000\(^79\).

**Does the person have capacity?**

A patient would be considered to have capacity (legal) and be competent to consent if they are able to:

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72 Chester v Afshar [2004] UKHL 41  
73 Rogers and Whittaker [1992] 175 CLR 479  
74 Chester v Afshar [2004] UKHL 41  
75 Gerber v Pines [1935] 79 SJ 13  
76 Daniels v Heskin [1954] IR 73  
77 There is no current legislation covering capacity in Northern Ireland (See Appendix 5). However, a Mental Capacity Bill is expected to be enforced by 2014. (http://www.dhsspsni.gov.uk/legislative-framework-for-mental-capacity.pdf accessed March 2012)  
78 Irish Law Reform Commission (Vulnerable Adults and the Law: Capacity LRC CP 2006)  
79 See Appendix 5. (http://www.scotland.gov.uk/Publications/2008/03/25120154/1 accessed March 2012)
Comprehend and retain the necessary information relevant to the decision (it having been presented in a clear way);
Believe this information;
Retain the information long enough to weigh it up, balancing the risks and needs to arrive at a choice;
Communicate the decision (whether by talking, using sign language or any other means including simple muscle movements such as blinking an eye or squeezing a hand).

**Competence**

A patient or a person seeking consent on behalf of child patients must be competent in order to be able to provide legally effective and valid consent.

Orthoptists must recognise the procedures of consent in cases of both competent and incompetent children and adults.

### 5.2.3 Consent in children and young people

**Consent in children and young people**

Orthoptists should involve children and young people in discussions about their care as much as possible even if they are not able to make decisions on their own. Information should be provided in an age-appropriate manner, their views listened to and treated with respect at all times.

**Children aged 16 and 17**

The Family Law Reform Act 1969 (section 8) states that children aged 16 and 17 years are presumed in law to be competent and can therefore consent to be treated as if they were of full age. Treatment in this case includes diagnosis and procedures ancillary to treatment (such as general anaesthetic). In addition, the Family Law Reform Act specifically preserves the common law powers of parental consent. In common law, parents may consent on behalf of their children until the age of 18, this being on the basis that the consent must be in the best interests of the child.

In Scotland, under the Age of Legal Capacity (Scotland) Act 1991, persons over the age of 16 are presumed to have the ability to make medical decisions and give consent to procedures. Common law rather than the Family Law Reform Act 1969 presides.

In the Republic of Ireland, under section 23 of the Non Fatal Offences against the Person Act 1997, a minor who has attained the age of 16 years can consent to any surgical medical or dental treatment but not refuse. This includes any procedure undertaken for the purposes of diagnosis and to any procedure which is ancillary to any treatment as it applies to that treatment.

Orthoptists should instil good practice and encourage competent children to involve their families in decision-making. In addition, orthoptists should not automatically presume that a child with learning disabilities is not competent to make their own decisions: their competence will be, in part, determined by the manner in which

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80 Stages 1-3 inclusive as in Re: C (1994) and form the basis of the determination of capacity in the UK and the Republic of Ireland.
81 Stage 4 added as part of the Mental Capacity Act 2005 and Mental Capacity Bill 2008 Republic of Ireland
82 More recently, the case of Fitzpatrick and Another v K and Another 2008 form the basis of capacity in the Republic of Ireland (see Appendix 4).
83 Age of consent is 17 years for sexual intercourse
the orthoptists present the information to the child and appropriate support through the decision-making process.

**Children under 16**

Children under 16 are not automatically presumed to be legally competent to make decisions about their health care. However, the concept of “Gillick competence” (Fraser competence) enables such a child to consent provided that it can be demonstrated that the child has “sufficient understanding and intelligence to enable them to understand fully what is proposed”.

In order to ascertain if the child here is competent, it must be ensured that the child understands the medical issues of their condition and treatment and it must be realised that the child only requires the maturity to consent to the particular issue in question. Gillick competence enables a child of under 16 to consent to research, donation and other activity for which consent is required. If the child is Gillick competent and able to give voluntary consent after receiving appropriate information, the consent is valid and sufficient.

Orthoptists should, however, encourage the child to involve their family in the decision-making process unless they have expressly wished not to be by the child in which case, their wishes must be respected and confidentiality maintained unless disclosure can be justified in the grounds that the orthoptist has reasonable cause to suspect that the child is suffering or likely to suffer, serious harm. In this case, the courts may become involved.

In Scotland, the Age of Legal Capacity (Scotland) Act 1991 does through statute what the Gillick case has done through common law in England and Wales.

In the Republic of Ireland, in law, the consent of the parent or legal guardian is required if a child is under the age of 16. However, it is reasonable to seek the consent of a minor with the capacity to understand the nature and implications of the proposed treatment or procedure (consistent with Gillick competence). This should not be problematic if the child and parents are in accord about the decision to consent to treatment. Difficulties arise if the patients of a minor are in disagreement with clinicians or the parents about what is in the child’s best interest. In the event of parents making a decision that is likely to affect the child adversely, it is advisable to contact the Health Service Executive. The Irish Constitution recognises the family as a “moral institution possessing inalienable and imprescriptible rights, antecedent and superior to the law” so the courts tend to take the view that parents’ wishes should only be overridden in exceptional circumstances (defined as a serious threat to life or wellbeing). If there is reason to believe that a parent’s refusal to consent to medical treatment is placing the child at risk, the health board can apply to the District Court for an emergency care order where consent for treatment can be granted.

There may be circumstances in which a person under the age of 16 who demonstrates the maturity to understand the implications of a particular treatment does not wish their parents to be involved in that decision. In this situation, the patient’s confidentiality should be respected and Orthoptists need to be mindful of this.

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84 Age of Legal Capacity (Scotland) Act 1991 – persons under the age of 16 years have legal capacity.

85 Gillick v West Norfolk and Wisbech AHA [1986] AC 112

86 Fraser competence is a modification of Gillick competence and relates to contraception

87 Act of Legal Capacity (Scotland) Act 1991 (see Appendix 5)

88 Constitution of Ireland (November 2004)

89 North Western Health Board v HW and CW [2001] 3 IR 622 (see Appendix 4)
Refusal of treatment

Where a young person of 16 or 17 years could consent or is Gillick competent, refuses treatment, such refusal can be over-ruled particularly if the child or young person may suffer harm, this usually being decided by the courts.\(^\text{90}\)

In the Republic of Ireland children and young people up to the age of 18 years cannot refuse consent to treatment and the parents or guardian may override their wishes and give legally binding consent on their behalf. If the parents decline to do this, then the court has ultimate authority to give consent on behalf of the child if it is considered that treatment in question is in the child’s best interest.

Children lacking capacity and parental responsibility

Where a child lacks capacity to consent and is therefore not Gillick competent, the Orthoptist must seek consent from anyone person with “parental responsibility”\(^\text{92}\) or in extreme cases by the court. This is usually, but not always, the child’s parents. However, the Orthoptist must be satisfied that those giving consent on behalf of child patients which may include a child who is under the age of 18, also have the capacity to consent to the investigation and treatment, be acting voluntarily and be sufficiently informed.

If the Orthoptist is doubtful about whether a person is acting in the best interests of the child or young person, it is advisable not to rely on the parent’s consent, perhaps identified by allegation of abuse by the child or parental support for psychiatric treatment for the child.

The Children’s Act 1989 provides the framework for the protection and care of children to establish clear principles to guide decision-making in relation to their care. Legally, the Orthoptist only needs to gain consent from one person with parental responsibility although it is clearly good practice to involve all those close to the child in the decision-making process. The Act, section 3 (5) states that a person with care of the child may do, “what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child’s welfare”. Orthoptists in the Republic of Ireland should familiarise themselves with the UN Convention on the Rights of the Child.\(^\text{93}\)

5.2.5 Consent in adults

Consent in competent adults

In English law, a person becomes an adult on their eighteenth birthday. Orthoptists need to recognise that where the person is a competent adult, there is no doctrine of consent by proxy and only that person can consent, even though it may not be in the patient’s best interest. Thus it is not possible for a husband to consent on behalf of his wife.

A competent patient has the absolute right to refuse treatment, even if without, they will die.\(^\text{94}\)

\(^{90}\) Applies to the UK and the Republic of Ireland

\(^{91}\) Applies to the UK and the Republic of Ireland

\(^{92}\) See Children’s Act 1989, UN Convention on the Rights of the Child (UNCRC) (Republic of Ireland) and The Children (Scotland) Act 1985. (See Appendix 5)


\(^{94}\) Re: B (Adult: Refusal of Treatment [2002] All 2 All ER 449 (See Appendix 4)
Consent in incompetent adults and young people

The treatment of a patient lacking capacity is governed by the Mental Capacity Act 2005 which came fully into force in October 2007 and applies in England and Wales. In the Republic of Ireland, where a person is considered incapable of managing their affairs an application to court has to be made to make that person a ward of court. However, a Mental Capacity Bill is imminent and orthoptists from the Republic are urged to consult it. The principle is a presumption that a person had capacity and the person would not be treated as unable to make a decision unless all practicable steps to help that person make a decision had been taken without success.

The equivalent in Scotland is The Adults with Incapacity (Scotland) Act 2000

The Mental Capacity Act 2005 provides a framework for all those working in health and social care and involved in the care, treatment or support of people over the age of 16 years who lack the mental capacity to act and make decisions for themselves on a wide range of issues.

The Mental Capacity Act 2005, section 2(1) states that a person lacks capacity if “he is unable to make a decision for himself in relation to the matter in question because of an impairment of, or a disturbance in, the functioning of the mind or brain”. Furthermore it does not matter if the disturbance is temporary or permanent. For specific examples of conditions, see Appendix (Mental Capacity Act 2005). For the purpose of the professional code, “person” will be referred to as “patient”.

The Code of Practice provides detailed guidance and has statutory force. Orthoptists have a legal duty to have regard for the Code of Practice which is underpinned by five principles, two of which are the presumption of capacity and that anything done for, or any decisions made on behalf of a person who lacks capacity must be done and made in the patient’s best interests.

Presumption of capacity

- Orthoptists must work on the presumption that every adult patient has the capacity to make decisions about their care and to decide whether to accept or refuse an examination, investigation or treatment. Patients must only be regarded as lacking capacity once it is clear that they cannot meet the four requirements for capacity and once they have received the necessary support.

- Orthoptists must not, under any circumstances, assume that a patient lacks capacity because of their age, appearance, behaviour, beliefs, disability, apparent inability to communicate or their medical condition, or because they make a decision which the orthoptist considers to be unwise.

- The onus of proof lies with showing that a patient does not have capacity.

Assessment of capacity

- Orthoptists must assess a patient’s capacity on their ability to make a specific decision at the time it needs to be made. Just because the patient lacks the capacity to make a decision on one occasion that does not mean that they will never have the capacity to make a decision in the future and about a different matter in the future. Capacity can be viewed as being “function specific”.

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95 In Northern Ireland, there is no relevant primary legislation and decision-making is governed by case law which requires that decisions are made in the patient’s best interests. However, the proposed Mental Capacity Bill should be enforced in 2014. (http://www.dhsspsni.gov.uk/legislative-framework-for-mental-capacity.pdf accessed March 2012)
Orthoptists’ assessment of the reasonableness of the patient’s decision must not be confused with capacity. Just because the patient makes an unwise decision, that does not render them lacking capacity under the Mental Capacity Act. A patient has the right to make what others might regard as an unwise decision: everyone has their own values, beliefs and preferences. If there is an obvious irrational decision on a misrepresentation of reality, the orthoptist should conclude that the patient may lack the capacity to make the decision in question.

Orthoptists should seek advice from other health professionals with specialist experience such as neurologists, psychiatrists, psychologists and speech and language therapists and nursing staff involved in the patient’s care, if they are doubtful about the patient’s capacity to make a decision.

The last resort would be to seek legal advice requesting the courts to determine the patient’s capacity. The courts will be concerned with whether the “balance of probabilities” favours capacity or lack of capacity.

Supporting decision-making and enhancing capacity

Orthoptists must recognise that a patient’s ability to make decisions is dependent upon the nature and severity of their condition and the complexity of that decision and the patient may be able to make decisions at certain times and not others.

Orthoptists should be flexible in regarding the place and time at which discussions occur and encourage the patient to consider different options to assist their retention of information (for example, being accompanied or being provided with written or audio information).

Orthoptists should be encouraged to speak to those close to the patient or other healthcare professionals about the optimum way of communicating, whilst at the same time respecting confidentiality.

Orthoptists should record any decisions are made, whether they are an acceptance of treatment or a refusal, whilst the patient has the capacity to understand and review them.

Decision-making when a patient lacks capacity

Orthoptists should observe the following principles whilst treating and caring for a patient who lacks capacity:

- Making the care of the patient their first concern;
- Treating the patient as an individual and respecting their dignity;
- Supporting and encouraging the patient to be involved as far as they wish and are able, in decisions regarding their treatment and care;
- Respecting the patient and not discriminating against them.

Best interests

The term “best interests” provides the benchmark against which lawful treatment of a patient lacking capacity is normally to be judged and as far as is reasonably ascertainable, orthoptists must consider:

- Patient’s past and present wishes and feelings;
- Their beliefs or values where they would have an impact on the decision;
- The likelihood that the patient will regain capacity and if so, to put off the decision until then;
The views close to the individual including family, friends and carer;

- The possibility of nominating someone to act under a lasting power of attorney or any deputy
  appointed to make decisions by the Court of Protection.

**Advance Decisions/ Directives**

The purpose of an advance decision is to extend patient autonomy. An advance decision/directive is a
statement made by a person at a time when they are competent, about how they would want to be treated in
the future were they to become ill and at the same time, incompetent to make decisions about or give
goodness for their treatment.  

**5.3 Expressions of consent and the recording of decisions**

Before accepting a patient's consent, orthoptists must consider whether the information has been given in a
manner that they want or need and are able to comprehend the details and implications of what is being
proposed. This is more important than how consent has been expressed or recorded.

Orthoptists may obtain consent in two ways:

- Implied consent
- Express consent

**5.3.1 Implied consent**

This is permission implied through the actions of the patient to a request to an investigation and to provide
treatment.

For example, in orthoptic practice, by tilting their head back for the instillation of drops or moving their hair
from the face for the application of an eye patch for vision assessment.

Orthoptists must recognise that just by turning up to hospital, it does not imply that the patient agrees to
treatment.  

**5.3.2 Express consent**

Express consent is a patient making it known to the orthoptist their willingness to be touched. It may be
written or oral.

Written consent is usually obtained where a procedure invasive such as surgery or perceived to carry a
material risk, and is often taken by means of a consent form. However, it is not sufficient to be able to
demonstrate either that the patient said "yes" nor is it to use tick boxes.

Orthoptists should be aware of the good practice of when obtaining consent, whether oral or written, that an
explanation of treatment and other material facts are recorded in the patient's file to corroborate the consent.
Consent must be contemporaneous.

**Role of the consent form**

A consent form provides a degree of evidential certainty to the orthoptist that the patient agrees to treatment.

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96 Mental Capacity Act 2005 (England and Wales); Adults with Incapacity (Scotland) Act 2000; Mental Capacity Bill 2008 for Republic of Ireland

97 O'Brien v Cunard SS Co 28 NC266 (Mass 1981)
A signature on a consent form does not itself prove that consent: the form, as described by the Medical Defence Union, serves as a “mechanism to provide evidence that the patient gave consent to the procedure on question and that it was obtained with due care and formality”. In Re: T (Adult: Refusal of Treatment) [1982], it was indicated that the consent form is only useful as the understanding of the person signing it. Orthoptists must be mindful of this in their practice.

Orthoptists must familiarise themselves with their Trusts’ policies for particular interventions and their own consent forms.

However, the Department of Health produces consent forms for a number of situations which are also available in an extensive range of languages to reflect cultural diversity:

- Patient agreement to investigation or treatment;
- Parental agreement to investigation or treatment for a child or young person;
- Patient/parental agreement to investigation or treatment procedures where consciousness is not impaired;
- Adults who are unable to consent to investigation or treatment.

5.4 Timing of consent

Orthoptists should be aware that as most surgery is not urgent, patients should be given plenty of time to think about their options before they consent to treatment and must be encouraged to ask further questions. This was a squint case. For many elective procedures, consent is taken in outpatient departments and sometimes, weeks in advance of admission. During that time, patients may wish to raise further questions and their condition may also change. It is good practice to confirm consent prior to the procedure using this an opportunity to ascertain if there have been any changes since consent was first obtained and to ask the patient if there are further questions.

5.5 Withdrawing consent

Orthoptists must recognise that consent is a continuous process and may be withdrawn at any time. A withdrawal of consent must be recorded and clearly distinguishable from an initial refusal to consent.

Orthoptists must accept that, in the event of a patient changing their mind and refuses to continue with treatment, the consent must ceases or trespass to the patient will occur. However, if the patient then decides to resume treatment, it is not necessary to explain the risk inherent in the procedure again.

5.6 Orthoptic practice

For the majority of orthoptic investigations, if the orthoptist is satisfied that the patient understands what is proposed, consent by implication or orally is usually sufficient. It is good practice to document in patients’ notes that consent has been gained. In cases that involve higher risk, it is important that written consent is obtained in order to ensure that everyone involved understands what has been explained and agreed.

98 Fitzpatrick v White [2007] IESC 51
5.7. Special considerations for consent

5.7.1 Carte blanche – blanket consent
Orthoptists must be aware of the concept of blanket consent with respect to surgical procedures, this enabling the surgeon to undertake surgery on the basis of findings at surgical intervention rather than delaying the procedure, this being particular useful in patients who have had previous surgery.

5.7.2 Consent in vision screening
Orthoptists involved in vision screening must ensure that they have a robust system for gaining consent to undertake vision screening and provide sufficient information to schools for parents to decide whether or not they want their child to be included in the screening visit. Ideally this should include the purpose of screening, the likelihood of positive/negative findings and follow up plans with respect to referral and treatment. Orthoptists need to be mindful of the need to provide the information in a number of languages to reflect the cultural diversity of the population within their area.

5.7.3 Education of students
Although it is not a legal requirement to inform the patient that the clinician is a student where the student undertakes investigations to further the patient’s care it is considered good practice for Orthoptists to inform the patient. However, if the student is performing investigations to enhance their education which is of no benefit to the patient, then consent must be sought prior to those investigations. Supervising Orthoptists should establish whether the patient is comfortable being assessed by a student and respect their wishes if they refuse to be seen by a student.

5.7.4 Audio and visual recordings
Orthoptists must ensure that consent is obtained for any audio or visual recordings including photographs and other visual images.
In addition, the purpose and future use of the recording to be made must be explained explicitly prior to seeking consent such as for audit, teaching or research purposes.
Orthoptists must also ensure that the patient is aware that if they refuse, their care will not be compromised and that, where possible, the recordings will be anonymised.

5.7.5 Research
Issues around consent in research are covered in Rule 12 – Research.
Rule 6: Duty to maintain records

Registered Orthoptists shall keep accurate records to maximise patient safety and high quality evidence-based health care on a day to day basis. They must keep such information secure and confidential in accordance with the legal, ethical and regulatory frameworks.

6.1 A health record

Data Protection legislation\(^{99}\) defines a health record as “a record consisting of information about the physical or mental health or condition of an identifiable individual made by or on behalf of a health professional in connection with the care of that individual”. The health records can be recorded in computerised or electronic form or a combination of both and include, in addition to what is required by an orthoptist, hand written clinical notes made during consultations, results of tests and their interpretation, consent forms, imaging films, video and audio-tapes, photographs, tissue samples, in addition to the correspondence between health professionals such as referral and discharge letters. They may also consist of other reports written for third parties, theatre list information and clinical audit data if the patient is identifiable from this data.

A health record has a primary purpose pertaining to a clinical and legal function and a secondary purpose for improving public health and services provided by the NHS.

With the establishment of NHS Connecting for Health, terminology to describe NHS records continues to dynamic and interchangeable. The Summary Care Record (SCR), formally the Electronic Health Record (EHR) applies to a longitudinal record of a patient’s lifelong health and health care combining information about a patient care contacts with primary health as well as subsets of information and episodic elements of care held in electronic patient records. Individuals can gain access to their Summary Care Record provided they are registered to use HealthSpace allowing them to have a degree of control of their healthcare and records. The Electronic Patient Record (EPR) refers to a record containing a patient’s personal details, their diagnosis and condition, and details of assessments and treatments undertaken by a clinician. Orthoptists must take responsibility for ensuring they are aware of their own country’s national policy on records and also ensure that they adhere to local policy\(^{100}\).

6.2 Information Governance

Information governance provides a framework which informs the NHS of the processes and procedures that must be adhered to in order to ensure that information is recorded clearly and accurately, kept secure and confidentiality is respected\(^{101,102}\).

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\(^{99}\) Data Protection Act 1998 Section 68(1)

\(^{100}\) NHS Care Record Guarantee 2011 and Health Service Executive


6.3 Duty to maintain records

Orthoptists must recognise that record-keeping, whether manual or electronic, is a professional requirement of all orthoptic practice and is essential to the delivery of high quality evidence-based health care. They have both a clinical and legal function.

Records facilitate clinical decision making, improve patient care through clear communication of diagnosis, treatment and its rationale and progress, and enable a consistent approach to team-working.

The legal function relates to use of notes as evidence where the standard of proof in a civil case of negligence is the balance of probability and thus failure to maintain records compromises any legal proceedings. It is customary practice for Human Resource departments to hold a record of any signatures in order to facilitate the interpretation of records should the need arise.

The legal framework covers ownership, security and access to records and is governed by a number of Acts.

6.4 Clinical function and principles of record-keeping

Orthoptists must respect the key features of good record-keeping and more specifically must ensure records are:

- Consistent, factual and accurate
- Written neatly and in black ink
- Written clearly, legibly and in such a manner that they cannot be erased
- Accurately dated, timed (24 hr clock) and signed with the signature being printed alongside the first entry and position
- Written contemporaneously or as soon after the interaction has occurred
- Chronological and consecutive
- Altered in acceptable manner by scoring out with a single line that does not obscure the error
- Consistent with the use of acceptable and approved abbreviations.

What to include:

- Orthoptists must recognise that records need to sufficiently detailed to demonstrate that the duty and standard of care have been maintained. They must include:
  - A complete record
  - Full investigation and results
  - Diagnosis and evidence of differential diagnosis where applicable
  - Details of treatment and information necessary for follow-ups, referrals
  - Evidence-based management plans (these may be made in conjunction with other members of the health care team)

103 Health Professions Council: Standards of conduct, performance and ethics/ Standards of proficiency (Orthoptics)/ Framework for Common Code of Professional Conduct and Ethics (Republic of Ireland)
Progress reports

Background and discussions within multi-disciplinary teams and outcomes

Copy of the clinical record of consent and associated discussions

Views of patients and relatives differentiated by use of “quotation marks”

Details of telephone calls, even if unanswered, to the patient or to others about the patient and any associated discussions arising with the time/ date and duly signed, possibly followed up by a letter if deemed necessary

All personal correspondence including letters, faxes, text messages, emails including correspondence between other health care professionals and the patient’s GP

Any differences of opinion on patient care

Record of non-attendance

Refusal of treatment.

The mnemonic SOAP is a useful reminder of the essential content to be included:

- **Subjective** – what the patient says
- **Objective** – what the health care professional detects – examination and results
- **Assessment** – conclusions – including a differential diagnosis
- **Problem list and plan** – management and follow-up

**Unacceptable practice:**

Orthoptists must take care not to adopt unacceptable practice when maintaining records and must not:

- Tamper with records including changing or adding entries once they have been signed without identifying the change, dating and signing
- Retrospectively alter records
- Use erasers, liquid paper or other obliterating agents to cancel errors
- Use unacceptable abbreviations, jargon, meaningless phrases, irrelevant speculations and offensive statements
- Include personal opinions regarding the patient.

Best practice would dictate that, in the event of amending notes, Orthoptists must enter the reason for this action unless it is deemed superfluous.

**6.5 The legal function of records**

Orthoptists must be aware that records may be required as evidence in legal proceedings and by the Health Professions Council for a professional misconduct hearing. This is where an appreciation of the need to avoid expressing and recording opinions is essential as they are open to interpretation and will be disputed. CORU is in the process of establishing its mechanism by which to handle complaints and it is envisaged that records will be required as evidence during investigations.
6.6 The legal framework of records

6.6.1 Ownership and security of records

The ownership of health records is the first basis on which access to health records is governed.

As regards to private patients, ownership is subject to the contract between the clinic and the health care professional such as the orthoptist. If a contract does not exist, the health record is owned by the clinic itself but if there is a contract, the health record status is dependent upon the relationship between the orthoptist and the patient. However, the ownership is normally vested in the clinic itself.

In the case of public patients i.e. NHS patients, NHS records are public records under the provisions of the Public Records Act 1958. More specifically, health records are held by the Trust whilst those held by the General Practitioner belong to the Strategic Health Authority. The Secretary of State for Health and all NHS organisations have a duty under this Act to make safe arrangements for the safe keeping under and eventual disposal of all records. Chief executives and senior managers of all NHS organisations are personably accountable for the safe keeping of records. Orthoptists in the Republic of Ireland are advised to familiarise themselves with the National Hospitals Office Code of Practice on Hospital Records Management which provides guidance on behalf of the Health Service Executive under S 39 of the Health Act 2004.

Orthoptists are accountable for any records, whether in manual or electronic form, that they create or use in the course of their duties and must ensure that records are kept safe and secure. On a practical level, an orthoptist must avoid leaving portable computers or similar, health notes and files in easily accessible areas and unattended in cars and when not being used, should be kept under lock and key. With respect to orthoptists working in the community, arrangements must be made to ensure that records are held securely in a lockable cabinet or, when transported, in the locked car boot and must never be left in the car overnight. Orthoptists must familiarise themselves with locally agreed procedures for safeguarding the information which will include the following:

- Ensuring the physical security of such records by locking them away when not required
- Ensuring that records and their binders are in a good state so information is held securely and any loose-leaf information such as test results are also properly secured thus preventing the loss of information from the records
- Maintaining security of access to information within the records so it cannot be read inadvertently by others
- Maintaining a written log of incoming / outgoing records through the use of a tracking system

NHS organisations should have protocols administered by the Caldicott Guardians and in conjunction with the Data Protection Act 1998 for the holding of electronic records and the Data Protection Act 1988 and Data Protection (Amended) Act 2003 (Eire). Further guidance can be found in Rule 7.

Orthoptists working in private practice should register as Data Controllers via Information Commissioners Office (UK) and Data Protection Commission for the Republic of Ireland.

104 Applies to all NHS Trusts in England, Scotland and Wales and Hospitals in Northern Ireland and the Republic of Ireland
6.6.2 Access to records

Individuals have a right to apply for access to health information held about them, and in some cases, information held about other people and all NHS organisations are required to have adequate procedures in place to enable patients to exercise this right. Rule 7 will address access to records.
Rule 7: Confidentiality

Registered Orthoptists shall ensure confidentiality and security of information acquired in a professional capacity and shall promote the dignity, privacy and safety of all patients. A duty of confidence arises when the patient discloses with the Orthoptist in circumstances where it is possible to expect that the information will be held in confidence.

7.1 Confidentiality

Confidentiality is an ethical tradition of health care and is encompassed within the Hippocratic Oath and relates specifically to respecting patient autonomy and a trusting relationship between the health care professional and the patient. A duty of confidence arises when one person discloses information to another in circumstances where it is reasonable to expect that the information will be held in confidence.

7.2 Professional duty of confidentiality

The professional requirement for confidentiality is stipulated in the Health Profession’s Council’s Standards of Conduct and CORU which stipulate that an orthoptist must respect the confidentiality of service users. This imposes a duty on orthoptists not to voluntarily disclose information gained in a professional capacity to a third party, enforced by the threat of professional discipline and potential removal from the HPC register.

7.2.1 Confidentiality and orthoptic students

To ensure that healthcare professional students are properly educated, students require access to confidential information about patients. From a legal aspect, patients have the right to refuse to be seen by students and to allow them to access their notes.

Orthoptic students have a duty to respect and keep confidential information about patients that they learn in the course of their clinical studies and it is expected that when they introduce themselves, they make it clear to patients that they are students and not a qualified Orthoptist.

In the event of a patient relaying something to the student Orthoptist and request that the student does not tell anyone else, it is advisable for the student not to promise to keep the information confidential but to share the information with their clinical tutor, rather than withhold that information that may ultimately prove to be significant either for the patient themselves or in the public interest.

7.2.2 Contractual duty of confidentiality

Confidentiality is an obligation for all NHS staff, contractors and volunteers and their contracts contain a confidentiality clause and those who breach confidence, inappropriately use of health records or abuse computer systems may lead to disciplinary action. HSE employees are also bound under a duty of confidentiality.

105 Health Professions Council: Standards of Conduct and Ethics (2008)
7.2.3 Legal duty of confidentiality

The legal duty is derived from case law and statutes which govern the storage, handling and disclosure of information.

The law of confidence is mainly a matter of civil law. The obligation arises out of a general duty on everyone to keep confidential information secret. In order to establish a breach of confidence, three elements must be satisfied:

- The information must have the necessary quality of confidence i.e. that the information is not generally known or available. Personal or intimate information would qualify and much health information is of this nature.
- The information has been imparted in circumstances giving rise to an obligation of confidence. The law has long recognised that particular relationships give rise to a duty of confidence such as health care professional- patient, client and solicitor and penitent and priest.
- The information has been divulged to a third person without the permission and to the detriment of the person originally communicating the information. An invasion of personal privacy will suffice.

In the event of revealing confidential information, Orthoptists could face a claim in negligence but the difficulty in such a claim would be the establishment of damages, these in tort usually being available for financial and physical loss as opposed to indignity and distress.

The Data Protection Act 1998 (DPA) forms the legal frameworks on the protection of individuals with respect to the processing of personal data and on the free movement of such data. Personal data is data that relates to an individual who can be identified from that data or from data and other information in the health professional's possession. In the Republic of Ireland, the Data Protection Act 1988 introduced to address concerns regarding the protection of data stored on computer (see Appendix 5).

The Computer Misuse Act 1990 it is a criminal offence to “hack” into a database to access confidential information. An offence under the Act is committed if an orthoptist has access to some parts of a database but who then accesses parts to which they are not authorised.

The National Health Service Act 2006 provides the power to ensure that patient identifiable information required to support essential NHS activity can be used without the consent of patients. This power can only be used to support medical purposes that are in the interests of the patients or the wider public in cases where consent is not a practicable alternative and where anonymised information is not sufficient.

Article 8 of the European Convention on Human Rights Act 1998 establishes a right to respect for private and family life. This right emphasises the duty to protect the privacy of individuals and, amongst its broad scope, preserve the confidentiality of their health records.

Orthoptists should be aware of the criminal aspect of records and confidentiality. Information is not property which is capable of being stolen but the piece of paper on which a medical report is written could be. If an orthoptist were to hand a medical report to a journalist, the journalist could be guilty of theft of the paper and

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107 Cornelius v De Taranto [2001] 68 BMLR 62
108 Lord Keith in Attorney General v Guardian Newspapers Ltd [1987]
109 Stephens v Avery [1988] 2 All ER 477
110 Margaret, Duchess of Argyll v Duke of Argyll [1967]
It therefore follows that if the orthoptist was to telephone a journalist and read out the report, there would be no conviction of theft.

### 7.2.4 Constitutional right to privacy

The right to privacy has been recognised by the Irish courts as a constitutional right as emphasised in *Kennedy and Arnold v Ireland* [1987] IR 587 in which the Supreme Court argued that the illegal wiretapping of two journalists was a violation of the Constitution and stated that:

“Though not specifically guaranteed by the Constitution, the right to privacy is one of the fundamental personal rights of the citizen which flow from the Christian and democratic nature of the State . . . . The nature of the right to privacy is such that it must ensure the dignity and freedom of the individual in a democratic society. This cannot be insured if his private communications, whether written or telephonic, are deliberately and unjustifiably interfered with.”

### 7.3 Protection of patient information

Orthoptists must ensure that any personal or confidential information about patients is protected effectively at all times and is not discussed improperly.

Patient information must be protected through a number of mechanisms:

- Keeping patient information private by not discussing identifiable information about patients where it may be overheard, for example, in a public place or an internet chat forum.
- When seeking advice about a patient’s care and treatment with a colleague, it is done in private so confidentiality is not inadvertently breached.
- Having personal ownership of passwords and not sharing them under any circumstances.
- Ensuring patients’ records either paper or on screen are not left unattended or where they can be seen by other patients, unauthorised healthcare staff or the public, for example, in clinics or on corridors.
- Becoming familiar with and following policies and procedures designed to protect patients’ privacy whilst working and when using computer systems. This includes laptops and portable media storage devices.
- Ensuring that patient information is stored securely either physically and electronically. Ideally, administrative information such as names and addresses should be accessed separately from clinical information so sensitive information is not displayed automatically.
- Ensuring that information is shared only with appropriate carers as and when agreed (refer to Rule 3 – Sharing information with patient’s relatives, partners, carers and friends).
- Ensuring that, in the event of an enquiry, that the enquirer is identified and orthoptists must check that callers, whether in person or by telephone, are who they say they are. Official identification must be sought: in the case of a telephone call, a return call can provide a check of identification.

#### 7.3.1 Role of Caldicott Guardians

Orthoptists should familiarise themselves with Caldicott Guardians. Each NHS organisation has a guardian of person-based clinical information who oversees the arrangements for its use and sharing. They ensure

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111 [https://www.privacyinternational.org/article/phr2006-republic-ireland#5](https://www.privacyinternational.org/article/phr2006-republic-ireland#5)
that patient-identifiable information is only shared for justified purposes and that only the minimum necessary information is shared in each case. More information is in Appendix 6.

Confidentiality is an important but not an absolute duty and personal information can be disclosed in certain situations if for example, the patient consents, or if it is required by law or is justified in the public interest.

### 7.6 Disclosure of information

Ideally, patients’ consent should be sought for use of information thus respecting the patients’ autonomy and ensuring that trust is maintained between the orthoptist and the patient.

All health care professionals have a professional ethical duty to respect patients’ confidentiality and should only access record if they are involved in the patient’s care. This is on a “need-to-know” basis.

#### 7.6.1 Disclosure with implied consent

An ever-widening circle of health care professionals legitimately have access to patient’s health records. Without access to health records and the sharing of information amongst health professionals and providers, the provision of appropriate diagnostic and therapeutic care would be impossible.

**Sharing information within the healthcare team or with other professionals providing care**

- Most patients understand and accept that sharing information within the health care team is in their best interests in order to provide optimum quality care. An orthoptist should ensure that such information is known to the patient explaining that personal information about them will be shared within the team, for example, within a paediatric assessment team or stroke rehabilitation team and within the ophthalmic team, and including administrative and other staff that support the provision of health care.

- An orthoptist must respect the wishes of any patient who objects to particular information being shared within the healthcare team or with others providing care, unless disclosure would be justified in the public interest such as driving with a visual disability.

- An orthoptist must ensure that anyone to whom information is disclosed is given in the strictest of confidence and is consistent with the legal duty of confidentiality.

- In the event of a patient objecting to the sharing of information, the orthoptist must explain that further treatment cannot be arranged and undertaken thus affecting the patient’s quality of care provision.

**Sharing information with the patient**

Although orthoptists have diagnostic roles, they are only permitted to inform a patient of their diagnosis when they are the health care professional responsible for that patient’s care. In the event of a patient being uncertain of the reasons for their referral, the orthoptist is advised to adopt a neutral approach and avoid being drawn into discussing the underlying cause.

**Use of information for purposes of clinical audit:**

- Orthoptists have a duty to participate in clinical audit. Measures need to be taken to ensure that in the event of disclosing identifiable information, the patient
has appropriate access to information informing them that their personal information may be disclosed for a clinical audit and that they have a right to refuse and

has not refused.

In the event of a patient refusing, the orthoptist should offer an explanation for the need for information and the likely benefits to their own and other patients’ care.

In the event of clinical audit being undertaken by a different team from those involved directly in the care and support, the information should be anonymised or coded. However, if this is not possible or the information is essential for the audit, information can only be disclosed if the orthoptist has gained expressed consent from the patient.

7.6.2 Disclosure with expressed consent

In the event of being asked to provide information to third parties such as a patient’s employer, insurance or a government department or agency, disclosure can only be undertaken if the following is respected and can be ensured that:

- The patient has sufficient information regarding the extent, purpose and likely consequences of the disclosure and that relevant information cannot be withheld;
- The patient or the person with the responsibility has given consent;
- Only factually substantive information presented in an unbiased manner is disclosed;
- The patient has been given the option to see a copy of their report for employment or insurance purposes before it is sent unless it is considered potentially harmful to the patient or there is a risk that information about another person may be revealed and or the patient may have indicated that they do not wish to see the report.

However, if it is not practicable to gain consent, information can be disclosed if it is required by law or it is justified in the public interest.

7.6.3 Disclosure in the public interest

Disclosure in the public interest may be primary where the purpose is to protect individuals or society from risks of serious harm such as crime, or secondary to enable research, education or other uses of information that will benefit society over time.\(^{112}\)

**Primary disclosure to protect**

Maintaining confidentiality within health care encourages people to seek advice and treatment and benefits not only individuals but society as a whole. It is considered acceptable to disclose in the public interest in order to protect individuals or society from risk of serious harm or to enable the advancement of research and education and the planning of health care provision.

\(^{112}\) The rules regarding disclosure of information in the Republic of Ireland are consistent with those for UK and Northern Ireland
It is good practice to gain the patient’s consent but where this is not possible breach of confidentiality is permissible if the benefits to an individual\textsuperscript{113} or to society\textsuperscript{114, 115} of the disclosure outweigh both the public and patient’s interests in keeping this information confidential. The harms must be weighed up against the possible harm to the patient and the public and the overall trust of the orthoptic-patient relationship.

Prior to any disclosure of personal information, consideration needs to be given whether it should be anonymised or is practical to do so.

Orthoptists must document the breach of confidentiality including the steps to seek the patient’s consent, to inform them of the disclosure and reasons for the disclosure without consent.

**Disclosure for medical reasons**

Orthoptists\textsuperscript{116} may be confronted with the need to disclose to the Driver and Vehicle and Licensing Agency (DVLA) who are legally responsible for determining whether a person should be deemed medically unfit to drive. The DVLA needs to know if a driving licence holder has a condition or is receiving treatment for a condition that is affecting a person’s ability to drive safely both presently and in the future.

Orthoptist should seek advice of a more senior colleague or the DVLA if they are not sure whether a patient is fit to drive or not.

Orthoptists must realise that the patient is responsible for informing the DVLA about such a condition or treatment. However, the Orthoptist has a duty to:

- Explain to the patient that the nature of their condition may affect their ability to drive and
- That they have a legal duty to inform the DVLA about the condition.

In the event of the patient refusing to accept the diagnosis or the effect of their condition on their ability to drive, the orthoptist should suggest that they seek a second opinion and help them to do so, but, in the interim period advise them to refrain from driving, giving them reasons for the advice.

In the event of the patient continuing to drive, the orthoptist should make every reasonable effort to persuade them to do so. The refusal of the patient to stop can be discussed with the patient’s relatives, friends and carers but only if the patient consents.

If the orthoptist is unable to persuade the patient to inform the DVLA, the orthoptist is justified to contact the DVLA immediately and disclose the relevant information in confidence. Preferably, the orthoptist should gain consent from the patient but a breach of confidentiality would be justified on the grounds of public interest\textsuperscript{117}.

Documentation must be included in the notes and a notification in writing to the patient sent.

**Secondary disclosure to benefit society**

Disclosure of information about patients for the purposes such as epidemiology, administration and planning of health services, public health surveillance, research and education and training is unlikely to have personal consequences for the patient but provide a wealth of information that can be used to benefit society.

\textsuperscript{113} Tarasoff v Regents of the University of California [1976] 17 Cal 3d 425; 552 P 2d 334

\textsuperscript{114} W v Edgall [1990] 1 All ER 835 (CA)

\textsuperscript{115} Palmer v Tees Health Authority [2000] PIQR1

\textsuperscript{116} Orthoptists in Northern Ireland are advised to refer the Driver and Vehicle Agency (the guidance being similar to those of the DVLA) and those in the Republic of Ireland to the Road Safety Agency where guidance is sparse

\textsuperscript{117} Duncan v The Medical Practitioners Disciplinary Committee [1986 ] 1 NZLR 513
in the future. In these circumstances the orthoptist should still obtain patients’ express consent to the use of
identifiable data or make arrangements for the data to be anonymised.

Where this is not practicable, the orthoptist must be satisfied that they have at least been informed in writing
of the intended disclosures:

- That their record may be disclosed to persons outside the team that provided their care
- Of the purpose and extent of the disclosure to produce anonymised data for use in education,
  administration, research and audit
- That the person given access to the records will be subject to a duty of confidentiality
- That they have a right to object to such a process and that this will be respected unless there is a
  need to protect the patient or someone else from harm.

Publication of patients’ personal information

Orthoptists must obtain express consent from patients before publishing personal information about them as
individuals in a media form to which the public has access such as in journals, textbooks, presentations and
teaching material, irrespective of whether or not you believe the patient can be identified. This covers
material such as case histories, photographs, videos and audio material.

7.6.4 Disclosures required by the judiciary or statutory bodies

Disclosures may be required by statute and by the courts.

The Health Professions Council has statutory powers to access patients’ records as part of the duty to
investigate complaints and an orthoptists’ fitness to practise. Whenever possible, patients should be
informed about such disclosures. If the patient refuses to consent, then the orthoptist can contact the HPC to
whether disclosure can be justified in the public interest.

An orthoptist must disclose information if ordered by a judge or court officer. If the information is deemed to
be irrelevant, the orthoptist has good grounds to object to disclosure. For example, this may include
information about another person not involved in the proceedings.

An orthoptist must not disclose personal information to a third party such as a police officer, officer of the
court or a solicitor unless required by law or can be justified in the public interest.

7.6.5 Disclosure about patients who lack capacity to consent

Orthoptists may be required to disclose information about patients over the age of 18 years who lack
capacity (such as stroke patients) and must ensure:

- The care of the patient is their main concern
- Respect the patient’s dignity and privacy
- Support and encourage the patient to be involved, as far as they are able, in decisions about
disclosure of their personal information

118 To include: Road Traffic Act 1998, Prevention of Terrorism Act 1989 (England, Scotland and Wales); Children Act
1989 (England and Wales); Children (Scotland) Act 1995; Road Traffic Act 2010 (Republic of Ireland); Terrorism
However, orthoptists must also consider whether there is any evidence of previously expressed preferences, if the lack of capacity is temporary or permanent and if there are views from other representatives that the patient may request you to consult.

### 7.6.6 Disclosure when abuse or neglect is suspected
Orthoptists owe a duty of care if they believe that a patient who lacks capacity to consent to disclosure, may be a victim of neglect or abuse (physical and emotional or even sexual abuse). The orthoptist must give information promptly to an appropriate responsible person within the Trust if you believe that disclosure is in the patient’s best interest. If, on the contrary, the Orthoptist considers that it would not be in the patient’s best interest, discussions with a more senior and experienced colleague are essential. Whether or not the orthoptist discloses, they must document any decisions/action taken in the patient’s record. More information regarding safeguarding of patients is covered in Rule 8.

### 7.6.7 Disclosure after the a patient’s death
The duty of confidentiality continues after the patient has died. It is unlikely that Orthoptists will be asked to disclose information and they are advised to refer the request to a senior colleague, namely the consultant.

### 7.7 Access to health records
Health professionals, including orthoptists may receive requests from people (who may include the patient and third parties such as solicitors) wishing to view or obtain copies of their own health records or those of others.

The main legislative measures that give rights of access to health records include:

- Data Protection Act 1998 (UK including Northern Ireland)
- Data Protection Act (Processing of Sensitive Personal Data) Order 2000
- Data Protection Act 1988 and Data Protection (Amendment) Act 2003 for Eire
- Access to Health Records Act 1990 (UK including Northern Ireland)
- Access to Medical Reports Act 1988 (UK including Northern Ireland)

The Freedom of Information Act 2000 for the UK and Northern Ireland (but excluding Scotland)\(^\text{119}\) makes provision for the disclosure of information which is held by public authorities and those who provide services to public authorities (including the NHS). It is not intended to allow people to gain access to private sensitive information such as information held in health records, the mechanism for which is through the Data Protection Act 1998.

Orthoptists must be aware of the main principles regarding disclosure of information access to health records other than the everyday use with other health professionals and thus be familiar with the purposes of the Acts in the event of receiving requests from patients or other individuals for which a charge is made.\(^\text{120}\)

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119 Similar law covering Scottish public authority exists in Scotland – the Freedom of Information (Scotland) Act 2002

7.7.1 Who may apply for access?

**Competent patients**
Competent patients may apply for access to their own records and may authorise third parties such as employers, insurance companies and lawyers to do so on their behalf, but in writing.

**Children and young people**
Competent young children (under the age of 16 years) may apply for access to their health record without providing evidence for the reason, provided that they meet Gillick/ Fraser competence. Access can be denied in the event of the Orthoptist or other health professional believing that the child is not capable of understanding the nature of the application for access. Where a child is considered competent to make decisions about their own medical treatment, the consent of the child must be sought prior to a parent or other third party can be allowed access.

**Parents or those with parental responsibility**
Parents may have access to their children’s health records if this is not contrary to a competent child’s wishes, as in the case of those with parental responsibility. In exercising this right, the orthoptist must give careful consideration to the duty of confidentiality owed to the child prior to disclosure. Access can be denied to a parent or an individual with parental responsibility where the information within the child’s records is likely to cause serious harm to the child or another person.

**Individuals on behalf of adult patients who lack capacity**
An individual’s mental capacity must be judged in relation to the particular decision being made, in accordance with the Mental Capacity Act 2005. In the event of a request for access by relatives or third parties, patient consent is required. Where patients do lack capacity, orthoptists and other health professionals may share information with any individual authorised to make proxy decisions and these nominated individual can be asked to consent to requests for access to health record but in the event of there being no such individual, access to health records must only be given if it is considered to be in the patient’s best interests.

**Next of kin**
A next of kin has no rights of access to health records.

**Police**
The police have no rights to access to health records although a health professional may consider it appropriate to breach confidentiality in some cases.

7.8 Data Protection Act 1998
In the case of living people, access to their health records is governed by the Data Protection Act 1998 (DPA). The DPA is not confined to health records held by NHS bodies: it is equally important in relation to the private health sector, employers who hold information relating to the physical and mental health of their employees if the record has been made by, or on behalf of, a health professional in connection with the care

121 Applies to all of the UK
of the employee. Under the DPA, “data subjects” (patients) have the right (“subject rights”) to be told by “registered data users” (Orthoptists) whether personal information is held on computer.

Data Protection Act (Processing of Sensitive Data) Order 2000 allows for sensitive personal data (such as relating to mental or physical health) may be lawfully processed where there is substantial public interest without expressed consent.

Reference to the Data Protection Act 1988 and Data Protections Act (Amended) 2003 (Eire) will be made in conjunction with the Freedom of Information Act 1997 and Freedom of Information Act (Amended) 2002.

### 7.7.1 Process and principles of access

#### Requests for access and granting access

The data controller is responsible for dealing with an access to health record request and has a legal entitlement to establish the purposes for which and the manner in which personal data is recorded.

Requests for access to health records should be made in writing on a form or letter or electronically and are referred to as Subject Access Requests (SAR) to the data controller and, providing that it is evident that consent has been given about whom that information is required, will enable the access.

The request should be complied with within 21 days (for health records). In the event of additional information being required before copies can be sent, then the time limit commences as soon as the additional information has been received.

In principle, there is no time limit after which consent for disclosure of information becomes invalid but it is good practice for the health professional to contact the patient to confirm that they are still willing to agree to the disclosure significant time has elapsed since the patient signed the letter or form and particularly if it is to be used by a third party.

An orthoptist may be consulted to assist with subject access requests on the following grounds, as set out by the Data Protection (Subject Access Modification) (Health) Order 2000:

- They are currently or were the most recent health professional responsible for the clinical care of the data subject in connection with the information which is the subject of the request; or
- Where there is more than one health professional and the orthoptist is the most suitable to advise on the information which is the subject of the request.

#### Cost of access

This is determined by the Secretary of State and is dependent on whether the records are held manually, either in full or in part, where it is £50 or on the computer for which the charge is £10, for providing access to and/or supplying copies.

#### Reasons for withholding access and not disclosing information

Each application for access to health records should be considered carefully with respect to whether:

- It is likely to cause serious physical or mental harm to the patient or another person who may be readily identifiable; or

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122 40 days for other requests for information
It relates to a third party who has not given consent for disclosure (i.e. that third party is not a health professional who has cared for the patient); or

It is requested by a third party and the patient had asked that the information be kept confidential; or

It is restricted by order of the courts; or

The records are subjected to legal professional privilege for the purposes of litigation.

As “data controllers” orthoptists should be aware of the need to block out any withheld information and that those reasons do not need to be justified. The “data controller” is not obliged to inform the patients of the grounds on which information is withheld.

Arrangements to view records

Once the appropriate fee has been paid, a date needs to be set for the relevant records to be viewed.

The DPA does not expressly allow patients to read their records where a copy is not required although they are permitted to do so with the agreement of the “data” controller but it is advisable for the appropriate health professional to be present to be able to explain terms and ensure that the patient does not alter their record. There may be occasions when a neutral person supervises the viewing.

However, there is nothing in the law that prevents health professionals from informally showing patients their records as long as no other provisions of the Act are breached. For example, orthoptists can show patients changes in the serial record of progress of their condition such as with Hess charts.

Amendment of health records

Orthoptists must not amend records because of a request for access. They must be aware that with patients’ rights to access, the need to maintain records as accurate and up to date cannot be overemphasised, this forming the legal basis for enforcing the correction of any inaccuracies. Amendments to such can be made and be clearly marked but if there is disagreement between the orthoptist and patient, then the data controller permits the patient to include a statement with their records to that effect.

7.9 Access to Medical Reports Act 1988 (UK including Northern Ireland)

Access to Medical Reports Act 1988 governs access by patients to medical reports made by a medical practitioner who is or has been responsible for clinical care of the patient for either insurance or employment purposes. Reports prepared by other medical practitioners such as those contracted by the insurer or employer, are not covered by the Act, these being covered by the Data Protection Act 1998.

In the event of an orthoptist receiving a request for a report, the patient must be contacted in order to provide consent but they do have the option of refusing consent for a report to be written about them. The patient has access to the report at any time prior to the submission to the insurer/employer and can request, in writing, amendments in the event of any part of the report that the patient considers incorrect. These amendments must be attached to the original report or the report re-written.

Access to the report by the patient may be denied in the main on the potential harm to physical and mental health of the individual or if a third person can be identified who has not consented to the release of the information or who is not a health professional involved in the individual’s care. The orthoptist must retain a copy of the report for at least six months following its supply to the insurer/employer during which time patients have a right of access but only by arrangement for a viewing.
7.10 Access to Health Records Act 1990 (UK including Northern Ireland)

Access to Health Records Act 1990 gives rights of access to deceased patients’ health records by specific individuals. These individuals are defined under Section 3(1) (f) of the Act that the patient’s personal representative and any person who may have a claim arising out of the patient’s death, and is the executor or administration of the deceased person’s estate. Individuals other than the personal representative only have a legal right of access where they can establish a claim arising from a patient’s death. Evidence of identity and to support their claim is required. The information that can be accessed is restricted to that covered by the Access to Health Records Act and applies to manually created health records made since 1 November 1999.


7.11.1 The Freedom of Information Act (FOIA)

The FOIA provides legislation regarding access to information in visual, written or electronic form and gives individuals rights to access personal information and non-personal information, have personal records amended or deleted where the information is inaccurate, incomplete or misleading and to seek reasons for decisions affecting them.

Under the FOIA, “Personal information” is defined as: “information about an identifiable individual that (a) would, in the ordinary course of events, only be known to individual or members of the family, or friends, of the individual, or (b) is held by a public body on the understanding that it would be treated as confidential”. Personal information thus includes personal health information. The FOIA applies only to public bodies and thus any health records held by a private practitioner, hospital or clinic are not accessible under the Act.

7.11.2 Making requests

Requests for information can be made for any records relating to yourself individually, regardless of when they were created, or all other records created after 21 April 1998.

Requests for information should be made in writing stating the request is being made under the FOIA and addressed to the FOI Liaison Officer of the public body, providing as much information as possible as to allow the public body to find the information and stating the format in which it is required.

Requests for amendments to a record should identify the record concerned and the actual amendment supported with evidence for the need for the amendment to be made.

Costs for requests

It is unlikely that fees will be charged in respect of personal records but in the case of fees being charged, the fees range from €15 to €150 depending upon the nature of the request (initial request for a record or internal reviews or reviews by information commissioner) whereas applications for amendments to incorrect information and reasons for a decision which may affect an individual are free. Fees for searching, retrieval

123 Health Service Executive, voluntary hospitals, major providers for those with physical and intellectual disabilities (http://foi.gov.ie/bodies-covered-by-foi/ - accessed March 2012)
and copying of records range from a few cents for photocopying to €10 for CD-ROM containing copy of
documents to €20.95/ per hour for labour costs involved.

**Reasons for denying requested information**

Exemptions provided for in the Act identify circumstances when requested information may not be released, for example to protect the confidentiality of another person. The Office for Information Commissioner is responsible for considering requests. Under the FOIA Section 28(3) access can be denied where release of the record might be prejudicial to the person’s physical or mental health, well-being or emotional condition but under Section 28(4) this information may be provided through a nominated health professional. This reinforces the position that rights of access to medical records are more restricted than other records. Further examples for exemption include circumstances where the request is deemed to be frivolous, vexatious or voluminous or the record would disclose deliberations of a public body.

**7.11.3 Freedom of Information Act and Data Protection Act**

Similarities and differences exist between the FOIA and DPA. The essential principle of data protection is the protection of individual privacy and ensuring safeguards are in place where personal information is collected, used, disclosed or transferred to other persons and even other countries. The DPA impose obligations on the individual, agencies, organisations and public bodies to keep the information private whereas the principle of the FOIA is that there should be access to records held by or under the control of public bodies whilst respecting the need to be consistent with the public interest and the right to privacy. Where a request for access is refused under the FOIA, the applicant can seek access under DPA.

**7.11.4 Special considerations regarding access**

**Parental access to records in relation to children**

Under the FOIA 1997 (Section 28(6)), regulations in 199 allowed parents and next of kin to access records on behalf of relatives who were unable to exercise their own rights of access themselves. Following McK v The Information Commissioner [2006] IESC 2 (see Appendix4), it was held that “as a matter of Constitutional and family law, a parent has rights and duties. In general, a parent would expect to be given medical information about his or her child. It would only be in exceptional circumstances that medical information about a child would not be given to a parent or guardian”.

**Access to records of deceased person**

Under the FOIA Regulations of 1999, superseded by 2009 Regulations, access to health records of the deceased may be given to three specific categories of people with specific interests:

- The deceased person's personal representative acting in the course of administration of his estate or someone acting with the consent of the personal representative or
- A person on whom a function is conferred by law in relation to the deceased person or his estate acting in the course of the performance of this function or
- The spouse or next of kin of the individual, where in the opinion of the head of the public body concerned, the public interest would, on balance, be better served by granting than by refusing to grant the request.125

Rule 8: Duty to report

Registered Orthoptists have a duty to report, to an appropriate authority, any concerns that may put patients, others or themselves at risk. These include unsafe working environments and practice, professional misconduct of colleagues and concerns regarding child protection. Registered Orthoptists also have a duty to ensure the necessary procedures are in place to minimise risk.

8.1 Introduction

The legal framework advocates a safe working environment, protection of children and vulnerable adults, and of professionals and respect for equality and diversity, further supported by health and social policy. The NHS Litigation Authority (2007) estimates that £500 million is paid out annually by the health service in compensation claims and fines for breaching health and safety laws.

Orthoptists are under a professional duty to act in the best interests of the service user and to report any concerns regarding their workplace which may put the safety of patients, visitors, others and themselves at risk. A duty to the patient under Article 2 of the Human Rights Act 1998 places a positive obligation on the NHS to protect life and under Article 3, torture and inhuman or degrading treatment are prohibited but what constitutes this is open to interpretation but nevertheless, there exists a duty to protect the patient from harm.

These concerns may be related to:

- Another colleague’s conduct, performance or health, unprofessional behaviour including issues related to equality and diversity
- Environment in which care is being delivered such as resources, products, people, staffing or organisational concerns
- Health and safety violations
- Clinical equipment
- Inadequate premises

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125 Freedom of Information Act, Regulation 2009, Regulation 4 (1) (b) (iii)


127 Statistics for the Republic of Ireland are unreliable but a figure for 2003 was of €32 million being paid out for medical negligence cases, representative of a 300% increase from 2002. (Irish Medical Insurance Association)

128 Health Professions Council: Standards of conduct, performance and ethics (Standard 1) and the Framework for Common Code of Conduct and Ethics.

129 As determined from the European Convention of Human Rights (articles consistent between HRA 1998 and the European Convention)
Orthoptists must act without delay if they believe that they or a colleague or anyone else may be putting someone at risk.

Orthoptists have a duty to familiarise themselves with and the use of clinical governance and risk management structures and processes within their Trust.

8.2 **Health and safety law**

The NHS as an employer has a legal duty to comply with the requirements relating to health and safety at work to prevent the avoidable loss of life and minimise days lost to absence. The Health and Safety at Work Act 1974 (see Appendix 5) is the basis of health and safety in the UK and sets out general duties that:

- Employers have towards employees and members of the public using their service
- Employees have to themselves and to each other.

Breaching or failing to comply with these duties constitutes a criminal offence.

Orthoptists must recognise that, as employees, it is their duty to:

- Take reasonable care of their own health and safety and of any other person who may be affected by their acts or omissions;
- Cooperate with their employer so far as is necessary to enable that employer to meet their requirements with regard to statutory provisions.

8.2.1 **Health and safety regulations**

The Health and Safety at Work Act 1974 is supplemented by a wide range of secondary legislation in the form of regulations and orders focus on specific areas of workplace health and safety, some of which are listed in Appendix 5.

Orthoptists have a duty imposed on them to be involved in workplace health and safety which requires the representative to:

- Consult with and be consulted by employers regarding:
- The introduction of measures that may affect health and safety
- Arrangements for appointing competent persons to assess risks
- Provision of health and safety information and training
- Investigate hazard, accidents and complaints
- Make representation to the employer on health and safety matters
- Perform workplace inspections
- Be given time off to perform their duties and undertake health and safety training.

8.2.2 **Managing health and safety**

The Health and Safety Executive (2006) requires workplace health and safety to be managed methodically to ensure that risks are minimised.

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130 Safety, Health and Welfare at Work Act 2005 (Republic of Ireland) (see Appendix 5 for further information)

131 Section 7 of Health and Safety at Work Act 1974
Orthoptists have a legal duty to:

- Assess and monitor risks:
  - Including assessment of risks associated with performing workplace tasks and identification of any workplace precautions that may be required and their successful implementation;
  - Monitoring through inspection and risk assessments;

- Review and audit:
  - Performance must be reviewed against an audit of documentation such as workplace inspections, risk assessments, accident and reports and attendance on health and safety training courses.

Orthoptists have a professional duty to not only act in the best interests of service users with respect to health and safety but also in minimising and managing risk of infection.

8.2.3 Workplace risk assessments

A risk assessment is the identification of hazards present in the workplace and an estimate of the risk associated with performing a task.

A hazard is something that has the potential to cause harm and a risk is the likelihood of that hazard causing an accident.

Orthoptists must give careful consideration to their working environment and take into consideration the diverse age range of patients when undertaking risk assessments. Orthoptists within a department must be encouraged to adopt a team approach to identify hazards and risks to ensure that it is complete.

Orthoptists should refer to their employer’s policy for further guidance.

8.2.4 Reporting accidents and incidents

Reporting accidents and incidents at work is an essential component of monitoring the effectiveness of health and safety measures, and preventing the recurrence of an incident.

Orthoptists have a duty to report adverse incidents or near misses arising out of or in connection with work to enable issues to be addressed, problems rectified and lessons learned without patients and others being harmed.

Orthoptists must recognise that there is a legal requirement to report certain categories of accidents that occur within the workplace to the Health and Safety Executive under the Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 1995.

8.3 Reporting conduct, performance or health of a colleague

Orthoptists have a professional duty to protect service users if they believe that any situation puts them in danger. There are specific procedures to which Orthoptists should adhere as far as is reasonably practicable.

Orthoptists in the Republic of Ireland are advised to contact the Health Service Executive and CORU for advice.

132 See Appendix 5 for Republic of Ireland

133 See Appendix 5 for Republic of Ireland
8.3.1 Potential obstacles to reporting

It is not uncommon for health professionals to be reluctant to report concerns and concerns are usually able to be addressed more effectively if the identity of the person reporting is known.

Orthoptists may be worried because they fear that it may:

- Cause problems with colleagues having an adverse effect on working relations
- Have a negative impact on their career or
- Result in having a complaint made against them.

However, it is imperative that concerns are raised and these fears do not affect your duty to do so.

- Orthoptists must remember their duty to put patients’ concerns first and override personal and professional loyalties
- Orthoptists who disclose information that raises serious concerns and exposes poor practice in the workplace are entitled to legal protection via the Public Disclosure Act 1998 against victimisation or dismissal
- Orthoptists are justified in raising a concern if they have done so promptly, with probity and through the appropriate mechanisms.

8.3.2 Mechanism for reporting

Orthoptists are advised to follow their employer’s “Raising Concerns” or “Whistle Blowing” policy. This should provide advice on how to raise their concern and provide details of a designated person who has responsibility for dealing with concerns in their Trust. Initially, an orthoptist may raise the concern with their line manager.

Orthoptists may wish to contact the Society for further guidance or the charity, Public Concern at Work (PCaW) who have a wealth of expertise and can provide independent and confidential support during the process.

Orthoptists must:

- Be clear, honest and objective about the reason for their concern
- Maintain a record of their concerns and the measures taken to resolve the concern.

Orthoptists may wish to escalate the concern by referring the concern to the appropriate regulatory authority\(^{134}\) with powers to investigate in the event of:

- Being dissatisfied from raising the concern through local channels
- An immediate risk to patients from a colleague and the regulatory body needs to be made aware of the concern straightaway. If this happens, it is pertinent to inform the employer of your actions
- The responsible person or the Trust being the major factor of the concern.

\(^{134}\) This may be the Health Professions Council, General Medical Council, General Optical Council, Nursing and Midwifery Council
8.3.3 Going public

Orthoptists may consider making their concerns public but must be mindful of breaching patient confidentiality, only if they feel the concern has not been resolved by any level of authority whether it be internal or external, and they have good reason to believe that patients are still at risk of harm. They are encouraged to seek guidance before making a decision of this nature.

8.3.4 Public Interest Disclosure Act 1998

The Public Interest Disclosure Act 1998 (PIDA) was introduced to provide protection for those who raised genuine concerns about wrongdoing or malpractice in the workplace and when doing so, are acting with good faith and in the public interest and not for personal gain and are subsequently victimised and/or dismissed for doing so.

The Act has a tiered approach to disclosure which at its lowest level, provides protection for raising concerns internally but it also offers protection for disclosure to regulatory bodies and in exceptional circumstances for wider disclosures.

Orthoptists are strongly urged to seek further advice in the event of disclosing135.

8.4 Child protection

Orthoptists have a duty to participate in child protection procedures and must safeguard and protect the health and welfare of children136.

Orthoptists need to be mindful of the processes of reporting and be familiar of the personnel to contact within their Trust or Hospital or Health Board. Every organisation has a designated person with responsibility for co-ordinating child protection services.

Orthoptists are advised to discuss the concerns with their manager, a named or designated health professional or member of staff, depending upon the organisational setting.

Child abuse may be categorised into four different types; neglect, emotional abuse, physical abuse and sexual abuse. Orthoptists must be aware of the indications of some form of abuse involving:

- Injury or behaviour consistent with abuse or an innocent explanation;
- Evidence of injury/ behaviour consistent with child abuse;
- Indication from the child that he or she is being abused.

Orthoptists should consult the appropriate documentation for their own member country but may include:


135 May include: Care Quality Commission/ Department of Health (England); Health Inspectorate Wales/ Care and Social Service Inspectorate; Scottish Commission for Regulation of Care/ NHS Quality Improvement/; Regulation and Quality Improvement Authority Northern Ireland/ Department of Health, Social Services and Public Safety/ Health Service Executive (Republic of Ireland). See Appendix 5 for further information.

136 United Nations Convention of the Rights of the Child (UNCRC)


Orthoptists must recognise that confidentiality is important and information sharing must be proportionate to the risk of harm.

Duty 9: Relationships with professional staff and others

Registered Orthoptists shall cooperate and work collaboratively with professional staff, external agencies, students and carers in the interests of the patients and shall avoid inappropriate criticism of their colleagues.

9.1 Obligations

Orthoptists, although autonomous practitioners, must work in an inter-professional manner to encourage the development of multi-professional working and professional relationships in order to promote the collaborative delivery of integrated patient-centred care and quality health care and improved job satisfaction. Such inter-professional working is informed by NHS policy 140. Orthoptists may involve working independently or in teams with colleagues within an ophthalmic care team (ophthalmologist, optometrists, ophthalmic nurses and technicians) but also in multi-disciplinary/professional teams such as rehabilitation and paediatrics and in a variety of locations.

Orthoptists must also take every opportunity to promote understanding of their profession and the contribution they make to, not just their roles within the ophthalmic team, but in their extended scope of practice.

Orthoptists also have an obligation to work professionally by:

- Assisting other health care in professional practice by, for example, educating health visitors and nurses about vision screening or educating specialist junior medical staff
- Assisting in the clinical education of orthoptic undergraduates in line with the government’s educational governance policies and to enable the professions’ further development
- Initiating and maintaining effective interaction with relevant external agencies including other health care professionals
- Deploying and managing staff effectively and efficiently.

9.2 Work effectively as part of a team

As an orthoptist working in a team, their professional accountability for professional conduct and care provided must not change. Orthoptists should aim to motivate and inspire their colleagues.

Orthoptists must:

140 Orthoptists working in the Republic of Ireland are guided by the HSE’s Code of Standards and Behaviour (2009) and emerging frameworks such as the Framework for Common Code of Professional Conduct and Ethics and Action Plans for Health Service (Improving Safety and Achieving Better Standards) (such as the one for the North East) should add further direction in this area. The launch of Centre for Advancement of Inter-professional Education (CAIPE) in 2007 should also promote collaborative working.
- Communicate effectively with colleagues within and outside the team;
- Respect the skills, expertise and contribution of their colleagues;
- Share skills and experience for the benefit of colleagues;
- Ensure that their colleagues understand their role and responsibility within the team and identify their responsibility in the care of the patient;
- Consult and take advice from colleagues when appropriate;
- Participate in regular reviews and audit the standards and performance of the team in relation to patient care and management of the team, taking steps to remedy any deficiencies;
- Support colleagues who have problems with performance, conduct and health but at the same time, protect their patients from the risk of harm posed by their colleagues’ conduct, performance and health and raise concerns if necessary (see Rule 8 – Duty to Report).

### 9.3 Respect

Orthoptists must treat their colleagues fairly and with mutual respect and without discrimination by not allowing their personal views to affect their professional relationship with them. They should challenge their colleagues if their behaviour does not meet this expectation.

Orthoptists must not make malicious rumours and unfounded criticisms of colleagues that may undermine patients’ trust in their care or treatment they receive.

### 9.4 Induction and development of staff

Orthoptists who employ new staff joining at a band 5 as a new entrant, or those returning to work after a five year break or entering a new field of practice, are strongly advised to engage in the preceptorship programme in line with the requirements as part of Agenda for Change and working within the Knowledge and Skills Framework. The preceptorship programme is a two way process with the preceptor and the preceptee.

Orthoptists are required to serve as a role model and to empower, support, provide guidance and feedback and facilitate the preceptee’s personal and professional development. Throughout the preceptorship programme, the preceptee remains accountable for their own actions within the context of their knowledge base. Orthoptists working in the Republic of Ireland are encouraged to consult the HSE website regarding workforce planning for further information[^141]. It is apparent that there are preceptorship programmes for some areas of health professionals. However, in the event of a Trust or the HSE not adopting a preceptorship programme, they are encouraged to adhere to the relevant BIOS guidance.

### 9.5 Delegation and supervision

Orthoptists may delegate tasks to another person to undertake on their behalf, such as asking a colleague to provide treatment on their behalf. Although not accountable for the decision and actions of those to whom the orthoptist delegates, they are still responsible for the overall management of the patient and accountable for the decisions made. In this event, the orthoptist must:

Establish that the person to whom they delegate is able to perform the tasks/ instructions, having the necessary knowledge, skills and experience;

Confirm that the outcome of any delegated task meets required standards;

Ensure that everyone for whom they are responsible is supervised and supported appropriately.

9.6 Referrals to and from another practitioner
Orthoptics is an autonomous profession and the responsibility for assessment and subsequent treatment remains with the individual orthoptist. Referrals involve transferring some or all of the responsibility for the patient’s care that is outside the scope of practice and beyond the level of competence. Written or verbal referrals may be accepted from across boundaries as well as within the ophthalmic team.

On accepting a referral, the orthoptist owes a duty of care to the patient and this includes a further referral for further treatment if it becomes evident the task is beyond their scope of practice. The orthoptist needs to ensure that the referral is appropriate and that the reasons for which it is being made are fully understood by the patient and by the referring or accepting practitioner.

9.7 Responsibilities
Orthoptists have a responsibility to ensure that interventions made on the basis of their assessment are necessary and appropriate.

These responsibilities include those:

- To the patient: to ensure that expectations are not raised that cannot be fulfilled, and not to waste time or treat patients for whom the treatment would not be beneficial or has ceased to be beneficial

- To themselves: by treating a patient who does not require such treatment, an orthoptist could be in contravention of a statement of professional conduct. It is morally wrong and unacceptable to give treatment when it is not required or when referral to another specialist is deemed more appropriate.

- To the employer: irrespective of whether the orthoptist is employed through a Trust if self-employed and working privately, it is ethically wrong to waste time and money by treating patients unnecessarily.

9.8 Sharing information with colleagues
Sharing information with other health care professionals is important for safe and effective practice, but at the same time being mindful of the need to respect confidentiality.

When sharing information, orthoptists must:

- Provide all relevant information about the patient when they refer;

- Inform the patient’s general practitioner/ health visitor of results of the investigation, treatment planned and information as necessary, unless the patient objects;

- Work with colleagues to monitor the quality of their work and maintain the safety of those in your care;

- Facilitate students and others to develop their competence.
Rule 10: Personal and professional standards

Registered Orthoptists shall adhere at all times to personal and professional standards that reflect credit on the profession. They must not engage in any criminal, unprofessional or any other lawful activity or behaviour. In addition, behaviour, approach and dress should not cause offence to the patient or carer.

10.1 Professional integrity
Orthoptists must act with probity and integrity, this being at the heart of health care professionalism by:

- Ensuring that their conduct justifies both the patients’ trust in them and the public’s trust in the profession of orthoptics;
- Ensuring that their use of social networking sites does not jeopardise their fitness to practise;
- Adhering to the laws of the country in which they practise;
- Informing the Health Professions Council and Health and Social Care Professionals Council (in Republic of Ireland) if cautioned, charged or found guilty of a criminal offence;
- Inform their employers about any health or personal issues that may affect their fitness to practise and gain advice accordingly;
- Demonstrate a personal and professional commitment to equality and diversity.

10.2 Upholding the reputation of the orthoptic profession
Orthoptists have a duty to uphold the reputation of the profession by:

- Ensuring they uphold the reputation in both the real world and online at all times;
- Not using their professional status to promote causes that are not related to health;
- Following the dress code or uniform policy of their employer so as not to cause offence to their patients and carers and other health professionals and in accordance with health and safety requirements;
- Being aware that their behaviour and conduct inside and outside their employment, including their personal life, may impact of their fitness to practise.

10.3 Use of social networking sites
The impact of social networking sites on professions and professionals is only just being realised. Orthoptists must recognise that by failing to uphold the reputation of their profession by embarking on inappropriate behaviour, they will put their registration at risk if they, for example:

- Post inappropriate comments about colleagues or patients;
- Pursue personal relationships with patients;
Orthoptists are advised to choose carefully the type of material that they place onto social networking sites. By considering the following guidance, an orthoptist should be able to maintain both their professional integrity and uphold the reputation of the profession:

- Separating their personal and professional life as much as possible;
- If, identifying themselves as an orthoptist, act responsibly at all times;
- Protecting their privacy and use strict privacy settings;
- Not discussing work related issues online whether it be with respect to colleagues or patients or their carers or raising concerns;
- Using a respectable photograph as it is public;
- Not accepting requests for friendships from current or former patients
- Realising that they have no control on what other people may post online and that such material can then be copied and redistributed.

It must be realised that despite these concerns, professional organisations are using social networking sites to engage with professional members but at the same time, orthoptists must take care and recognise the impact it may have on their professional life if used inappropriately. Future employers regularly review applicants on social networking sites as a way of finding out more about their potential suitability for employment.

10.4 **Disciplinary procedures**

In the event of not acting with integrity and upholding the reputation of the profession, orthoptist will face disciplinary action.

10.4.1 **Disciplinary procedure by the Health Professions Council / Health and Social Care Professionals Council**

Any adverse findings by the Health Professions Council (UK) or Health and Social Care Professionals Council (RoI) will render an orthoptist liable to disciplinary proceedings. Matters brought before either Council may be raised as a breach of the British and Irish Orthoptic Society’s Rules of Professional Conduct and Code of Ethics

10.4.2 **Disciplinary proceedings by an employer**

Disciplinary proceedings by an employer concluding with dismissal from employment may also lead to a charge of professional misconduct. This applies even if the orthoptist has not been involved in court proceedings. A disciplinary proceeding resulting in a reprimand or warning will not normally give rise to disciplinary action by the Society or the Health Professions Council.

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142 The framework for Health and Social Care Professionals is emerging and not yet complete but it is anticipated that it will mirror the practices of the HPC
10.4.3 Personal conduct derogatory to the reputation of the profession

Personal conduct that does not result in a conviction or disciplinary action by the employer, may be deemed sufficiently serious to warrant disciplinary action by the Society if such conduct is judged to be derogatory to the reputation of the profession. Misuse of alcohol, drugs and other toxic substances may be dealt with as a health matter in the first instance and then progress to a disciplinary hearing. Orthoptists must not undertake any professional activity after consuming alcohol, drugs or other toxic substances.

10.4.4 Conviction by court

It is important that all circumstances that have resulted in a conviction are considered, as the conviction might be evidence that the orthoptists’ continued practice may imply a risk to the patient and public. Not all convictions will result in action being taken.
Rule 11: Advertising and financial dealings

Registered Orthoptists must ensure that they pay due regard to the way in which they advertise and accept remuneration for their services and that any conflict of interest is transparent.

11.1 Advertising

Orthoptists can publish information about their service but such information must be factually accurate, verifiable and professionally restrained. It is important to maintain a professional patient and health care practitioner relationship and thus it is unethical to appeal in person to potential patients. Care must be taken to ensure the appropriate use of qualifications on any advertising material and the use of the British and Irish Orthoptic Society’s logo can only be used when endorsed by the Society.

Unjustifiable claims should not be made in respect of personal skills and the quality and outcomes of services provided including the guarantee of successful treatments.

Orthoptists must not exploit patient’s vulnerability or lack of relevant medical knowledge.

11.2 Financial dealings and potential conflicts of interests

Orthoptists must be honest and transparent in any financial arrangements with patients and organisations. More specifically, orthoptists must:

- Inform patients about their fees wherever possible prior to gaining consent for treatment;
- Declare any relevant financial or commercial interest when buying or selling goods or services whether this is a direct arrangement or through a third party;
- Act in the patient’s best interest when making referrals and must not ask or accept any inducements which may be seen to affect the way in which a patient is treated.

They must not:

- Exploit patient’s vulnerability and/or lack of medical knowledge when making charges for services and treatment;
- Encourage patients to give, lend or bequeath gifts or money that will either directly or indirectly result in personal gain and therefore must observe local policy;
- Place pressure on patients and their families to make donations to others and organisations;
- Place pressure on patients to accept private treatment;
- Allow any involvement that they have with any organisations providing health care or other related industries influence the manner in which patients are treated and must inform the patient of this involvement.
Failure by Orthoptists to observe these requirements may result in disciplinary action being taken by the Health Professions Council (standard 14). Orthoptists in the Republic of Ireland should monitor the emerging framework from the Health and Social Care Professions Council.
Registered Orthoptists who undertake research have a duty to respect autonomy and to safeguard individuals taking part in research from harm. The central concern is that the interests of society or enthusiasm of the researcher do not override the interests of the individual.

12.1 Introduction

A key distinction needs to be made between research and clinical audit as certain similarities exist between the two but they involve significantly different ethical and legal frameworks.

Both research and clinical audit start with a question, both expect the answer to change or influence clinical practice, both require formal data collection on patients and both depend on using an appropriate method and design to reach sound conclusions. However, clinical audit is a clinically-led quality improvement process that seeks to improve patient care and outcomes through a systematic review of care against explicit criteria, referred to as gold standard, and acts to improve care when standards are not met. If required, improvements should be implemented at an individual team or organisation level and then the care re-evaluated to confirm improvements. Research investigates what should be done and why some treatments are more effective than others whilst audit investigates whether best practice is being followed. The interface between research and audit is that audit can identify areas where research is lacking and research can identify areas for audit. Clinical audit also assists with the dissemination of evidence-based practice.

Orthoptists have a duty to undertake clinical audit as part of a mechanism to ensure clinical excellence and to attain clinical governance.

12.2 Regulation of research

The regulation of research involving humans focuses on safeguarding individuals who take part from harm or failing to respect autonomy, the central concern being to ensure that the interests of society or the enthusiasm of the researcher, do not override the interests of the individual. The regulation of research is governed by a patchwork of legislation, common law and international regulation. Responsibility for the regulation in the NHS is shared by local NHS research and development (R&D) management and NHS research ethics committees. The National Institute for Health Research (NIHR) was established in 2006 with a remit to improve the health and wealth of the nation through research.

Orthoptists should be mindful of the main sources of law.

145 Health Professions Council Standards of Proficiency
146 Research and Development Directorate, Department of Health; Best Research for Best Health 2006
12.2.1 Declaration of Helsinki

The World Medical Association first agreed the Declaration of Helsinki in 1964 but has been reviewed regularly since then, most recently in 2008. Although not directly enforceable in law, it is likely to be taken into account when deciding whether or not researchers are negligent and will be used by research ethics committees when deciding whether to approve research projects.

Orthoptists should be aware of the following principles when undertaking in research:

- The need for consent for all competent participants in research
- The rights of subjects to withdraw from the research
- Human experimentation is to be used as a last resort where other forms of research not involving human subjects are not possible
- There must be proportionality between the benefits of the research and the risks run by the subject.

Paragraph 6 of the Declaration contains an overarching principle:

"In medical research involving human subjects, the well-being of the individual research subject must be take precedence over all other interests"147. The significance of this principle is that one cannot in the name of "science" justify doing something that risks the well-being of the individual.

12.2.2 The criminal law

Orthoptists must be aware that touching someone without their consent amounts to a criminal offence. Thus, obtaining consent in the course of clinical practice provides a defence and it is also important in the course of medical research. The Law Commission148 offers a clear statement:

"A person should not be guilty of an offence if he causes injury to another, of whatever degree, if such injury is caused during the course of properly approved medical research (i.e. approved by a Research Ethics Committee (REC) and with the consent of the other person).

Any health care professional conducting research that has not been approved by an Ethics Committee could be guilty of a criminal offence if they caused the patient harm, even if the patient had consented.

12.2.3 Legislation

Orthoptists need to be aware of the following legislation, although not exhaustive, that is relevant in medical research: Data Protection Act 1998; Data Protection Act 1988-2003 (Eire); Mental Capacity Act 2005; Mental Capacity Bill 2008; Adult Incapacity (Scotland) Act 2000.

12.2.4 Research Governance Frameworks

Orthoptists should be aware of Research Governance Frameworks which are designed to ensure that the procedures and powers of ethics committees are less fragmented and more effective in producing high-quality and ethically sound research than in the past.

Orthoptists should familiarise themselves with the framework which is relevant to their country.

- Research Governance Framework for Health and Social Care (Department of Health 2010);

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In the event of a clinical trial of a new medicine involving human participants, researchers must follow the requirements of the Medicines for Use (Clinical Trials) Regulations 2004.

12.2.4 Human Rights Act 1998
Orthoptists must take due care to respect a participant’s rights to ensure that are not infringed under the European Convention of Human Rights, Articles 3 and 8 if research is undertaken without the consent. A Research Ethics Committee would need to ensure that any approved research did not infringe their rights.

12.2.5 Local and multi-centred research ethics committees
These committees have been established to regulate and oversee research in their particular areas. They can refuse to authorise a research project or place conditions on its operation which need to be satisfied prior to the commencement of the research. However, research ethics are not responsible for giving legal advice.

12.2.6 Common law (tort or contract)
Orthoptists undertaking research owe a participant a duty of care in the tort of negligence and could be sued if they breach that duty. It is extremely unlikely that there would be a contract between the Orthoptist and participant but in that event, a claim for breach of contract can be made.

12.3 Consent
Orthoptists should realise that the same legal principles apply when seeking consent from a person for research purposes as when obtaining consent for investigation and treatment i.e. for consent to be valid, the person must be competent and have legal capacity, be properly informed and free from coercion.

However, Orthoptists should be aware of four particular issues that are particularly relevant in research.

- Informed consent
- Duress
- Right to withdraw from the research project
- Payment of participants.

12.3.1 Informed consent
Orthoptists must ensure that participants are involved of the risks attached to the research.

Orthoptists may find the guidance offered within Paragraph 24 of the Declaration of Helsinki useful in relation to competent human subjects:

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Each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher (University/Trust/Health Board), the anticipated benefits and potential risks of the study and the discomfort it may entail, and any other aspects of the study.

The potential subject must be informed of the right to refuse to participate or withdraw consent to participate at any time without reprisal.

Special attention should be given to the specific information needs of individual potential subjects as well as to the methods used to deliver the information.

After ensuring the potential subject understands the information, the researcher or another appropriately qualified individual must then seek the potential subject’s freely-given informed consent, preferably in writing.

If the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed.

Furthermore, good practice dictates that each potential subject should be provided with the following information:

- The purpose of the research and confirmation of its ethical approval
- Whether the participant stands to benefit directly and, if so, the difference between research and treatment
- The meaning of relevant research terms
- The nature of each procedure, and duration and frequency
- The potential benefits and harms (immediate and long-term)
  * Could include how the proposed treatment differs from the normal well established methods and the reasons for it being offered along with any additional risks.
- The process involved such as randomisation
- Arrangements for reporting adverse events
- The legal rights and safeguards for participants
- Details of compensation of harm results from participating
- How their health data will be stored, used and published
- The name of the researcher they can contact in an emergency
- The name of the health care practitioner directly responsible for their care
- How they can withdraw from the project
- What information they will receive about the outcome
- That withdrawal will not affect the quality of health care

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150 British Medical Association Guidance cited by Herring, J. 2010 *Medical Law and Ethics* Oxford University Press 3rd edition
In the event of the research taking the form of a clinical trial, under the Medicines for Human Use (Clinical Trials) Regulations 2004, Orthoptists are required to pay particular attention regarding informed consent in keeping with points 4 and 5 stated above.

**Addressing the amount of information**

The amount of information required for a potential subject to digest is significant and Orthoptists should consider the best way in which this information should be recorded. It may be advisable to consider presenting potential subjects with the major risks and then provide a further document with less significant risks.

**Legal consequences of informed consent in relation to research**

It is reassuring that, to date, there have been no cause for legal proceedings in relation to informed consent and research.

12.3.2 Duress

Orthoptists must take every effort not to pressurise a patient to consent to participate in research. A safe option is to consider involving an independent practitioner to discuss the issue with the patient and confirm that they are consenting freely.

12.3.3 Withdrawal of consent

Orthoptists must recognise that a participant is free to withdraw from a research project at any time. However, concerns have been raised regarding the consequences of this in relation to skewing results\(^{151}\). However, the freedom of individuals to withdraw is a fundamental right and researchers should not pressurise participants to continue\(^{152}\).

12.3.4 Payment of participants

Orthoptists must be aware that there is no legal regulation of this issue (except in the payment of organs). Payment in cash or kind to volunteers should only be for expense, time and inconvenience but and not at a level where people may be tempted to participate against their better judgement. However, it has been argued that participants are not paid enough considering some are putting their health at risk\(^{153}\).

12.4 Research involving children

The law on research on children is a little uncertain but it would be logical to consider the normal principles of law involving children i.e. those who are Gillick competent (or equivalent in member countries) and thus deemed able to give consent and those with parental responsibility who consent on their behalf.


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12.4.1 Children aged between 16 and 17 years

Orthoptists should be aware that although the Family Law Reform Act 1969 (Section 8) allows competent 16-17 year olds to consent to treatment, no reference is made to research and thus common law principles apply.

If the child is Gillick competent, there is no good reason why researchers should not be able to rely on this sole consent. However, the legal position is unclear particularly as Gillick placed weight on treatment being in the child’s best interest. It is therefore advisable for Orthoptists to obtain consent from someone with parental responsibility in addition to the consent from the child. If the 16-17 year old lacks consent, the provisions of the Mental Capacity Act 2005 (or equivalent) apply (see 12.5 for further guidance) or the Family Law Reform Act can be followed.

12.4.2 Children and young people under 16 years

Orthoptists should be aware that the legal position is governed by common law and mirrors the incompetent 16-17 year old with respect to parental responsibility. Here consent can be given by the person with parental responsibility for the child to participate in a research programme.

12.4.3 The question of assent

Where a potential research participant is deemed to be incompetent, they may be able to give assent to decisions about participation in research. Here the Orthoptist must seek that assent in addition to the consent of the legally authorised representative, thereby ensuring that child patients are involved in the consent process. However, if the child dissents Orthoptists must respect its view.

12.5 Research involving incompetent adults (and young people)

Research in patients who lack capacity is regulated by Sections 30-34 of the Mental Capacity Act 2005 (or equivalent) and is considered unlawful in the absence of consent.

Orthoptists must be aware of the conditions that have to be met in order that intrusive research (anything that involves touching) can be undertaken. These are:

- Approval of the research project by a research ethics committee
- Research must be connected to an “impairing condition” (defined as one that causes or contributes to the impairment of, or disturbance in, the functioning of the mind or brain) from which the person suffers or its treatment
- There must be reasonable grounds for believing that research of comparable effectiveness cannot be carried out if the research is limited to, or only relates to, persons who have capacity to consent to the taking part
- The research must either:
  - Have the potential to benefit the person and not impose a burden on them which is disproportionate to the benefits or
  - Be intended to provide assistance in the treatment or care of people with a similar condition, as long as the risk to the person from the research is negligible and does not interfere with the person’s freedom, action or privacy in a significant manner to be unduly invasive.
Reasonable steps must have been taken by the researcher to identify the person’s carer or person involved in their welfare. Here, information regarding the research must be provided and their opinion sought as to whether they think that the person for whom they care, would wish to participate. The researcher must respect that decision.

Research must not be undertaken in the event of an advanced decision or similar statement being made.

Nothing must be done to the person in the course of research to which the person appears to object, unless it is to protect the person from harm.

Appropriate means must be used to maximise the person’s understanding of the research process, and if possible, involve the patient in the decision-making process.

The normal requirements related to research are satisfied.

In the event of these conditions not being met, Orthoptists who continued to perform research would not be acting in the person’s best interest and this would constitute an infringement of the Mental Capacity Act’s principle of promoting the person’s best interest.

12.6 Ethical considerations

12.6.1 Autonomy of the research participant

Orthoptists must recognise that if a potential research participant is fully informed, competent and not coerced, then that person has every right to take potentially part in research even though it is dangerous. However, this approach is not acceptable and it is important for Orthoptists to recognise that research participants should not normally be put at any more risk than a minimal level.

12.6.2 Risk of harm

Orthoptists undertaking research have a duty to ensure that the potential participant is not put at risk of harm through participation in research. However, the level of harm has to be considered in relation to the benefits. The risk of harm to participate must be justified by the benefits gained in the future for others. Orthoptists should be aware that the Declaration of Helsinki gives much greater weight to the benefits to the research participants then those in the future.

12.7 Confidentiality

Orthoptists must be aware of their duty of confidentiality involved in the collection of information concerning research participants.

Orthoptists undertaking research could be found negligent if they failed to take reasonable precautions to ensure that information is anonymised and that it is stored in a secure manner. Information should only be passed to another person with the explicit consent of the research participant.
In 1992, Lord Benson, as part of the Benson Commission, stated that to be a professional is to operate within specific criteria as stated below:

- The profession must be controlled by a governing body, which in professional matters directs the behaviour of its members.

- The Governing Body must set adequate standards of education as a condition of entry and thereafter ensure that students obtain an acceptable standard of professional competence. Training and education do not stop at qualification. They must continue throughout the member’s professional life.

- The Governing Body must set out the ethical rules and professional standards that are to be used by the members. They should be higher than those established by the general law.

- The rules and standards enforced by the Governing Body should be designed for the benefit of the public and not for the private advantage of the members.

- The Governing Body must take disciplinary action, if necessary, expulsion from membership should the rules and standards it lays down are not observed, or should a member be guilty of bad professional work.

- Work is often reserved to a profession by stature – not because it was for the advantage of the member, but because of the protection of the public. Persons with the requisite training, standards and disciplines should carry it out.

- The Governing Body must satisfy itself that there is fair and open competition in the practice of the profession.

- The members of the profession, whether in practice or in employment, must be independent in thought and outlook. They must not allow themselves to be put under the control or dominance of any persons or organisation that could impair that independence.

- In its specific field of learning, a profession must give leadership to the public it serves.

The British and Irish Orthoptic Society promotes these criteria to direct the professional activities of its members.
Introduction

One of the first acts of the World Medical Association, when formed in 1947 on the initiative of the British Medical Association in an attempt to unite the profession throughout the world in a single community, was to produce a modern restatement of the Hippocratic Oath, known as the Declaration of Geneva, and to base upon it an International Code of Medical Ethics. The amended version (1994) provided below is appropriate for all health professions.

> Whatever, in connection with my professional practice or act in connection with it, I see or hear on the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret.

> I solemnly pledge myself to consecrate my life to the service of humanity:

> I will give to my teachers the respect and gratitude which is their due;

> I will practise my profession with conscience and dignity;

> The health of those in my care will be my first consideration;

> I will respect the secrets that are confided in me, even after a patient has died;

> I will maintain by all the means in my power the honour and the noble traditions of my profession;

> My colleagues will be my sisters and brothers;

> I will not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation or social standing to intervene between my duty and my patient;

> I will maintain the utmost respect for human life from its beginnings, even under threat, and I will not use my specialist knowledge contrary to the laws of humanity:

> I make these promises solemnly, freely and upon my honour.
The NHS Constitution: Core Principles

- The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief.
- Access to NHS services is based on clinical need, not an individual’s ability to pay.
- The NHS aspires to the highest standards of excellence and professionalism.
- NHS services must reflect the needs and preferences of patients, their families and carers.
- The NHS works across organisational boundaries and in partnership with other organisations in the interests of patients, local communities and the wider population.
- The NHS is committed to providing best value for taxpayer’s money and the most effective, fair and sustainable use of finite resources.
- The NHS is accountable to the public, communities and patients that it serves.
This annex provides a review of relevant case law and legislation, many of which are landmark cases which provide a “persuasive authority” for courts by which jurisdiction decisions are based and have been referred to within the rules. Facts of the case set the context in which decisions are made.

Note: although the term “doctor” is stated, the law applies to all health care professionals.

1 Human Rights

1.1 Rationing of treatment

R v Cambridge HA ex p B [1995] 2 All ER129

A 10 year old girl (B) suffered leukaemia and it was estimated that she had between six and eight weeks to live and the medical team decided that no further treatment should be offered. Her father found some medics in USA who would offer her treatment but the Health Authority believed the treatment to be experimental and too expensive. A judicial review of the resources was sought.

Judgement:
The right to life under Article 2 was emphasised and it was held that there had to be a compelling reason before refusing life-saving treatment. Limited resources were an inadequate argument. However, the Court of Appeal overturned the decision stating that the court was not in the position of assessing such decisions. The court had to look at competing claims of all the other patients that a local authority had to consider.

R (Rogers) v Swindon PCT [2006] EWCA 392

Mrs Rogers had breast cancer and asked her PCT to fund the cancer drug Herceptin, yet to be licensed. Early trials indicated that Herceptin was effective for the type of cancer from which Mrs Rogers suffered. The PCT had adopted the policy that the drug could only be used in exceptional cases.

Judgement:
The Court of Appeal found that decision to be unlawful and accepted that it was permissible for a health authority to have an “only in exceptional circumstances” policy. However, it was only applicable if the health authority really believed that there could be an exceptional case but in fact the health authority operated a policy of never funding it. The health authority had yet to determine a policy to establish “exceptional” and the authority had not referred to cost being a relevant factor that the authority would take into account and thus could not rely on funding issues to deny her treatment.

R (Otley) v Barking and Dagenham NHS PCT [2006] EWHC 1927 (Admin)

Mrs Otley sought a judicial review of the decision of her PCT to refuse funding for an anti-cancer drug. Other treatments had not been successful and her consultant recommended Avastin, not yet approved for use in the NHS. She privately funded five cycles of treatment which proved successful and the oncologist then applied for further treatments from the NHS which were denied as it was concluded that the drug would not
significantly prolong Mrs Otley’s life and therefore would not be cost-effective. A detailed report on the drug recommended its use.

_Judgement:_
The Court of Appeal held that the panel that had failed to recognise that these drugs could provide Mrs Otley with a significantly prolonged life expectancy. The PCT had not sought to rely on a lack of resources and the question that had to be considered was whether the drugs appeared to offer a reasonable benefit which they did.

**AC v Berkshire West PCT [2010] EWHC 1162 (Admin)**

A PCT refused to fund a breast augmentation for C who suffered from gender identity disorder and was living as a woman. The Trust only funded core surgical procedures for gender patients which included genital surgery but not breast augmentation. C made reference to another patient (X) who had been born a woman but who had a congenital absence of breast tissue and had received funding on the basis of a history of psychological illness related to the issue.

_Judgement:_

It was held that in rationing cases, the courts had to acknowledge that NHS budgets were under severe pressure due to new drugs and procedures and the rising longevity of the population. Correct policy dictates that Trusts have procedures which are routinely funded and also some that are funded in exceptional cases. X had suffered significant psychological distress but C’s was not of the same extent. There had not been any discrimination against a transsexual patient as the same test had been applied to both X and C.

### 1.2 Confidentiality

**Z v Finland [1997] EHRR 371**

During an investigation of the husband for rape, the medical records of the wife were seized without her consent. These included the fact that she had been infected with HIV and she objected to the publication of her name and HIV status in the criminal proceedings.

_Judgement:_

The European Convention of Human Rights held that it especially important to keep confidential health information about individuals, particularly in relation to her HIV status. Where the state sought to disclose such information without consent, there had to be a strong justification. The use of her medical information as part of the prosecution was justified, but there was no compelling reason why her name and status had to be disclosed in the publication of the judgement. Her right to respect for her private and family life were therefore justified.

**MS v Sweden (Application No. 20837/92) (ECtHR, 27 August 1997)**

A woman was required to release her medical notes in order to claim social security following a back injury at work. The medical records disclosed that she had had an abortion as a result of her back problem.

_Judgement:_

The requirement of the disclosure did breach her rights, it was considered a proportionate means of pursuing a legitimate state interest in ensuring that a person could claim the benefit.
2 The right to determination and respecting autonomy

_Schloendorff v Society of New York Hospital_ 105 NE 92 [NY1914];

“Every human being of adult years and sound mind has a right to determine what shall be done with his own body and a surgeon who performs an operation without the patient’s consent commits an assault (battery)”. (Although this is a US case, the statement concerning battery has been incorporated into English common law).

_R (on the application of Burke) v GMC_ [2005] 3 FCR 169, para 30:

“Where a competent patient makes it clear that he does not wish to receive treatment which is, objectively, in his medical best interests, it is unlawful for doctors to administer that treatment. Personal autonomy or the right of self-determination prevails”.

2.1 Criminal law – Practising after removal from professional body

_R v Richardson_ (1998)

A dentist was banned from practising dentistry by her professional body but she continued to practise her profession. She was charged with an assault occasioning actual bodily harm (Offences Against the Person Act 1861, s 47).

_Judgement:_

She was convicted, not on the grounds of poor treatment, but as it was considered that her patients would not have consented to treatment had they been aware of her disqualification to practice. The Court of Appeal overturned the conviction on the basis of that the deception did not relate to her identity or to the nature of the acts and thus the deception did not negate consent.

2.2 Expressions of consent

_O’Brien v Cunard SS Co_ 28 NC266 [Mass 1981]

A woman was vaccinated against smallpox on a boat bound for Boston. She was told by the doctor that she had to be vaccinated for which she held out her arm and rolled up her sleeve to accept the injection. She later tried to sue for trespass but was told by the court that consent had been implied by her actions.

3 Scope of practice and inexperience

_Wilsher v Essex AHA_ [1986] 1 All ER 871

Martin Wilsher was born approximately 3 months prematurely and was admitted to the neonatal unit where he was managed by the defendants. He required extra oxygen to survive and the junior doctors failed to monitor the oxygen levels correctly on two occasions and he suffered blindness. It was unclear whether the blindness was caused by the premature birth or by the negligent care that he received. The claimant failed because he could not show on the balance of probabilities that the harm was caused by the negligence. However, this case highlights the need to consider the personnel in post.

154 Herring, J. Medical Law. 2011 Oxford University Press
Judgement
If a person is acting in a particular capacity, then they must exercise the skill expected of such a person. The fact that they are inexperienced, or a student or aged is irrelevant.

**Nettleship v Weston [1971] 2 QB 691, CA**

A learner driver was given lessons by an instructor who made sure that the car was properly insured. Weston was a careful learner driver but on the third lesson, she failed to straighten out after turning left and struck a lamp post and Nettleship suffered an injury.

Judgement
The Court held that a learner driver owes a duty of care to their instructor to drive with proper skill and care, the test being that of the ordinary careful driver. It was no defence to say they were a learner driver doing their best. The duty of care owed by a learner driver is the same as that owed by every driver and Weston was liable for damages.

### 4 Negligence

A person seeking compensation for negligence has to establish:

- That the defendant (health care practitioner) owed him a duty of care
- That the defendant was in breach of that duty (related to a specific standard) and that he was careless
- That the breach of that duty caused the claimant harm and that the harm warrants compensation.

In clinical negligence, there are two distinct causes of action:

- Negligent treatment or diagnosis
- Breach of the doctrine of informed consent.

Specific tests for negligence have been established in the various jurisdictions.

#### 4.1 Standard of care and breach: England, Wales and Northern Ireland

**Bolam v Friern Hospital Management Company [1957] 2 All ER267**

Bolam was given electroconvulsive treatment for severe depressive illness and as a consequence suffered a fractured pelvis from the contraction induced by the ECT. At the time, some doctors gave such patients muscle relaxants or limb restraints or indeed, neither which was the case with Bolam. He claimed that the doctors had been negligent but the evidence before the courts was that, although most doctors with expertise in this area would use either relaxants or limb restraints, there was a body of medical opinion that supported the method used for Bolam.

Judgement
The test for negligence in English law is whether:

“...The standard of the ordinary skilled man exercising and professing to have that special skill..... A man need not possess the highest expert skill at the risk of being found negligent. It is well established law that it is sufficient if he exercises the ordinary skill of an ordinary man exercising that particular art......... A doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a medical man skilled in that particular art”.
Thus a doctor will not be found negligent if the court is satisfied that there is a responsible body of medical opinion that would consider that the doctor had acted properly. That responsible body need not be the majority of the profession.

4.2 Standard of care and breach: Scotland

Hunter v Hanley [1955]

The pursuer (plaintiff) suffered injury as a result of a hypodermic needle breaking in the course of an injection.

Judgement:
Unusually for civil cases, this involved a jury. The trial judge directed the jury that “there must be such a departure from the normal and usual practice.... as can reasonably be described as gross negligence. On the grounds that that the jury had been misdirected by the judge, a new trial was filed. At the retrial it was established that to establish liability where deviation from the normal is alleged, three facts must be established that:

- There is a usual and normal practice
- The defender (health care practitioner) did not adopt that practice
- The course the doctor adopted is one which no professional man of ordinary skills would have taken if he had been acting with ordinary care

Thus the true test for establishing negligence in diagnosis or treatment on the part of the doctor is whether he has been proved to be guilty of such failure as of no doctor of ordinary skill would be guilty of if acting with ordinary care.

4.3 Standard of care and breach: Republic of Ireland

Dunne (an infant) v National Maternity Hospital [1989] IR91

The mother of an infant was pregnant with twins. When she arrived at hospital, the practice at the time was to monitor the first twin heartbeat, a difficult procedure in itself. Unfortunately, one of the twins died and the remaining infant suffered severe brain injury due to distress and lack of oxygen.

Judgement:
In the case the judged stated that “if a medical practitioner charged with negligence defends his conduct by establishing that he followed a practice which was general, and which was approved of by his colleagues of similar specialisation and skill, he cannot escape liability if in reply the plaintiff establishes that such practice has inherent defects which ought to be obvious to any person given the matter due consideration.”

This judgement forms one of the Six Dunne Principles which are adopted by the Courts in cases of medical malpractice.


1. The true test for establishing negligence in diagnosis or treatment on the part of a medical practitioner is whether he has been proved to be guilty of such failure as no medical practitioner of equal specialist or general status and skill would be guilty of if acting with ordinary care.

2. If the allegation of negligence against the medical practitioner is based on proof that he has deviated from a general and approved practice, that will not establish negligence unless it is also proved that the course he did take was one which no medical practitioner of like specialisation and skill would have followed had he been taking the ordinary care required from a person of his qualification.

3. If a medical practitioner charged with negligence defends his conduct by establishing that he followed a practice which was general, and which was approved of by his colleagues of similar specialisation and skill, he cannot escape liability if in reply the plaintiff establishes that such practice has inherent defects which ought to be obvious to any person given the matter due consideration.

4. An honest difference of opinion between doctors as to which is the better of the two ways of treating a patient does not provide any ground for leaving a question to the jury as to whether a person who has followed one course rather than the other has been negligent.

5. It is not for a jury (or for a Judge) to decide which of two alternative courses of treatment is in their (or his) opinion preferable. But their (or his) function is merely to decide whether the course of treatment followed, on the evidence, complied with the careful conduct of a medical practitioner of like specialisation and skill as that professed by the Defendant.

6. If there is an issue in fact, the determination of which is necessary for the decision as to whether a particular medical practice is or is not general or approved within the meaning of these principles, that issue must in a trial held with a jury be left to the determination of the Jury.

Note:

- “General and approved practice” need not be universal, but must be approved of and adhered to by a substantial number of reputable practitioners holding the relevant specialist or general qualifications.

- Though treatment only is referred in some of these statements of principle, they must apply in identical fashion to questions of diagnosis.

5  Information required for consent

In addition to those cases for the test of negligence, the following are significant in relation to standard of care and breach.

5.1 Standard of care and breach of the standard

_Bolitho v City and Hackney Health Authority [1998] AC232_

A child (Patrick Bolitho) was admitted to hospital suffering from respiratory difficulties. On two occasions, the nurse summoned the doctor in charge and on both occasions, the doctor failed to turn up to examine Patrick. Patrick later collapsed and suffered a cardiac arrest which resulted in severe brain damage. Expert evidence suggested that had a doctor attended, an intubation to ensure an airway would have been arranged and that this would have avoided a cardiac arrest.

**Judgement:**
The judge, rejecting the claim, found the doctor had breached the duty in failing to attend, but that had she attended she would not have arranged for the intubation. The court had to determine whether the doctor had been negligent in failing to attend. In this case:

“The court has to be satisfied that the exponents of medical opinion relied on can demonstrate that such opinion has a logical basis. In particular, in cases involving, as they so often do, the weighing up of risks and against benefits, the judge before accepting a body of opinion as being reasonable, responsible or respectable will need to be satisfied that, in forming their views, the experts have directed their minds to the questions of comparative risks and benefits and have reached a defensible conclusion on the matter.”

**Maynard v West Midlands RHA [1986]**
Mrs Maynard consulted a physician and a surgeon with symptoms indicative of tuberculosis but also displayed symptoms which might indicate Hodgkin’s disease. A diagnostic operation which carried a risk of damage to the vocal cords was undertaken and Mrs Maynard suffered such damage. She claimed that the doctors were negligent in subjecting her to the operation. The plaintiff’s expert witness argued that the operation should not have been done saying it was far more likely that she had tuberculosis. However, the defendants’ formidable number of expert witnesses testified that the fatality rate for Hodgkin’s if treatment was delayed justified the defendants in exposing Mrs Maynard to the risks of the diagnostic procedure.

**Judgement:**
The original judge preferred the plaintiff’s expert witness and was overruled. A judge’s “preference” for one body of distinguished professional opinion to another also professional distinguished is not sufficient to establish negligence in a practitioner.

The Bolam test was reinforced provided “that there is a body of competent professionals which supports the decision as reasonable in the circumstances, then negligence cannot be established”.

**Smith v Tunbridge Wells HA [1994] 5 Med LR 334**
A 28 year old man required rectal surgery and was not informed of the risk of impotence which was inherent with the surgery. The surgery was carried out competently.

**Judgement:**
The claim was successful despite some expert evidence from a body of experts that would not warn the patient of that risk. It was stressed that evidence should be reviewed in context and that the defendant had acted in a manner that was neither “reasonable nor responsible” bearing in mind his age and gender.

**Marriott v West Midlands HA [1999] LL Rep Med 453**
A patient had suffered a fall for which the GP prescribed painkillers but did not suggest a full neurological examination. The patient deteriorated and collapsed and admitted to hospital where he was found to have a large extradural haematoma which was operated on and surgery revealed a skull fracture and internal bleeding. The plaintiff was left paralysed and with a speech disorder.

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160  Respecting the beneficence/non-maleficence principles of ethics

Judgement:
The defendant's expert acknowledged that the defendant should have recognised that there was a risk that the plaintiff could have had a clot on the brain but contended that the risk was so small that it was not negligent to fail to refer the plaintiff for further tests.

The trial judge evaluating the evidence held that, although the risk was small “….the consequences, if things go wrong are disastrous to the patient. In such circumstances, it is my view that the only reasonable prudent course…..is to re-admit for further testing and observation”162 and that the view that a neurological examination was not necessary as illogical.

5.2 Amount of information

Chatterton v Gerson [1981] 1 All ER 257

Mrs Chatterton suffered pain as a result of a trapped nerve. Dr Gerson, a specialist in pain management, performed surgery to relieve the pain. He failed to inform her that the operation carried a small risk of permanently affecting the mobility of the leg, which unfortunately, resulted. Mrs Chatterton said that had she not been informed of the risk, she would not have agreed to the operation. She sought damages in the tort of battery. The claim was dismissed as she had been informed of the broad nature of the procedure. The failure to disclose the risk of paralysis was not sufficient to imply that she had not consented.

Judgement

“In my judgement, once the patient is informed in broad terms of the nature of the procedure which is intended, and gives her consent, that consent is real, and the cause of the action on which to base a claim for failure to go into risks and implications is negligence, not trespass (battery)” (J Bristow).

5.3 Failure to provide information including about specific risks

Daniel v Heskin [1954] IR 73

The plaintiff required stitching after childbirth and during the procedure, the needle broke. The defendant left the broken part of the needle in her body. The defendant had left instructions that the patient required an x-ray within six weeks if the needle had not been found. When this was done, and an examination undertaken by another doctor, an operation was performed to remove the needle. The Court considered the duty of the doctor to inform the patient of the incident.

Judgement

The majority of the Supreme Court held that there was no obligation on the doctor to inform the plaintiff or her husband of the presence of the needle. It was agreed by three judges that if a dangerous operation was planned, the doctor should disclose the risk involved but where it was not a dangerous operation the doctor could decide for himself whether or not to make disclosure. Interestingly, this judgement has not been referred to in other judgements regarding disclosure of risks.

Sidaway v Board of Governors of Bethlem and Maudsley Hospital [1985] 1 All ER 643

Mrs Sidaway’s spinal cord was damaged during an operation which rendered her paralysed. She brought an action in negligence on the basis that the risks connected with the operation were not properly explained to her. There was no suggestion that the operation had been performed improperly.

**Judgement**

The body of opinion must be respectable. No responsible body of medical opinion would hold that a doctor
would not disclose a risk of a 10% chance of a stroke (for example) but where the risk of paralysis is so
small, and there is a body of opinion in favour of non-disclosure it did not have to be disclosed (as per Bolam
test) (Lord Bridge). It was held that some, but not all, neurosurgeons would have considered it as acceptable
not to inform the patient of this risk of paralysis.

*Walsh v Family Planning Services [1992] IR 496 (Republic of Ireland)*

The plaintiff underwent a vasectomy for contraceptive purposes. Prior to the procedure he had been told that
the operation would not have a negative impact on his sex life but there may be some discomfort and
swelling after the operation with a very rare chance of pain for some years later. Unfortunately, he suffered a
variety of problems which included severe groin pain, impotence and eventual removal of his left testicle.
Expert evidence showed that he suffered from a rare consequence of vasectomy, named orchialgia. At the
time of the procedure, there was no known practice regarding disclosure of this particular risk.

**Judgement:**

The fact that this was an elective procedure was important in determining the extent of the disclosure.
However, the judge adopted a clear approach that it was a matter for the trial judge to determine general
negligence principles of reasonable doctor test as stated in Dunne Principles. Regardless of the risk,
however exceptional or remote, of grave consequences, the exercise of the duty of care owed by the
defendants requires that such possible consequences should be explained in the clearest language to the
plaintiff.

*Rogers v Whittaker [1993] 4 Med LR 79*

Ms Whittaker had suffered a penetrating eye injury which resulted in loss of vision and a cosmetically poor
secondary strabismus. The doctor (Mr Rogers) failed to inform Mrs Whittaker of a 1:14,000 chance of going
blind in her other eye from sympathetic ophthalmia which was an inherent risk of surgery and was held
negligent. Mrs Whittaker had made her concerns about the risks of losing her sight altogether very clearly.

*Pearce v United Bristol Healthcare NHS Trust [1998] 48 BMLR 118*

Mrs Pearce had a stillbirth. She claimed that earlier intervention would have resulted in a live birth. She
begged to be induced or have a caesarean section when she was 14 days beyond the due date for delivery
but was informed by Mr Niven to wait for a natural birth. On admittance to hospital some 7 days later, there
was no foetal heartbeat or movement and an ultrasound confirmed that the foetus had died. Even in
discussions, Mr Niven had not discussed the risk of stillbirth with Mrs Pearce, having put it at between 0.1
and 0.2 percent but Mrs Pearce claimed that had she been told, she would have requested a section. The
claim failed on account of an even reasonable doctor would not mention such a small risk particularly as the
mother was in a distressed state and that it was considered that she would still have followed Mr Niven’s
advice even if she had been informed of the risks.

**Judgement**

The medical opinion not to disclose has to be reasonable and responsible and if there was a significant risk
that would affect the judgement of the reasonable patient, then the patient should be informed of the risks.
Geoghegan v Harris [2003] 3 IR 536 (Republic of Ireland)

The plaintiff required a dental implant which involved a bone graft from the plaintiff’s chin. This was alleged to have damaged a nerve leaving the patient with chronic neuropathic pain. It was alleged that the dentist failed to disclose prior to the operation the risk that such pain might be a consequence of the procedure. The defendant accepted that he did not disclose this risk as he was of the opinion that he had a duty to disclose complications where the risk exceeded 1% and he felt that this pain was not associated with the procedure. The plaintiff argued that he would not have gone through with the operation even if the risk was 0.1%.

Judgement:
The standard of risk of that of the “reasonable” patient and the judge concluded that the patient should have been informed of any material risks and that the defendant had been negligent in failing to provide the plaintiff with this information as, had the patient been privy to this information, would have chosen not to proceed with the surgery.

Chester v Afshar [2004] UKHL 41

Ms Chester suffering lower back pain from lumbar disc protrusion and Mr Afshar, a consultant, recommended an operation to remove spinal discs. Mr Afshar discussed the operation but failed to warn Ms Chester that there was a foreseeable risk of paralysis of between 1 and 2% albeit an unavoidable risk of the surgery. It was agreed that this was a risk about which she should have been informed. She agreed to the operation which was performed in an appropriate way but it resulted in severe pain and mobility difficulties. Failure to warn was not a direct cause of injury but it did result in negligence.

Judgement

Lord Bingham stated:

“A surgeon owes a general duty to a patient to warn him or her in general terms of possible serious risks involved in the procedure. The only qualification is that there may be wholly exceptional cases where objectivity in the best interests of the patient the surgeon may be excused from giving a warning... in modern law, medical paternalism no longer rules and a patient had a prima facie right to be informed by a surgeon of a small, but well established risk of serious injury as a result of surgery”.

It was considered that the claimant’s right to autonomy and dignity and their right to make informed choices justified a narrow and modest departure from traditional causation principles.

Birch v University College London Hospital NHS Foundation Trust [2008] EWHC 2237

The plaintiff suffered a stroke as a result of a cerebral catheter angiogram. The doctors failed to discuss with the patient, the different imaging methods of a MRI scan and an angiogram and the comparative risks and benefits associated with each.

Judgement:
The judge said that patients should be informed not only of the objectively significant risks of the proposed procedure but also how this risk compared to the risks associated with other procedures which might be more relevant. More specifically, the judge stated that “the duty to inform a patient of the significant risks will not be discharged unless she is made aware that fewer, or no risks, are associated with another procedure. In other words, unless the patient is informed of the comparative risks of different procedures, she will not be in a position to give her fully informed consent to one procedure rather than another”.

Montgomery v Lanarkshire Health Board [2010] CSOH 104 (Scotland)

During labour, the baby’s head was delivered and he showed no signs of shoulder dystocia. The rest of his body was delivered approximately 12 minutes later, during which time he sustained acute hypoxia resulting in renal damage, epileptic seizures and cerebral palsy in addition to other injuries. The pursuer, who suffered from diabetes and was of short stature, brought an action against the consultant obstetrician who had delivered her son. She also alleged that no ordinary competent obstetrician would have failed to advise her of the risks of shoulder dystocia in diabetic mothers of around 10% in babies weighing over 4 kg and with an adverse outcome of 1-2 percent, during vaginal delivery and should have offered her a caesarean delivery.

Judgement

Surprisingly, the pursuer lost her case on both allegations, on the basis that non-intervention was made on a logical basis and that the defendants had considered the comparative risks and benefits of a caesarean and weighed them up with those inherent with a normal delivery. Interestingly enough, this case has been criticised for its rather historical approach from the courts.

6 Timing of consent

Re: Fitzpatrick v White [2007] IESC 51

Mr Fitzpatrick was admitted to the Royal Victoria Eye and Ear Hospital as a day case for surgery to correct a squint for cosmetic reasons. Unfortunately, although the procedure was performed proficiently, over the following months there was a gradual slippage of the medial rectus muscle which caused a worsening in his appearance and double vision. Mr Fitzpatrick brought proceedings against the hospital, claiming negligence but lost his case. His appeal to the Supreme Court was restricted to the claim that his consent was not valid because it had only been obtained half an hour prior to the operation.

Judgement

The court did not uphold his appeal on the grounds that there was nothing in the evidence to suggest that the plaintiff could not assimilate or properly understand what he was told. However, Kearns, J did recognise that in other cases where a warning is given late in the day, particularly in the case of elective surgery, the outcome might be different. He emphasised that at a time so close to surgery, a patient may be particularly stressed, in pain or under the influence of medication and these factors might contribute to a patient’s ability to make a calm and reasoned choice. A number of expert witnesses believed that this practice of warning the patient on the day can have advantages equally it could be that the patient is deprived of a true choice and thus not able to make a free decision.

7 Coercion

Re T (Adult) [1992] 4 All ER649

A 20 year old pregnant woman (T) was injured in a car accident and developed complications which required a blood transfusion. She had been raised as a Jehovah’s Witness but had not been involved in the religion for several years. She was happy to consent but following a visit from her mother, a practising Jehovah’s Witness, she refused to consent. The Court of Appeal concluded that T’s refusal was not an expression of her own independent decision but was a result of improper pressure from her mother. The Court allowed the blood transfusion to proceed.

**Judgement**

T's decision was flawed as the combination of injuries and medication impaired her mental capacity.

# 8 Competence and capacity

## 8.1 Refusal of treatment and test for capacity in United Kingdom

*Re C (Adult: refusal of treatment)* [1994] All ER 819

C had paranoia schizophrenia and was detained in Broadmoor secure hospital. He developed a gangrenous foot and was told by doctors that he would probably die if he did not agree to have his foot amputated. He refused to consent as he disagreed with the views of the doctors. He had delusions of his status and believed that God would heal him.

**Judgement**

J Thorpe held that as he understood the diagnosis and accepted that the doctors were truthfully expressing their views, he understood the relevant information. The fact that he disagreed with the doctors’ views did not mean that he was lacking capacity. He was therefore entitled to refuse treatment. The fact that a person has a mental illness does not automatically mean they lack capacity to make a decision about medical treatment.

## 8.2 Test for capacity in Republic of Ireland

The following case and decision sets out the test for the assessment of capacity in Ireland.

*Fitzpatrick and Another v K and Another* [2008] IEHC 104

K, a 23 year old woman from Congo, gave birth to a baby in an Irish hospital in 2006. Shortly afterwards, she suffered a post-partum haemorrhage which resulted in a cardio-vascular collapse. As preparations were being made for a blood transfusion, the medical team was informed that K would not accept a transfusion for religious reasons but without this, K would die. Following discussions with K and the Master of the hospital (most senior obstetrician with responsibility for clinical governance), K repeatedly refused blood transfusion. K’s capacity to make such a decision was questioned and an application to the High Court for an emergency order to transfuse K was made. K was informed of the court order and a blood transfusion was performed during which time K was sedated. K later claimed that the court order should not have been given and that the transfusion was unlawful and constituted an assault and trespass and that she was entitled to refuse treatment by virtue of her Constitutional rights and those under Articles 8 and 9 of the European Convention on Human Rights. The question of whether K had capacity to refuse the transfusion was at the centre of the case.

**Judgement**

The judge considered that although K’s capacity was not impaired, the rights of the newborn child had to be taken into consideration. A number of principles applicable to the determination of capacity were seen as relevant:

- Presumption of capacity;
- Whether the patient was deprived of capacity by reason of permanent cognitive impairment or temporary factors to the extent that he or she does not understand sufficiently the nature, purpose and effect of the proffered treatment and consequences of accepting or rejecting at the time the decision is made;
The patient’s cognitive ability will have been impaired to the extent that he or she is incapable of making the decision to refuse the proffered treatment if the patient has not comprehended nor retained the necessary information and has not assimilated the information as to the consequences likely to ensure from refusing treatment;

The patient has not believed this information;

The patient has not weighed it up, balancing the risks and needs to arrive at a decision;

The treatment information by reference to which the patient’s capacity is to be assessed is the information that the clinician is under a duty to impart (why treatment is indicated, risks and consequences);

In assessing capacity, it is necessary to distinguish between misunderstanding and misinterpretation of information in the decision-making process and an irrational decision or decision made for irrational reasons, the former may being linked to the evidence of lack of capacity.

The Court was satisfied that K had received the necessary information to enable her to make an informed choice but that the necessary factors regarding her medical condition and indeed her communication difficulties, had been taken into account and that K’s capacity was impaired to the extent that she did not have the ability to make a valid refusal of the treatment proffered to her.

8.3 Refusal of treatment by competent adults

*S v St George’s Healthcare NHS Trust* [1998] 3 WLR 936

A pregnant woman refused a caesarean section even though without it she and her foetus would die.

**Judgement:**

A pregnant woman of sound mind has exactly the same right to accept or refuse treatment as any other adult and the unborn child enjoys no legal personality which entitles the court to force its mother to submit to any form of intervention she chooses to decline.

*Re: B (Adult): Refusal of Medical Treatment* [2002] 2 All ER 449

B was a 43 year old paralysed woman requested removal of artificial ventilation not withstanding that this would result in her death. She was a well-informed woman with a high degree of mental competence. The medical team tried hard to persuade her to keep the ventilator on.

**Judgement:**

Dame Butler-Sloss held that B’s wishes should be respected by doctors irrespective of the outcome as, just because she was physically disabled, she has the same right to personal autonomy as the able-bodied patient and thus clinical views as to the patient’s best interests are irrelevant. B was entitled to damages for the prior interference with her right to refuse the treatment.

9 Children and young people

*Gillick v West Norfolk and Wisbech AHA* [1986] AC 112

Mrs Gillick was concerned about a Department of Health circular which permitted doctors to provide contraceptive advice and treatment to under-16-year-old without parental permission. She argued that it should be unlawful for a doctor to treat an under-16-year-old without parental consent.
**Judgement**
The House of Lords held that a doctor could give contraceptive advice and treatment to a young person under the age of 16 years if she had sufficient maturity and intelligence to understand the nature and implications of the proposed treatment and it was considered to be in her best interests (Gillick competence).

**Fraser guidelines**
Lord Fraser raised concerns regarding the provision of contraceptive advice/treatment to children under the age of 16 years. Practitioners may be accused of procuring sexual intercourse with a child of such an age which constitutes a criminal offence. Protection is thus required and such advice can only be given on clinical grounds.

**North Western Health Board v HW and CW [2001] 3 IR 622**
This case related to the Supreme Court having to deal with parental authority to refuse consent for a PKU test to be carried out on their child, Paul, to determine the presence of any associated disorder.

**Judgement**
In the original High Court case the judge set out the following issues:

“There is no doubt that medical opinion would emphatically state that it is in Paul’s best interest to have the PKU test done.... the question I have to ask is whether this objective benefit to Paul overrides the rights of his parents, in effect, to decide that they do not want Paul to have the discomfort, and discomfort is as strong a word as could be used for it, of a pinprick in his heel, and are prepared to take the risk that he does not suffer from any of the relevant conditions.... if the State were entitled to intervene in every case where a professional opinion differed from that of parents, or where the State considered to parents were wrong in their decision, we would be rapidly stepping towards the Brave New World in which the State always knows best. In my view, that situation would be totally at variance with both the spirit and word of the Constitution”.

A balance needs to be achieved between the child’s rights within and to his family, and the family (as an institution) rights, and the parents’ right to exercise their responsibility for the child, and the child’s personal constitutional rights, the threshold of which will depend upon the circumstances of the case. If the child’s life is in danger (immediate) then there would be good grounds to be put on the child’s personal rights superseding the family and personal consequences.

10 **Legal duty of confidentiality**
Permission to disclose confidential information in the form of explicit consent, preferably signed, is preferred by the courts.

**Tarasoff v Regents of the University of California [1976] 131 Cal Rptr 14 (Cal Sup Ct)**

**Facts of the case**
Tarasoff and Poddar were students at the University of California. Poddar believed that they had a serious relationship whilst Tarasoff thought otherwise. Poddar started to stalk her and developed a wish for revenge in which he expressed his intention to kill Tarasoff. Poddar became emotional unstable and sought help from Dr Moore at the university’s hospital. A diagnosis of acute and severe paranoid schizophrenia was made and Poddar was detained. He later stabilised and was released but then fulfilled his threat by killing Tarasoff. Tarasoff’s parents sued Moore, claiming that Moore should have warned Tarasoff of the threats.

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Judgement:
The California Supreme Court held that Dr Moore owed Tarasoff a duty of care and disclosure was essential to avert the danger, a protective privilege ending where the public interest begins.

**Duncan v Medical Practitioners Disciplinary Committee [1986] 1 NZLR 513**
A bus driver underwent a triple bypass operation of his heart and had obtained a certificate from his treating surgeon that he was fit to drive and resume work. However, his general practitioner, Dr Duncan, formed a different opinion and told people in the community about his condition and not to travel on his bus. The bus driver complained.

Judgement:
The court held that Dr Duncan was in breach of his duty of confidence to his patient.

The surgeon who was treating the patient considered the patient fit and had certified the patient as fit to drive a bus.

Judge Jeffries stated that the doctor should ensure that recipients of such information is a respectable authority and that Dr Duncan should have made his complaint to an appropriate authority that had responsibility for granting bus drivers’ licenses and then such disclosure would have met the public interest requirements but in this case, the mechanism used to disclose was unacceptable.

**W v Edgall [1990] 1 All ER 835 (CA)**
W had been convicted of a number of violent killings and was detained under the Mental Health Act 1983. W applied for parole and Dr Edgall prepared a report for a Mental Health Tribunal which had to consider whether W should or should not be concerned that those caring for him did not appreciate the situation. W decided not to pursue his application for parole and withdrew it but Dr Edgall disclosed his report to those caring for him and the Home Office. W objected to this disclosure as he had not given consent for this information to be used in this manner.

Judgement:
The Court of Appeal held that disclosure of the report would breach confidentiality but that the disclosure was justified in the public’s best interest. There was a real risk of significant harm to others and this justified the disclosure and W lost his case.

**Palmer v Tees Health Authority [2000] PIQR1**
A health authority was caring for a man, Mr Armstrong, who was suffering from a personality disorder. He had been admitted to hospital on several occasions but whilst being treated in the community, he killed a four-year old girl who lived in the neighbourhood. The girl’s parents claimed that the hospital was negligent in releasing the man or, at least, for not warning those who lived close by.

Judgement:
It was held that there was no reason for the local authority to believe that the man posed a risk to the girl. The health authority did not owe her or her parents a duty of care.

Comparison of Tarasoff and Palmer
The different decision in Palmer was justified as the danger was not directed towards an indentified individual.
Cornelius v De Taranto [2001] 68 BMLR 62

Mrs Cornelius, a teacher, claimed to be suffering from work-related stress and, as part of her evidence, visited a psychiatrist privately. The psychiatrist sent a copy of her report to the teacher’s GP, general consultant psychiatrist and her solicitor. Mrs Cornelius sued for breach of confidentiality.

Judgement:
The Court of Appeal held that there was a breach of confidentiality, as she had not expressly consented to the distribution of the report. The report had nothing to do with her treatment so distribution was not justified on therapeutic grounds. The doctor could not rely on implied consent.

11 Parental access to records in relation to children under the Freedom of Information Act 1997 (Republic of Ireland)

McK v Information Commissioner [2006] IESC 2

A father, a widower, had been separated from his late wife, and was joint guardian of his children. It was questioned whether, under the FOIA 1997, he was entitled to information in the form of hospital notes about his daughter’s illness. There had been unproven allegations of sexual abuse by the man of his daughter prior to couple’s separation. The man had been given supervised access to his children and at the time of his wife’s death, they had been working towards unsupervised access. Following the death of the wife, the children went to reside with the wife’s brother. There were three guardians – the children’s father, the brother-in-law and his wife. The child was admitted to hospital with a suspected viral infection and the father sought further information from the hospital but it was not forthcoming, the other guardians having refused permission for release of the information. The father appealed to the Information Commissioner.

Judgement:
It was decided that where there is disagreement between parents/ guardians regarding the release of records relating to a minor, release will only be directed if there is tangible evidence that such release would be in the minor’s best interest.
This annex provides an overview of the relevant statutes which impact on practice and is presented in the order consistent with the Rules.

**Rule 1: Accountability**

**Civil Liability and Courts Act 2004 (Ireland)**

This addresses clinical negligence claims in the Republic of Ireland and under this Act, anyone wishing to make a claim in negligence has to act within two years of the event (unlike personal injury claims) that caused the initial injury or the “date of knowledge but there are some considerations. Time does not run against the mentally disabled until full mental capacity is regained, or for those under the age of 18 years until the eve of their 18th birthday and until the injury caused by the negligent action is discovered and confirmed. Clinical negligence claims are excluded from the scope of the Personal Injuries Assessment Board 2003.

**Rule 3: Non-judgemental practice**

**The Human Rights Act 1998**

The Human Rights Act 1998 (HRA) is an Act to provide greater effect to the rights and freedoms guaranteed under the European Convention on Human Rights (the Convention). The HRA only incorporates the rights in Articles 2 to 12 and Article 14 of the Convention and those in the First Protocol (rights to property, education and free elections) and Sixth Protocol (abolition of the death penalty).

As far as it is possible to do so, primary legislation and subordinate legislation must be read and given effect in a way that is compatible with these Convention rights. It is unlawful for public authorities, including the NHS, to act in a manner which is incompatible with these rights.

The HRA requires that all public bodies must ensure that everything they do is compatible with the Convention rights unless an Act of Parliament prevents this. They must provide a mechanism for people to challenge a public body if it is believed that it has acted, or intends to act, in a way that is unlawful under the HRA.

The main public authorities in health care are:

- Courts and tribunals
- NHS Trusts
- Private and voluntary sector contractors when performing public functions under contract to the NHS
- General Practitioners, dentists, optometrists and pharmacists when undertaking NHS work
- Primary Care Trusts and Local Health Boards
Bodies having functions of a public nature such as the Health Professions Council.

The Convention Articles relevant in decisions about health care investigations and treatment are:

- Article 2: right to life
- Article 3: right to be free from torture, inhuman or degrading treatment
- Article 5: right to liberty and security of person
- Article 8: right to respect for privacy and family life, his home and correspondence
- Article 9: right to freedom of thought, conscience and religion
- Article 10: right to freedom of expression including the right to hold opinions and to receive information
- Article 12: right to marry and have a family
- Article 14: right to be free from discriminatory practice in respect of these rights

Other Articles:

- Article 4: right to be free from slavery or forced labour
- Article 6: right to a fair trial
- Article 7: right to no punishment without law
- Article 11: right to freedom of assembly and association
- Article 1 of Protocol 1: right to peaceful enjoyment of possessions
- Article 2 of Protocol 1: right to education
- Article 3 of Protocol 1: right to free elections

United Nations Convention of the Rights of the Child (UNRC)

The UN Convention of the Rights of the Child was adopted by the United Nations in 1989 and sets out the rights to which all children are entitled. The provisions are categorised into protection, provision and participation.

Protection

The protection provision includes those rights that address the child’s right to protection from harm and abuse. The most significant aspect is covered in Article 19 which requires the State to take all measures to protect children from harm, abuse and ill-treatment.

Provision

This category of rights details the rights of the child to have their needs met, including the right to health and healthcare (Article 24), the right to an adequate standard of living (Article 27), and the right to education (Articles 28 and 29). It also makes provision for rights of children with disabilities (Article 23) and for children deprived of their family environment (Article 20) and refugee children (Article 22).
Participation

This category covers a wide range of rights. Article 12 recognises the child’s right to be heard in all matters affecting them. It is significant with respect to autonomy and evolving capacity and consent. Further areas addressed are fundamental civil rights such as the child’s right to freedom of expression (Article 13), freedom of religion (Article 14), freedom of association (Article 15), right to access appropriate information (Article 17) and the State’s duty to make children and adults aware of children’s rights (Article 42).

Equality Act 2010 (England, Scotland and Wales)

The Equality Act 2010 brings together a number of existing laws into one place – a single equality act – including the Race Relations Act 1976, the Sex Discrimination Act 1975, and the Disability Discrimination Act 1995. It aims to remove inconsistencies, making it easier to understand and apply.

Under the Act, all public authorities (including the NHS and Health Boards) must have due regard to the need to: eliminate discrimination, harassment and victimisation and any other conduct prohibited under the Act; advance equality of opportunity between persons who share a relevant protected characteristic and those who do not; and foster good relations between persons who share a relevant protected characteristic and those who do not.

It is unlawful to discriminate anyone with a particular protected characteristics, namely age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race (with the possibility of including caste); religion or belief; sex and sexual orientation. The Equality Act has strengthened and extended the types of discrimination:

- **Discrimination** means treating one person worse than another because of a protected characteristic (direct discrimination);
- **Indirect discrimination** occurs when a rule or policy is put in place that has a worse impact on someone with a protected characteristic than someone without one, when this cannot be objectively justified;
- **Harassment** includes unwanted conduct related to a protected characteristic which has the purpose or effect or violating someone’s dignity or which creates a hostile, degrading, humiliating or offensive environment for someone with a protected characteristic;
- **Victimisation** is treating someone unfavourably because they have taken (or might be taking) action under the Equality Act or supporting someone who is doing so;
- **Perception** is treating someone differently because it is thought that they have a protected characteristic.

**Discrimination of disability**

People who currently have a disability are protected because of this characteristic against harassment and discrimination (including discrimination arising from the disability) and a failure to comply with the duty to make reasonable adjustments.

People who have had a disability in the past are also protected against harassment and discrimination. Non-disabled people are protected against direct disability discrimination only when they are perceived to have a disability or are associated with a disabled person.
Definitions of disability

A person will have the protected characteristic of disability of they had had a disability in the past, even if they no longer have the disability.

In the Act, a person has a disability if:

- They have a physical or mental impairment (includes sensory impairments such as sight and hearing)
- The impairment has a long-term and substantial adverse effect on their ability to perform normal day-to-day activities. Long-term means that the effect of the impairment has lasted or is likely to last for at least 12 months or for the rest of the person’s life; substantial means more than minor or trivial.

Where a person is taking measures to treat or correct an impairment (over and above using spectacles or contact lenses) and, but for those measures, the impairment would be likely to have a substantial adverse effect on the ability to carry out normal day-to-day activities, it is still to be treated as though it does have an effect. This means that “hidden” impairments such as diabetes, epilepsy, mental health illness) are also covered within the Act providing they meet the definition within the Act.

Progressive conditions such as cancer, HIV infection and multiple sclerosis are all protected by the Act from the point of diagnosis whilst those with fluctuating and recurring effects will meet the definition in certain circumstances.

Equality Acts: Northern Ireland

Northern Ireland has a mixture of legislation, some originating from direct rule in the form of Orders in Council and some originating in the devolved Northern Ireland Assembly. In addition, there are pieces of legislation in force in Northern Ireland that refer to the whole of the United Kingdom, where competencies are not devolved, such as immigration law. In Northern Ireland, anti-discrimination law is a devolved matter.

However, equality provisions are extensive, with a duty on public bodies to have due regard for equality between specified groups and legal protection against discrimination against particular identities, although the level of protection varies between groups. The legislation retained in Northern Ireland\textsuperscript{166} includes the following with a number of amendments over time:

- Sex Discrimination Order 1976
- Disability Discrimination Act 1995
- Race Relations Order 1997, most recent amendment being Race Relations Order (Amendment) Regulations (Northern Ireland) 2009
- Fair Employment and Treatment Order 1998
- Employment Equality (Sexual Orientation) Regulations 2003
- Employment Regulations 2006

Further information regarding these Acts and associated Amendments can be accessed via the Equality Commission for Northern Ireland website\textsuperscript{167}.

Equality Acts: Republic of Ireland


The Employment Equality Act came into operation in October 1999 and replaced the Anti-Discrimination (Pay) Act 1974 and the Employment Equality Act 1977 but has been amended by the Equality Act 2004. Orthoptists should be aware of the impact of the Employment Equality Acts in relation to employment issues (equal pay, access to employment, promotion or degrading and dismissal) and the promotion of equality with reference to the prohibition of sexual harassment and harassment, provision of appropriate measures for people with disability in relation to access, participation and employment, promotion of equal opportunities on the grounds of age and positive integration of people over 50 years, those with disabilities and those from the travelling community.

**Equal Status Acts 2000 and 2004**

The Equal Status Act 2000 has been amended by the Equality Act 2004 and, together, they are referred to as the Equal Status Acts 2000 and 2004. The principle is that everyone has an equal right to participate in our society. Orthoptists must be aware that people should not be denied access to services (including health care), facilities and amenities on the grounds of race, age, religion, disability or membership of a traveller community. They should be seen as being of equal worth and should be treated on merits and not on the basis of prejudice or stereotype. The Equal Status Act 2000 provides protection against direct and indirect discrimination outside of employment on the same nine grounds – age, gender, religion, sexual orientation, racial or ethnic origin, marital status and membership to the traveller community. In addition, it prohibits sexual harassment and harassment, victimisation, and requires reasonable adjustment for people with disabilities.

**National Disability Authority Act 1999**

This Act underpins the new mainstream framework for the provision of services with disabilities. Under this Act, an independent body, the National Disability Authority (NDA) was established.

**Rule 5: Decision-making and consent**

**CHILDREN**

**The Children Act 1989 (England and Wales)**

The Children Act 1989 came into force in England and Wales in 1991 and articulates a number of principles in addition to providing specific legal procedures:

*Principles of the Children Act:*

1. The child’s welfare is paramount;

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accessed March 2012


169 For further information, see: [http://www.nda.ie/](http://www.nda.ie/) accessed March 2012
2. The child is a person, not an object of concern: children of sufficient maturity should be listened to (although not necessarily be given full power of attorney);

3. Children should be brought up by parents, or wider family, without the interference of the State, unless placed at risk;

4. Family links should be maintained if a child is placed out of the home;

5. Cooperation, negotiation and partnership should be the aim when conflicts arise;

6. Avoid delay when legal processes are required.

The involvement of the child in the decision-making process is also a major principle. Whilst the considerations set out below, equivalent to a welfare check list, apply to decisions to be made under the Children’s Act, there are good reasons for Orthoptists to follow these same considerations in the care of the child, namely:

- The ascertainable wishes and feelings of the child concerned, and in relation to their age and understanding;
- The child’s physical, emotional and educational needs;
- The likely effect on the child of any change in circumstances;
- The age, sex and background of the child, and any characteristics the court considers relevant;
- Any harm the child has suffered or is at risk of suffering;
- The capability of parents and any other person in relation to whom the court considers the question to be relevant to meet the child’s needs;
- The range of powers available to the courts.

Although the Children’s Act 1989 remains the principle statute concerning children, it has been supplemented by several subsequent Acts. The Children Act 2004 makes radical changes to the system of children’s services with the intention of providing a better integrated service for the protection of children. Orthoptists should be aware of the Act’s provision for a national database that will enable local authorities, the NHS, and other agencies to share information on suspected abuse and neglect, with the aim of achieving early intervention. The Act also sets the powers and duties of the Children’s Commissioner whose role is to act as a champion for children by promoting an awareness of the rights, views and welfare and interests of children.

More specifically, the Act addresses the issues of potential conflict in the care of children such as:

- Care arrangements if parents split up;
- Decision-making where those with parental responsibility for the care of the child cannot come to an agreement (for example, with respect to medical treatment);
- Arrangements to protect a child from harm, either in an emergency or in the longer term.

**Parental responsibilities**

Orthoptists need to understand the significance of parental responsibility as it is essential to the question of who is able to give consent for medical assessment and treatment of a child not yet old enough and mature enough to give their own consent.
More than one person may have parental responsibility for a child (typically both parents will have such responsibility). This is referred to as automatic parental responsibility – mother of child and father if married to the mother at the time of the birth (S3);

Many actions or decisions, including consent to medical assessment and treatment, can be carried out by just one person with parental responsibility, and there is no duty for that person to consult anyone else with parental responsibility before acting or giving consent to treatment;

Parental responsibility cannot be normally be transferred or surrendered;

Acquired parental responsibility: since December 2003 where the father is not married to child’s mother and was not registered as the child’s father he can acquire under an agreement from mother (S3);

Step-parents: since December 2005, a step-parent who is married to child’s natural parent can acquire parental responsibility (S4);

Those who care for a child but do not have parental responsibility are allowed to do what is reasonable to promote or safeguard child’s welfare (S3(5)).

The Children’s Act is a key piece of legislation relevant in England and Wales. Scotland has its own Act.

**The Family Law Reform Act 1969 (England and Wales)**

The Family Law Reform Act 1969 is relevant to treatment for patients aged 16 and 17 years in England and Wales. It is not relevant in Scotland.

The Family Law Reform Act S8 states that the consent of an minor who has attained the age of sixteen years to any surgical, medical or dental treatment, shall be as effective as it would be if he were of full age (i.e above 18 years) and it shall not be necessary to obtain any consent for it from his parent or guardian (or those with parental responsibility).

**The Children (Scotland) Act 1995**

The Children (Scotland) Act 1995 applies to Scotland and was a major piece of social legislation that affects many areas of common and statute law concerning children. A key aim of the Act was to move towards a more child-centred approach and is based on 3 principles:

1. The welfare of the child is paramount;
2. The views of the child must be taken into account where practicable; a child aged 12 years and over is presumed to form a view;
3. A court, or hearing, should make an order concerning a child’s future only if it is convinced that making an order is better than not making it.

The Children (Scotland) Act makes more explicit reference to children’s views than the Children’s Act 1989, but has similar orders to protect children, whilst at the same time, resolve disputes within the English Act. Parental responsibilities and rights are clearly defined and under the Act, a parent has a responsibility towards a child up to the age of 16 years to:

- Safeguard the child’s health and welfare and development;
- Provide direction and guidance;
Maintain personal relations and direct contact with the child on a regular basis (if not living with the child).

The responsibility to provide guidance lasts until the child is 18 years old. A parent has a right to:

- Have a child live with him or her, or regulate where a child will live;
- Control, direct or guide the child’s upbringing
- Maintain personal relations and direct contact (if the child is not living with the parent).

**Age of Legal Capacity (Scotland Act) 1991**

The Act gives statutory power to mature minors under the age of 16 years to consent to treatment. The Act (Section 2(4) states that “a person under the age of 16 shall have legal capacity to consent on his own behalf to any surgical, medical or dental procedure or treatment where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedures or treatment”, consistent with Gillick competence. The Act does not affect a parent’s ability to give consent on behalf of a person aged less than 16 years.

**Child Care Act 1991 and Children’s Act 2001 (Republic of Ireland)**

Children’s legislation in the form of the Child Act 1991 and the Children’s Act 2001 cannot be compared with similar named laws in the other member countries. For information, these Acts make provision for the child to be heard in child care and criminal proceedings. Advice regarding children should be taken from the Department of Children and Youth Affairs.

**ADULTS – MENTAL CAPACITY**

**Mental Capacity Act 2005 (England and Wales)**

The Act provides a legal framework for making decisions in relation to people who lack capacity, aged over 16 years. It addresses:

- Who can make decisions, including decisions about health care and treatment, for people who are unable to decide for themselves;
- How those decisions should be made.

Section 1 of the Act sets out five key principles that apply to any action taken and decisions made under the Act. These are:

1. A person must be assumed to have capacity unless it is established that they lack capacity
2. A person is not treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success
3. A person is not to be treated as unable to make a decision merely because they make an unwise choice
4. An act done, or decision is made, under the Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests

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5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action.

In the Act, people lack capacity in relation to a specific matter if, at the material time, they are unable to make a decision for themselves in relation to the matter because of an impairment of, or a disturbance in, the functioning of the mind or brain (section 2(1)).

Health care professionals must have regard to the supporting Code of Practice which explains how the Act should work on a day to day basis and sets out the steps that those using it and interpreting it are required to follow when:

- Assessing a person’s capacity or
- Reaching a decision in the best interests of a person who does not have capacity.

**Adults with Incapacity (Scotland) Act 2000**

The law in Scotland generally presumes that adults are capable of making personal decisions for themselves and of managing their own affairs.

This Act provides ways to help safeguard the welfare of people aged 16 years and over who lack the capacity to take some or all decisions for themselves, because of a mental disorder or inability to communicate. It also enables others to make decisions on their behalf. The Act provides a number of methods to take decisions and actions on behalf of an adult who lacks capacity and includes issues related to health care.

Within the Act, incapacity means being incapable of acting on, making, communicating, understanding or remembering decisions by reason of mental disorder or inability to communicate due to a physical disorder; but a person shall not fall within this definition by reason only of a lack or deficiency in a faculty of communication if that lack or deficiency can be made good by human or mechanical aid (whether interpretative nature or otherwise); and incapacity shall be construed accordingly.

The Act sets out the principles that must be followed when deciding whether to intervene.

**Principle 1: benefit**

Any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably achieved without it;

**Principle 2: least restrictive option**

Any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person’s freedom as little as possible.

**Principle 3: take account of the wishes of the person**

In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as this may be ascertained. Some adults will be able to express their wishes and feelings clearly, even although they would not be capable of taking the action or decision which you are considering. The person must be offered help to communicate his or her views. This might mean using memory aids, pictures, non-verbal communication, advice from a speech and language therapist or support from an independent advocate.
Principle 4: consultation with relevant others
Take account of the views of others with an interest in the person’s welfare. The Act lists those who should be consulted whenever practicable and reasonable. It includes the person’s primary carer, nearest relative, named person, attorney or guardian (if there is one).

Principle 5: encourage the person to use existing skills and develop new skills
The Code of Practice supports the Act and sets out guidance for those acting under the legislation including health professionals who are treating patients who lack capacity.

Northern Ireland
There is no current legislation in capacity covering Northern Ireland. Decisions regarding health care treatment in people lacking capacity are made in accordance with the common law, the patient’s best interests being central to any decision making. However, a Mental Capacity Act is expected to be introduced in 2014.

Mental Capacity Bill 2008 (Republic of Ireland)
Mental Capacity Bill 2008 has been introduced to address the outcome of a report from the Law Reform Commission which highlighted the need to provide a modernised framework to protect vulnerable adults who due to illness, accident or intellectual ability are unable to make decisions for themselves or exercise their legal capacity (rather than applying to make that individual a ward of court). The following principles apply for the purposes of this intended Act171 and every person concerned in the implication of the Act or in making any decision, declaration or order or giving of any direction under the Act shall have regard to them:

- It will be presumed that a person has capacity;
- No intervention is to take place unless it is necessary having regards to the needs of and individual circumstances of the person, including whether the person is likely to increase or regain capacity;
- A person will not be treated as unable to make a decision merely because he makes an unwise decision;
- Any act done or decision made under this Act must be done in the way which is least restrictive or the person’s rights and freedoms of action;
- Due regard must be given to the need to respect the right of a person to his or her dignity, bodily integrity, privacy or autonomy;
- Account must be taken of a person’s past and present wishes, where ascertainable;
- Account must be taken of the views of any person with an interest in the welfare of a person who lacks capacity, where these views have been made and,
- Any act done or decision made under this Act for or on behalf of a person who lacks capacity must be done or made in his or her best interest.

Rules 6 and 7: Duty to maintain records and Confidentiality

Data Protection

**Data Protection Act 1998**

The Data Protection Act 1998 (DPA) covers the processing of personal data. It covers all personal data including medical information and all data stored in systems albeit electronic or paper.

**Schedule 1: Principles of the Act**

- Personal data shall be processed fairly and lawfully and shall not be processed unless –
  - At least one of the conditions in Schedule 2 is met, and
  - In the case of sensitive personal data, at least one or the conditions in Schedule 3 is also met.
- Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.
- Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.
- Personal data shall be accurate and, where necessary, kept up to date.
- Personal data processed for any purpose or purposes shall not be kept for longer than is necessary for that purpose or those purposes.
- Personal data shall be processed in accordance with the rights of data subjects under this Act.
- Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing of personal data and against accidental loss or destruction of, or damage to, personal data.
- Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

**Schedule 2: Conditions relevant for the purpose of the first principle (processing of any personal data)**

The data subject has given consent.

- The processing is necessary for the performance of a contract with the data subject.
- The processing must comply with any legal obligations other than a contract.
- The processing is necessary to protect the vital interest of the data subject i.e. life or death situation.
- The processing is necessary to carry out public functions and the administration of justice.
- The processing is necessary to pursue the legitimate interest of the controller unless prejudicial to data subject interests.

**Schedule 3: Conditions relevant for the purpose of the first principle (processing of sensitive personal data)**

The data subject has given explicit consent to the processing of personal data.

- The processing is necessary to comply with legal rights or/ obligations as an employer.
The processing is necessary to protect the vital interests of the data subject or another.

The information has been made public deliberately by the data subject.

The processing is necessary to obtain legal advice and for exercising legal rights in connection with legal proceedings.

The processing is necessary for medical purposes undertaken by a health professional or someone with equivalent duty of confidentiality.

The processing is necessary for equal opportunities monitoring.

The processing is necessary for the purposes of research whose object is not to support decisions with respect to any particular data subject otherwise than with the explicit consent of the data subject and which is not likely to cause substantial damage or substantial distress to the data subject or any other person.


The Data Protection Act (1988) was introduced to address concerns regarding the protection of data stored on computer and focused on the ease with which computerised data could be retrieved and transferred without the knowledge of the individuals to whom the data related. The Act enables an action at common law in relation to mishandling of data such as breach of privacy, defamation and negligence, the latter being facilitated by providing under section 7 that the duty data controller owes a duty of care to the data subject for the purpose of the law of torts.

Principle of the Act

Data must:

- Have been obtained and must be processed fairly;
- Be accurate and kept up to date;
- Be kept for only one or more specified and lawful purpose;
- Not be used or disclosed in any manner incompatible with that specified purpose or purposed;
- Be adequate, relevant and not excessive in relation to the purposes specified;
- Only be kept for as long as is necessary for the specified purpose.

Data Protection Act 2003

This Act was introduced to implement the EU Data Protection Directive (1995). The 2003 Act extend data protection laws to:

- Manual data or paper files that are held in filing systems, data being that recorded as part of a relevant filing system or with the intention that it should form part of a relevant filing system and where,

- Relevant filing system means any structured set of personal data which is readily accessible according to specific criteria.

Conditions of processing

At least one of these conditions needs to be met prior to processing:

172 Article 2(c) of the Directive, defined in the Data Protection Act 2003, s2
- Obtaining consent of the data subject;
- Processing is necessary:
  - For the discharge of a legal obligation;
  - To protect vital interests of the data subject;
  - For the legitimate interests of the data controller or a third party to whom the data is disclosed;
  - In order to obtain legal advice;
  - For medical purposes and is carried out by a health professional or a person who would also owe a similar duty of confidentiality.

“Health professionals” include medical practitioners, registered dentists or any other class of health worker and “medical purposes” pertains to preventative medicine, medical diagnosis, medical research, provision of care and treatment and the management of health care services.

**Consent**

For the purpose of processing, consent may be:

- Expressly given in writing by signing a consent form or alternative form in which processing of personal information is indicated or,
- Implied by the actions of the patient in attending a health care practitioner where notices informing patients that their personal data will be processed should be displayed.

### Rule 8: Duty to report

**General Health and Safety in the United Kingdom**

**Health and Safety at Work Act 1974**

*General duties on employers and others*

These duties are outlined in sections where the obligations are qualified by the phrases “so far as is reasonably practicable” and “best practicable means”.

- **Section 2:** Employers’ duties to employees
- **Section 3:** Employers’ duties to non-employees
- **Section 7:** Employees’ duties

**Section 2: Employers’ duties to employees**

- To ensure that plant systems of work are safe and without risk to health
- To ensure that the use, handling, storage and transportation of articles and substances are safe and without risk to health
- To provide suitable and sufficient information, instruction, supervision and training
- To maintain the premises in a safe condition, without risk to health and with suitable means of access and egress
- To maintain the workplace in a safe condition, without risks to health and with adequate facilities and arrangements for their welfare.
**Section 3: Employers’ duties to non-employees**

The employer has a duty to conduct his work in such a manner that it is without risk to health and safety of non-employees such as:

- Patients
- Clients
- Visitors
- Contractors

**Section 7 and 8: Employees’ duties**

- To take reasonable cadre of themselves and others who may be affected by their acts and omissions
- To co-operate with the employer and to meet any health and safety requirements placed on them
- Not to intentionally or recklessly interfere with or misuse anything provided by the employer in the interests of health, safety and welfare.

**Other Health and Safety Regulations relating to the NHS**

A number of other regulations are applicable to the orthoptic practice and include:

- **Management of Health and Safety at Work Regulations 1999**
  Sets out how employers are required to assess risk in all work activities, implement control measures if required, provide information and training, and appoint competent persons.

- **Manual Handling Operations Regulations 1992**
  Cover the moving and handling of objects either by hand or by bodily force.

- **Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 1995**
  Require employers to notify certain types of injury, disease and dangerous occurrences to the Health and Safety Executive.

- **Workplace (Health and Safety and Welfare) Regulations 1993**
  Cover such issues as flooring, workstations, ventilation and temperature.

- **Health and Safety (Display Screen Equipment) Regulations 1992**
  Set out requirements for the use of visual display units, workstations, seating etc.

- **Health and Safety (First Aid) Regulations 1981**
  Concern first aid requirements such as the contents of the first aid boxes and the number of trained first aid personnel.

- **Health and Safety (Safety Signs and Signals) Regulations 1996**
  Specifies the minimum requirements for safety signs at work.
Health and Safety Republic of Ireland

Safety, Health and Welfare at Work Act 2005

Section 8: Employers’ duties
The employer has a duty to ensure that the employees’ safety, health and welfare at work as far as is reasonably practicable. In order to prevent workplace injuries and ill health the employer is required, among other things to:

- Provide and maintain a safe workplace which uses safe plant and equipment
- Prevent risks from use of any article or substance and from exposure to physical agents, noise and vibration
- Prevent any improper conduct or behaviour likely to put the safety, health and welfare of employees at risk
- Provide instruction and training to employees on health and safety
- Provide protective clothing and equipment to employees
- Appointing a competent person as the organisation’s Safety Officer

Section 13: Employees’ duties

- To take reasonable care to protect the health and safety of themselves and of other people in the workplace
- Not to engage in improper behaviour that will endanger themselves or others
- Not to be under the influence of drink or drugs in the workplace
- To undergo any reasonable medical or other assessment if requested to do so by the employer
- To report any defects in the place of work or equipment which might be a danger to health and safety

Additional requirements

Risk Assessment: every employer is required to carry out a risk assessment for the workplace which should identify any hazards present in the workplace, assess the risks arising from such hazards and identify the steps to be taken to deal with risks. The employer must also prepare a safety statement which is based on the risk assessment.

Reporting Accidents: all accidents should be reported to the employer who should report the details of the accident. This will help safeguard social and welfare and other rights which may arise as a result of occupational accident.

Public Disclosure Act 1998

The Act protects workers from detrimental treatment or victimisation from their employer if, in the public interest, they blow the whistle on wrongdoing. Whistleblowers are protected to encourage people to speak out if they find malpractice in an organisation or workplace.

**Type of disclosures**

For a disclosure to be protected by the Act’s provisions, it must relate to matters that “qualify” for protection under the Act. Under Section 1 of the Act, qualifying disclosures are disclosures which the worker reasonably believes shows that one or more of the following matters is either happening now, or took place in the past or is likely to happen in the future:

- Criminal offence
- Breach of a legal obligation
- Miscarriage of justice
- Danger to the health and safety of an individual
- Damage to the environment
- Deliberate concealment to cover up any of the above

However, the Act does not cover whistle blowing if:

- A breach of the law occurs when making a disclosure
- The information is protected under legal professional privilege (for example: if the information was disclosed when requiring legal advice)

**Protected disclosure**

For disclosure to be protected by law, it should be made to the right person and in the right was on the following grounds. There is good reason to believe that the:

- Disclosure was in good faith (with honest intent and without malice)
- Information is substantially true;
- Disclosure is being made to the right “prescribed” person.

**In the event of dismissal or victimisation for whistle-blowing**

Under Section 5 of the Act, if an employee, a claim for unfair dismissal can be made for complaining about malpractice at work or under Section 2, in the event of victimisation or detrimental treatment, a claim can be made for “detrimental treatment”.
The hyperlinks in this section are in small type to ensure that you can easily select them for copying and pasting into your web browser.

**Department of Health**

**Guidance for Access to Health Records Request (February 2010)**

**Human Rights in Health Care (December 2008)**

**Reference Guide to Consent for Examination or Treatment (Second edition) (August 2009)**

**NHS Code of Confidentiality**

**Confidentiality: NHS Code of Practice: Supplementary Guidance (November 2010)**

**Seeking consent: working with people with learning disabilities.**

**Seeking consent: working with children**

**STATUTES/ACTS**

**Adults with Incapacity (Scotland) Act 2000**

**Age of Legal Capacity (Scotland Act) 1991**

**The Children Act 1989**

**The Children (Scotland) Act 1995**

**Child Care Act 1991**

**Children’s Act 2001**
Civil Liability and Courts Act 2004

Data Protection Act 1998


Equality Act 2010
http://www.equalityhumanrights.com

Equality Acts in Republic of Ireland
www.dublinpact.ie/word/Equality-Legislation-IRL.doc

Equality Acts in Northern Ireland
http://www.equalityni.org/site/default.asp?secid=home

Family Law Reform Act 1969

Health and Safety at Work Act 1974

Health, Safety and Welfare at Work Act 2005

Human Rights Act 1998
http://www.equalityhumanrights.com/

Limitation Act 1980

Mental Capacity Act 2005

Mental Capacity Bill 2008

Public Disclosure Act 1998

United Nations Convention of the Rights of the Child
http://www.unicef.org/crc/
http://www.direct.gov.uk/en/Parents/ParentsRights/DG_4003313
Other websites

Department of Children & Youth Affairs (RoI)

CORU (RoI)
http://www.coru.ie/

British Institute of Human Rights

General Medical Council
http://www.gmc-uk.org/

Nursing and Midwifery Council
http://www.nmc-uk.org/

The Medical Protection Society
http://www.medicalprotection.org/uk

NHS Constitution

British Medical Association
http://www.bma.org.uk/ethics/health_records/AccessHealthRecords.jsp

Health and Care Professions Council
http://www.hpc-uk.org/publications/

Texts and journals


