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## **Confidentiality and patient autonomy in a healthcare framework**

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Morals and Ethics surround us in our daily lives and are even more important in healthcare<sup>1</sup>. While all health practitioners need to be familiar with the general concepts of confidentiality and autonomy, there are believed to be some conflicts of understanding within podiatry<sup>2</sup>. The purpose of this short paper is to offer some information on the ethical principles of confidentiality and autonomy which may help provide a base level of understanding to inform and underpin clinical practice.

Morals are the principles of right and wrong behaviour; and ethics are the theory or system of moral values<sup>3</sup>. Working ethically requires practitioners to work within a framework that allows consistency in ethical practice as a Healthcare Professional (HCP), whether in the fields of private or NHS work<sup>4</sup>. All HCPs including podiatrists have a need to follow moral and ethical frameworks in their work to protect the patient, themselves and their organization<sup>5</sup>. Referring to Kant's theory of ethics, Seedhouse notes that HCPs must act in a way:

*"not influenced by self-interest, nor consideration of social benefit. Moral people do their duty because they must"*<sup>3</sup>.

Ethical theory and varying individual morals can however conflict. Within NHS practice there are checks and balances to combat ambiguities relating to differences in individual values and ethical theory which are enshrined within the seven ethical principles<sup>6</sup>. Two examples of important ethical principles relevant in current healthcare practice are patient confidentiality and autonomy. These principles can significantly impact on patients, carers and organisations alike. Challenges that arise in relation to confidentiality and autonomy are managed using frameworks to help clarify difficulties in ethical practice.

In relation to the ethical principle of confidentiality ‘Confidentiality, NHS Code of Practice’ explains that:

*“the NHS is committed to the delivery of a first class confidential service... ensuring that all patient information is processed fairly, lawfully and transparently as possible to the public”<sup>7</sup>*

This refers to the confidentiality model whose role is to protect, inform, provide choice and constantly improve guidelines. To embrace this, the HCP must keep consistent, legible and accurate patient records, securing them physically, electronically and verbally. Patients can also access and be informed as to how their information is being utilised enabling them to decide when or to whom it is disclosed to. This framework allows patients to be able to trust the NHS with treatment and in holding their information.

Case law and “*common law nature of confidentiality*”<sup>7</sup> ensures that the NHS constantly updates and amends practice improvement policies. HCPs are responsible for implementing associated changes<sup>8</sup> and in doing for constantly optimising patient confidentiality. NHS

confidentiality models acknowledge that changes in disclosure are necessary to improve services so patients receive the best service with any necessary disclosure of their information occurring within the legal framework.

Despite patient confidentiality being a key priority, circumstances exist where information disclosure is demanded. In the safeguarding of children or vulnerable adults, disclosure is required to prevent harm and similarly to prevent criminal activity from occurring<sup>7</sup>.

Disclosure must be approached carefully due to the continuing need to protect patients' personal information. Caldicott outlined six confidentiality principles to protect all parties by justifying information disclosure and recommending the removal of patient identifiable information (PII) to retain anonymity. Guidelines explain that disclosure when necessary should be on a 'need to know' basis with due care being taken to act within a legal framework when using patient information<sup>7</sup>.

The NHS provide information to patients and staff to ensure confidentiality and HCPs can use specified models to evaluate whether disclosure is necessary<sup>7</sup>. Clarity around confidentiality and disclosure processes is essential. HCPs have access to information for completing paths of disclosure, and similarly patients have access to information explaining how their data will be used. This allows information transparency to raise public trust that the NHS and HCPs will keep their personal information safe and use this information appropriately within the stated frameworks. Leaflets on care, treatment and managing information are generally available to enable patients to make their own choices on the use of their personal information and its disclosure.

Patients unhappy with management of information, have procedures in place to deal with complaints. This allows patients to give feedback about their experiences as a part of the drive for the NHS to constantly improve services to the public.

The transparent presence and impact of confidentiality helps maintain trust between a patient and HCP. This enables an important relationship to develop which facilitates the delivery of the best healthcare. Confidentiality guidelines provide transparency which in turn empowers and reassures patients at the same time keeping them informed and able to make free choice on the use of information by the NHS. This trusting relationship and use of feedback allows patients to have an active role in delivery of their healthcare and in the use of their personal information. This is essential to fulfil the requirement for constant improvement of guidelines and processes – improvements which rely upon patient responses. Whilst these principles are enshrined within NHS policy, the enactment of them is equally as important in non-NHS scenarios. All areas of clinical practice; the private, independent, voluntary and educational sectors of the podiatric profession, should encompass these principles in their own governance documentation. More importantly is the individual responsibility of all HCP's to embrace these policies in their daily conduct.

The second principle considered here, that of autonomy may have an unclear definition in healthcare but it is, however extremely important within practice. Patient autonomy ensures the patient has been given the maximum level of control over their own healthcare, and that any interventions made are approached with this in mind<sup>3</sup>. Information transparency allows the patient to make informed decisions about their treatment so long as age and mental capacity allows<sup>9</sup>. Frameworks in the NHS allow HCPs to make decisions for the patient

when autonomy may be questioned due to a lack of capacity. In such cases, decisions made on behalf of the patient would follow a professional assessment governed by the Mental Capacity Act 2005. Part of the legal framework of the Mental Capacity Act 2005 offers provisions about the decision that can be made on behalf of others but within a set of key principles that asserts a person's best interests<sup>10</sup>.

For a patient to have autonomy over their treatment they must first be ready to be empowered<sup>11</sup>; particularly they must possess enough information, and confidence to make their own informed decisions. Williamson noted that HCPs withholding information had less awareness of patient's rights towards healthcare and in turn less understanding of their need for their autonomy<sup>12</sup>. Transparency of policy information assists patient autonomy by increasing the awareness of these rights.

Despite NHS policy, in minor procedures, consent or ability to decline is often overlooked, and does not wholly acknowledge that the patient has a right to exercise a choice contrary to policy and guidance<sup>13</sup>. While this is a common issue in relation to the performance of minor procedures, this can also be the case in more significant general medical interventions. A recent Supreme Court judgment in a negligence case involving obstetrics noted that a value judgment and not a purely medical judgment appeared to have been made by the consultant involved in this case<sup>14</sup>. Here it was stated in the Judgment that the consultant had viewed vaginal delivery to be "in some way morally preferable to a caesarean section" to the point that the actions taken by the medical consultant had justified "depriving the pregnant woman of the information needed for her to make a free choice in the matter"<sup>14</sup>. It is therefore apparent that there are some areas of practice where autonomy still appears to be overlooked despite the requirements of policy and the principles of informed consent.

HCPs must consider the need for autonomy regardless of treatment. One of the key principles for ascertaining a person's best interests is that a person is not to be treated as unable to make a decision merely because they make an unwise decision<sup>10</sup>. This principle is a common conflict for HCP's who consider the patient is making a decision that they disagree with from a medical and professional perspective or indeed from a policy or provision limitation.

This provides a challenge to the HCP who is often working in isolation from the multi-disciplinary team. Current legislation in the form of the Mental Capacity Act (MCA) 2005 outlines that a person with mental capacity should make decisions on their own healthcare unless their capacity is proven otherwise<sup>15</sup>. This means that if someone refuses treatment which a reasonable person would have, and it is in their best interests to have this treatment, whether in the public, private, or independent sectors; the HCP has to abide by their wishes unless their mental capacity is proven to be unsound. Proving this can be a lengthy process, and there can be contradictions between the requirements of the Human Rights Act (HRA) 1998<sup>16</sup> and of the MCA 2005<sup>15</sup> as the former challenges the human rights of the mental health sufferer where treatment is seen as being forced. Dimond (2008) emphasises "*training, organisational and management repercussions are immense. So too are the resource implications*"<sup>17</sup> in the involvement of the MCA and the effect on patient autonomy.

A case in 2012 involved force feeding of an anorexic sufferer<sup>18</sup> and considers difficult grey areas in the assessment of mental health, and in the deliberations of where patient autonomy ends. The court's decision was ultimately based on the 'preservation of life' and demonstrates the difficulties in seeking clarity where legislation and policies cross at practical levels when applying principles of autonomy in practice.

Power inequalities inherent in medical practice are in some way negated by patient autonomy which contributes to resolving concerns about medical paternalism<sup>19</sup>. There is, however also an issue with respect to the level of autonomy that a patient wishes to adopt. Adams et al<sup>20</sup> found that many patients preferred clinicians to assume the major role in the decision making related to their clinical management. Conversely the patient wished to remain in control when choosing modes of care or initiating changes in medications<sup>20</sup>.

While suggesting that patients welcome autonomy when selecting their medication, it has also been suggested that a patient expects the HCP to have the best knowledge behind recommendation of treatment<sup>21, 22</sup>. Autonomy in relation to pharmacological management aspects of care benefits patients and care providers where there is excellent communication between the two groups. Where communication between HCPs and patients works well this can ensure that patients receive the most appropriate treatment that they themselves feel will optimize their health. HCPs who communicate well with their patients set an environment in which patients can explain openly and in a timely manner when problems occur with medication, (i.e. when adverse side effects are experienced), and enable their treatment to be changed.

Communication with patients is vital to service improvement. Without patient autonomy, this would be difficult as high quality dialogue with patients can be important in ensuring successful service development and improvement. In this context complaints procedures also feed into patient autonomy by allowing a forum of communication which in turn can help the NHS to continually improve current practice.

## **Conclusion**

The application of ethical principles in healthcare is generally aimed at providing a positive experience for the patient. The presence of confidentiality and patient trust in HCP practice, enables good relationships to be developed between the two parties. To facilitate and support this, frameworks and legal guidelines clarify required practice in these areas in an attempt to offer positive outcomes for the patient and HCP alike.

It is imperative that HCPs remain mindful of their actions and fully embrace confidentiality and autonomy, especially as the 'grey' areas of practice can be difficult to assess. Respecting confidentiality up to the point where disclosure may be necessary, is part of the ethical role of a HCP. The dynamic ability to assess each case that may require disclosure on its own merit is paramount to a successful and ethical practitioner. Protecting patients or others from distress; either through confidentiality or disclosing information allows management of the situation to remain optimal for all parties involved, however it is recognized that this can be difficult.

The acceptance of patient autonomy within healthcare should involve the use of information and decision sharing as the foundation to ensure that the best possible care for the individual is being provided. HCPs must be able to understand individual patients, their motivations and the concerns that they have about their care. Where this understanding is present an empathic model of delivery which encourages individual tailoring of patient management will be engendered. Good communication, genuine relationships and good ethical practice are defining factors in the delivery of successful healthcare.

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