

THE USE OF ANONYMISED CASE STUDIES WITHIN NHS Lothian FOR EDUCATIONAL PURPOSES

INTRODUCTION

As a result of a specific incident within NHS Lothian where a clinician delivering a teaching session to a group of healthcare students within an HEI inadvertently provided the cohort with enough relevant information for them to identify the patient in a case study, there was a need to review the practices related to the use of patient information for the purposes of education.

The issue and ethics of confidentiality go to the heart of the healthcare system in the Western world and is an immensely complex and detailed one. This paper will however maintain a focus on the specific aspects of confidentiality relating to the incident described providing advice to practitioners to ensure that patient confidentiality is not breached during educational events.

CURRENT HEI POLICIES IN RELATION TO THE USE OF PATIENT INFORMATION IN EDUCATION

An exploration of policies relating to the use of patient information within educational events in the three local Higher Educational Institutes (HEIs) relating to the involvement of clinicians in undergraduate medicine, nursing and midwifery programmes suggested that policies varied somewhat. It was established however that each HEI requires that the clinician satisfy local requirements to show that they are the appropriate level professionally to undertake a particular educational session. This may be in the form of a Curriculum Vitae, formal appointment as a visiting lecturer (or equivalent role) or recommendation from a trusted clinical source. As such the clinician would also be subject to their employer's confidentiality policies and their respective professional bodies code of professional conduct regarding confidentiality.

In terms of vicarious accountability of the HEI, should for example, a serious factual or procedural error be disseminated, there is a consensus within the HEIs that the programme leaders are ultimately responsible for content. This responsibility to ensure that any education provided upholds patient confidentiality is subsequently devolved to module leader (or equivalent role) colleagues engaging the clinician to contribute to the educational event. Where staff, have dual employment the use of any NHS live system to support lecture delivery can pose a breach of confidentiality. Where staff are unclear, advice should be sought from the relevant departments i.e. eHealth.

ENSURING ANONYMITY OF PATIENT INFORMATION

Whilst all the health and indeed other professions have clauses in their codes of conduct, most of them refer, understandably, to issues of confidentiality in terms of provision of care; communication within the care team; ethical considerations and so on. There is little in these documents however addressing use of confidential information relating to education or teaching situations.

The British Medical Association (2011) makes the following assertion around sharing of confidential information with other health professionals in an anonymised form: 'Information may be used more freely if the subject of the information is not identifiable in any way. Usually, data can be considered to be anonymous where clinical or administrative information is separated from details that may permit the individual to be identified such as name, date of birth and postcode. Even where such obvious identifiers are missing, rare diseases, drug treatments or statistical analyses which have very small numbers within a small population may allow individuals to be identified. A combination of items increases the chances of patient identification.'

When anonymised data will serve the purpose, health professionals must anonymise data to this extent and, if necessary, take technical advice about anonymisation before releasing data. Whilst it is not ethically necessary to seek consent for the use of anonymised data, general information about when their data will be anonymised should be available to patients.'

Taken from [Confidentiality and disclosure of health information tool kit](#)

Throughout this guidance the BMA emphasises that disclosures of information should involve the minimum necessary to achieve the objective. Thus wherever possible, anonymous or aggregated data should be used in preference to identifiable information.'

NHS Scotland (2003) within the Code on Protecting Patient Confidentiality gives the following guidance:

'Data are said to be anonymised when items such as name, address, full postcode, date of birth and any other detail that might identify a patient are removed; the data about a patient cannot be identified by the recipient of the information; and the theoretical probability of the patient's identity being discovered is extremely small.'
(p13)

CONSENT TO USE ANONYMISED PERSONAL INFORMATION

Within all professional codes of conduct the importance of maintaining confidentiality at all times is highlighted. However, in an educational environment, there is also the implicit expectation that case studies based around real patients and situations, are used in order to promote learning for the profession. A patient has the right to expect that their individual details are not identifiable. NHS Scotland (2003) also highlight the need for the patient to be informed that their information will be used for disease registries, medical research, education and training in an anonymised format. The patient must consent to the use of this information in these circumstances and that their choice as to whether they agree to their information being used in this manner respected.

Again there is little if any literature referring specifically to this aspect, understandably focussing on consent within the realms of 'care'. The BMA (1999) notes that: 'It cannot be assumed that identifiable health information can be automatically shared with any other health professional or health service employee. Care must be taken to ensure that disclosures are not made inadvertently, that those receiving the information in a professional capacity also have obligations

(professional, contractual and/or legal) to maintain confidentiality, that only information necessary to achieve the objective is disclosed and it is understood that the information should only be used for the purpose for which it is disclosed.'

Transposing this to the educational environment, the professional who intends to use patient information for educational purposes has two obligations:-

i) the responsibility to inform the patient that their details (relevant to pathology) may be used in the future in order to assist in Continuing Professional Development and/or Practice Education. They must gain their consent for information to be used in this manner.

ii) the responsibility to ensure that all identifiable personal information will be changed or deleted in order to maintain confidentiality

USE OF CASE STUDIES IN EDUCATION

Case studies by their nature are often used to highlight 'typical' or indeed atypical cases of pathology. They are commonly used in both undergraduate and postgraduate education as tools in assessment in clinical practice. Invariably, under these conditions the learner will need to gain consent from the patient/client/carer in order to use patient details, and also ensure that as far as possible, these details are kept confidential.

Most of the health professions in the United Kingdom have adopted a problem based learning (PBL) approach within the Universities and colleges to help engage students, provide a 'real' scenarios and to enable cross-boundary clinical and theoretical education. The essence of PBL is that the student addresses a scenario designed to mimic (to a greater or lesser extent) a clinical situation, and hence gain experience of dealing with real issues without the risk to the patient.

Case studies whilst not exclusively within the domain of PBL, can help illustrate a complex medical scenario very effectively. They also have a considerable benefit to both teacher and student of providing extra information or challenge that either requires, simply by definition, to be based on true events. In other words the reality of the situation provides a richness of experience where a purely fictional scenario probably could not.

It is therefore not surprising that clinicians will frequently refer to anonymised case studies to illustrate particularly interesting, representative or complex cases.

ENSURING ANONYMITY WHEN USING CASE STUDIES

Prior to preparing a session that will include information about real patients/clients/carers, it is suggested that the clinician should go through the following checklist:

- Is case study the best way to approach this topic – would another way be as effective?
- Could the case study be completely fictional instead?

- Could the case study be as effective if aggregated from a number of patients?
- What information is pertinent to the learning required for this particular cohort of students?
- What information, if any, has been retained, that may jeopardize a patient/client/carer's anonymity? Specifically:
 1. Image (or part of an image), body morphology, tattoo or birth mark, presence of any readily recognisable feature including voice in the case of video or audio tape.
 2. Demographic information on sex, date of birth, race, address, religion, profession.
 3. Any form of identification easily or *potentially* 'decoded' by the audience such as initials, DoB, CHI or patient number.
 4. Does the patient fall into the category of 'rare' in terms of diagnosis, drug therapy regime or very specific populous.
- Can further information relating to one, *or a combination of*, pieces of information that may jeopardize anonymity be omitted?

The professional also requires to be aware that it may be the supplementary information that the teacher provides, as 'background' to the case study, that may be the most hazardous in terms of breaking confidentiality and needs to be avoided. The issue of consent also needs to be addressed. Clearly if an individual clinician is undertaking development of a case study based on an individual patient event.

CONCLUSION

The dearth of literature around this topic would suggest that this incident is a rare one, with the temptation therefore to dismiss the possibility of it happening again as infinitesimal. Whilst recognising this to be the case, this particular incident has had widespread consequences both personal and professional for all those involved. When undertaking educational events, all professionals must take cognisance their professional bodies codes of conduct in relation to patient confidentiality and adhere to the NHS Lothian and HEI policies related to patient confidentiality and the use of patient information for educational purposes.

Information Governance guidance in education

The following guidance is intended for NHS Lothian Staff, Module Leaders and Module Teams developing and delivering modules / courses delivered by NHS Lothian or modules within the Collaborative Agreements between NHS Lothian and Queen Margaret and Edinburgh Napier Universities.

Guidance on the use of anonymised information

It is recognised that information from the practice arena may be used in an educational environment to promote professional learning. In such circumstances information must be anonymised. Anonymised information is information that does not identify a specific individual and all patient, staff, relative or carer information used in course / module material must be anonymised. If a patient, staff member, relative or carer could identify specific individuals or specific practice areas in any educational material used in then it is not anonymous. It is therefore recommended that all training materials use composite information to ensure teaching materials are truly anonymised. NHS Lothian policy on Confidentiality of Personal Health Information (2011) states that consent must be obtained to use anonymised personal information (P.18).

To ensure that the confidentiality of patients, staff, relatives and carers is preserved, the following guidelines must be followed when using any practice based material in the educational environment:

- A.** Names, addresses and any other identifiable personal details of patients, staff, relatives or carers should not be used in any circumstances.
- B.** Identifiable work areas such as NHS directorates, hospitals or wards should not be used.
- C.** Identifiable information relating to critical incidents or fatal accident enquires should not be used.
- D.** Where there is an uncommon diagnosis or other distinctive circumstances that could potentially lead to identification of a patient, member of staff, relative or carer this information should not be used without significant adjustment to ensure anonymity is maintained.
- E.** In circumstances such as D above, aggregation of data or information from a number of patients or the use of composite information from multiple sources may be used to ensure anonymity.