

# **Ethical and Funding Issues**

## **Ethical Principles and their Application**

### **Introduction**

The education programmes are dependent on students learning from the everyday experiences of patients who are currently accessing health and social care services. It is therefore vitally important that robust processes are in place to protect the rights and confidentiality of these volunteer patients, and to ensure that the information discussed in these programmes is sensitively handled and fulfils the requirements of the Data Protection and Freedom of Information Acts. The following processes are in place to provide this level of protection.

### **Education Institution**

The educational content and methodology requires approval from the Educational Policy Committee of the Higher Education Institute.

The ethical sub-committee of the Educational Policy Committee should be consulted.

### **Educational Methodology**

It is a requirement of the UK Data Protection Act and Caldicott that if questionnaire material is required of patients or health and social care staff supporting these patients, formal ethical approval should be sought.

The Leicester Model of education learning cycle identifies unmet needs or issues affecting patients, formal agreements must be made with organisations that they are willing to receive, and if appropriate, act upon this information for the patient's benefit.

### **Academic Co-ordinators, Tutors and Administrators**

Compulsory training ensures academic co-ordinators, lead tutors and administrators responsible for delivering the programme are fully aware of:

- their responsibilities in dealing with confidential patient information;
- processes to record and resolve incidents which may arise during the programme;
- patient induction, including knowledge of patient withdrawal processes;
- patient involvement pre and post interviews;
- their role in familiarising locality tutors in these ethical principles;
- student induction for these education programmes.

### **Health and Social Care Organisations**

Organisations involved in the educational programmes are provided with a copy of this Guide and details are formally presented to their organisational boards.

## Agency Representatives

Agency representatives and other stakeholders involved in student interviews are informed on these ethical principles during their recruitment into the programme. They are instructed how to respond to the information gained by students during the patient interview. They are aware that they should not discuss any information about the patient unless this has first been raised by the student group.

## Patient Identification and Induction

There is a two-stage process for patient identification and enrolment, with exit points in place at every stage of the process as follows:

- the lead tutor obtains the names of potential patients who fit the selection criteria via a secondary referral process from primary care teams or specialist services (e.g. children's care). See Part 3 – The Patient Pathway;
- patients are first approached by a professional who knows them best. They are given an introduction about the programme and are asked if they would like to consider their future involvement;
- if the patient indicates a willingness to become involved, the lead tutor arranges a visit to provide more details about the programme and their involvement, they are instructed that at any stage they may withdraw without any impact on their health and social care;
- patients are in full control of the information provided to the student group. They also identify which agency representatives should be interviewed as part of their case study;
- patients know that agency interviews will not divulge any information which has not first been discussed by them, or agreed to be released for inclusion on the case study information sheet;
- patients decide how they wish to be identified, students will never be privy to their full name, only an agreed first name;
- patients sign a contract to confirm their informed consent to taking part.

For patients with learning disabilities, enrolment follows the standard guidelines for informed consent. This is normally obtained with a family member or guardian.

## Students

Students are informed about their requirement to protect patients' confidentiality. This is provided during their introductory lecture, in their workbook and repeatedly by the tutors throughout the programme.

Students are not allowed to remove details of the patient case study from the education venue, nor write or present details of the patient's name or address in an identifiable format. They are also not allowed to discuss their case in public places. Failure to comply will result in disciplinary action in line with their Higher Educational Institution's conduct policy.

Students are instructed to report any untoward incidents they may uncover during the interviews to the tutor. An incident process is triggered which requires written details to be forwarded to the academic co-ordinator who will take appropriate action. Students are informed that they should not directly discuss untoward incidents or unexpected findings with the agency representatives involved in their interviews. Tutor debriefing after each interview provides a second opportunity to identify and address these unlikely events.

## **Evaluation**

Routine post-programme evaluation provides opportunities for all stakeholders to reflect on ethical issues arising from their involvement.