The Patient Unit
Leicester Medical School
Autumn 2015

Framework Document

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Acknowledgements

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Appendix
1. Background and Introduction

Introduction
Patients and carers have always been involved in Leicester Medical School; this document is about how we take this journey forward.

This document outlines how we will formalise a volunteer patient and career group who will form an active community within the Leicester Medical School. The purpose of this group is to enhance student learning. The group will offer an active rather than passive level of curriculum involvement and help to design bespoke pre-planned learning activities. This work is in line with modern views of teaching that patient’s perspectives offer valuable new insights for humanity which is central to all medical practice.

Patients are viewed as pivotal in supporting medical student learning. Every day patients allow medical students to learn about clinical and supportive care during their consultation(s) with doctors and other healthcare professionals. Enabling patients to influence curriculum design and lead teaching has remained a challenge, despite directives to Medical Schools to engage patients within faculty teams (GMC, 2010).

History of the Patient Unit at Leicester Medical School
Since 1995, patients have been involved in designing student learning within the interprofessional theme of Leicester’s curriculum. This is in line with the ladder of involvement as described by Tew and colleagues, or as perceived by others as active engagement within a curriculum (Tew et al., 2004; Towle et al., 2010). This early work of involving patients in steering groups led to the design of the Leicester Model of Practice-based Interprofessional Education, where ethical principles for working with patients were outlined. This has led to numerous publications on learning possibilities (Lennox & Anderson, 2007; Anderson & Lennox, 2009; Kinnair et al., 2012). Further involvement with curriculum design took place in 1998 when disabled people from the Leicester Centre for Independent Living, both led and supported student teaching on a course entitled, ‘Learning from Lives’ (Anderson et al., 2003; Anderson & Smith, 2010).

In 2005 patients again became partners in education and were supported to develop teaching they felt was relevant for health and social care students. Using a participatory action research design, patients designed a one-day event called the Listening Workshop (Anderson et al, 2011). In the workshop patients/service users and carers tell their stories of experiences of health and social care to small groups of interprofessional students. Students engage in a conversation and are required to actively listen. The service users and carers join the students who feedback their key learning relating to their patient conversations. Recently links have been made with patients using e-technologies enabling patient and students conversations on clinical situations and care under the initiative ‘Patient Knows Best’, led by Dr R Hsu. We have now trained some patients/carers to lead teaching and learning and involve them in faculty work.
The Listening Workshop has been the catalyst for the formation of a formalised patient group. This work since 2005 has offered many patients and carers the opportunity to share their stories with medical and other students in a one-day interprofessional workshop (Anderson, Ford & Thorpe 2011). Over 60 people are involved throughout the year with teaching that takes place during the clinical component of the medical school curriculum. Two leading teaching roles have emerged from this work, providing opportunities for patients and carers to further engage with the curriculum; these roles are i) ‘Co-Tutor’ and ii) Mentor. Patients and carers have been given formal training to take on these roles.

**Identity of the Group**

Branding will give the group a tangible identity for members to gather around.

- **Name:** The group have proposed the name, *The Patient and Carer Group*
- **Logo and strap line:** The logo, as seen on the front cover, contains the strap line ‘forming a bridge between theory and practice’.

![Image of the Patient and Carer Group logo](image)

**Developing the Community**

The Patient and Carer Group will develop literature, newsletters and electronic systems. They will have a presence on the Medical School webpage. There will also be physical spaces made available for the emerging and developing group within existing medical school buildings.

The welcome meeting: The first step of involvement includes an invitation to a welcome meeting where experienced patients and carers (those who have been teaching in the Medical School for some time) will take on a supporting and welcoming role. There will be a process for informal assessment for suitability and patient support need(s). The welcome meeting will include not only an introduction from the Medical School but also the opportunity for mentors and new members to briefly share their experiences (See exemplar invitation letter - Appendix).

It is envisaged that there will be an advocate student link representative from each of the curriculum years to form a student group who proactively support and engage with the Patient and Carer Group.
2. Statement of Values

Leicester Medical School Patient Centred Curriculum (2016)
As Leicester is a rich multicultural City many medical experiences, on a global scale, can be found here. The potential to link this breadth of patient(s) within the new medical curriculum offers fantastic student learning opportunities. Building on our history the following sections will outline an open and transparent community of practice in which the authenticity of the patient/caterer experience is valued. The Patient and Carer Group will aim to enrich the quality of learning for training medical students.

Mission statement
The Group has decided on the following statement: “The Patient and Carer Group ‘forms a bridge between theory and practice’, working in partnership with students, academics and clinical teachers. It draws on the group’s experiences of today’s health and social care systems, informing teaching to improve the quality of patient care”.

How we will work together?
We will ground our values using the principles of ‘Good Medical Practice’ (GMC 2009)\(^1\):

- Good communication
- Being open and honest
- Maintaining trust
- Consent
- Confidentiality
- Respect as colleagues
- Good conduct.

Ethical principles will be paramount as patients and carers volunteer to become a member of the group. A two-way consent process will operate in which the Medical School will ensure that the values laid out above are assured through support for participants. This includes listening to the needs of individuals and working with them to offer suitable times, places and templates for engagement (see Appendix for consent form). People will be treated fairly and equally. Patients and carers will personally agree terms for their involvement with the Medical School and sign a consent form which provides a necessary outline for entry into a data base (see data base).

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\(^1\) Good Medical Practice (2009). General Medical Council Regulations Ensuring Good medical Practice. GMC. London
Diversity and Equality
The Patient and Carer Group will over time grow a diverse group of patients who represent the many groups within Leicester and with whom students will learn in preparation for their work as qualified doctors. In response the group will become integrative partners within the Medical School offered respect and valued using the above principles. Patients/carers will enable dialogue between the medical school and communities within Leicester.

The Patient and Carer Group will record and hold data on members (see section on data base). This data will uphold the relevant legal requirement to describe an individual person e.g. culture, religion, disability needs etc. This data will be available for GMC quality returns.

Patients/carers should be offered the normal support for anyone with a disability such as access, reading materials, diet, religion and transport.

Patients/carers that work within and represent the Medical School like academic staff require update training and appreciation of diversity issues. This should lead to sensitivity concerning how to behave and work alongside Leicester’s rich and diverse population. This will include awareness of the University of Leicester’s and the Medical School’s policies on diversity (see section on training).

The group will align to the Medical School and University policies on diversity and equality.

Joining the Group
All patients and carers who wish to support teaching will volunteer to join this group. All those who volunteer will be valued in the following roles:

- teaching
- mentoring
- committee work
- research
- admissions
- student support
- outreach work
- conferences

This list offers a platform for early developments but is not limited and new roles may be created as new possibilities are explored.

Support
It is widely recognised that patients/carers who share personal narratives feel vulnerable and emotionally fragile and this should be recognised (Spencer et al, 2011). The Patient and Carer Group will seek to identify the individual physical and/or emotional support needs
which patients and carers may require. Access should be made available for follow up support and counselling where necessary. Patients/carers could be offered access to ‘Mindfulness Training’ and other support systems accessed by students (see training).

Working with the Medical School will obligate the patient/carer and the Medical School to a code of conduct. This will clearly set out expectations for each party.

3. Roles

Introduction

We recognise that all those patients and carers who come to join this group do so willingly as volunteers. The majority of this volunteering is to tell stories and share experiences of health and social care. There are a range of teaching possibilities for this to happen and we anticipate these will grow within the new curriculum. There will be opportunities for sharing experiences of health and social care in the introductory weeks and within the science teaching in the early years of the curriculum. There will also be volunteering roles in the clinical components of the course as groups are aligned to specific areas of teaching, such as General Practice, Stroke Units etc.

After training and with experience a wider range of teaching possibilities will become available and these cover the following:

- Leading teaching roles
- Mentoring
- Committee work
- Educational research
- Admissions
- Support roles within the group
- Participation in open day for new prospective students
- Student support
- Outreach work within Leicester and beyond
- Participating in conferences

Mentoring

New systems and processes will need to be set up for supporting patients and carers in their new roles. Mentors will support and recruit members. We expect this work will take the form of group induction sessions in which new volunteers will be guided through the processes of joining the group and supported when teaching for the first time.

There will also be opportunities for mentoring work which will be outreach in nature and may involve giving presentations to groups. These opportunities will develop over time with experience of involvement.
Training
We envisage that there will be a trajectory of training. All members will require the following:

- Induction training (new members)
- Diversity, equality
- Data protection

Preparation sessions will be required for:

- Telling your stories
- Mentor training
- Listening Workshop training and preparation (existing programme)
- Admissions Group (on-going)

Members of the Patient and Carer group can also access faculty development on:

- Teaching skills

Quality Control
Any activity undertaken by patients/carers should lead to regular feedback and appraisal mechanisms. This is to ensure that engagements reaches acceptable standards and enhances the quality of teaching and learning within the Medical School. This will assure dialogue between the Medical School and the Patient and Carer Group.

4. Recruitment
The Patient and Carer Group will require a wide range of members for future work. These members should represent the diversity of the population of Leicester and the range of health and social care needs. All members will help to grow the community. This will happen through informal and formal contacts. Members will have access to written material, cards and newsletters for this purpose. Outreach meetings will take place within communities to present and encourage engagement. Enrolment within the community will include the completion of data information sheets recording personal information managed confidentially. Outreach work will only be undertaken by trained members of the group.

Working with GP's
There are many GP practices working with the Medical School whose outreach within the varied communities of Leicester can help to grow membership of the unit. Many GPs have lists of patients who have helped with teaching medical students and these patients can be referred to the unit via members of the Primary Health Care Team. We hope that this work
will help GPs to grow sub-units of patients who can work with students during their GP placements.

**Community Hubs**
These are specialist groups that cater to, or appeal to, various ethnic groups within the Leicester Community such as the Caribbean, Asian, Somali, Eastern European etc. This will also include various tenants groups e.g. St Matthews Tenants Association, special schools, and specialist patient and carer groups and charities.

**Hospitals**
University Hospitals of Leicester has a patient involvement group of volunteers. We anticipate connections with this group. The consultants whose teams are aligned to the Medical School and who work with a wide range of patients will be able to not only identify patients for medical school examinations but also direct those who are interested to remain engaged in teaching and join the Patient and Carer Group.
5. Reward and Payment

By definition all participants are volunteers. There should be no barriers to participation and Leicester Medical School will offer a range of compensation dependent on level of participation and need. We wish to show appreciation for time given by members of the group. The Patient and Carer Group will have a base and offer free refreshments. However there is a limited set of funds for the work of the group and this will be used in terms of levels of participation below (see appendix):

- **Level One**: Telling stories and sharing experiences of receiving treatment within the NHS. All participants will be offered reasonable travel costs. We are not able to cover caring costs for this work.

- **Level Two**: Sharing experiences relating to a particular clinical condition. Here patients/carers will be required to support formal teaching on a clinical condition e.g. stroke, and after selection will be offered a voucher.

- **Level Three**: Advanced roles paid at hourly rates. These will involve committee work, admissions, assessment and teaching for which training is required. For example, the Listening Project where patients not only share stories, but offer student feedback and interactive guidance at a presentation session; some lead the teaching sessions as co-tutors. All hourly rates are aligned to job descriptions aligned to university paid rates/grades.

- **Training**: Where patients/carers receive formal or mandatory training they will be offered this as part of their personal development. There will be no payment but those who require help with transport will receive this.

- **Other**: This list offers a platform for early developments but is not limited and new roles may be created as new possibilities are explored. These may evolve into permanent part-time or full time posts.

*Unitemps* is used for payments within the University of Leicester. An administrator will guide new members through this process. Several pieces of documentation have to be completed before payments can begin and then the system ensures payment within 6 weeks; but sometimes this may take longer. Once the work is set up payment will follow at the end of every month.
6. Database

Communications, access and sharing
All members will need to provide personal information and an outline of their clinical condition and support needs including equality and diversity information. Data protection mechanisms will be in place and a limited number of people will have access to the full content of this database. Permission will be sought prior to sharing any information. Responsibility will be given to update the data base annually.

The database will be designed so that medical conditions will be anonymised but cross referenced to each patient record. This will allow search by condition without identifying individual patients. Academics will access patients using a gate keeper known to the patients. The database can be used for wider group anonymised emails on events, sharing of newsletters etc.

The database will offer any doctor or academic a search-base for identifying appropriate patients that might like to help them with teaching; however, this must be accessed through agreed pathways.

7. A Community of Practice
The community will require a presence on the Medical School website. This will be an opportunity for the Medical School to show case best practice.

- **Newsletter**: This will be authored by group members and an electronic version will be available twice a year.
- **Social Group**: The Patient and Carer Group will offer two social events a year so that members can have an opportunity to catch up with one another and share experiences of membership of the group.
- **Open days**: The Patient and Carer Group should become an integral element of the Medical School and have a presence on University Open days.
Proposed Action Plan: Year One

**Launch event to grow the community**
Open invitation and invite potential recruits.

**Recruitment process established**
Admit new recruits - complete database and begin induction training.

**Developing new work**
Open dialogue with the Medical School concerning new learning possibilities.

**Work Streams**
- Committees
- Early curriculum involvement
- Listening workshop
- Stroke teaching June 2016
- and more..
References


General Medical Council (2010). *Patient and public involvement in undergraduate medical education. Advice supplementary to Tomorrow’s doctors.* GMC, London.


Appendix

Invitation letters

Date

Dear patient/carer,

We all have a story to tell about our experiences with today’s NHS system. Whether it’s a journey of many years or a brief experience, everyone’s story matters. Listening to real stories and hearing real felt experiences is an important part of every medical students learning pathway.

The Medical School at the University of Leicester is launching a patient participation group that will be known as ‘The Patient and Carers Group’. We invite you to consider joining us and become a member of a lively and supportive group that has a positive impact on the way Leicester medical students learn.

We have enclosed a leaflet that will tell you more about our group and what we do. If you have any questions please do not hesitate to contact us on the email/ telephone number below.

We look forward to meeting you!

Best wishes

XXXX XXXXX
**Consent form: Exemplar** *(amended for particular events)*

![University of Leicester and The Patient and Carer Group logo]

**Consent to take part in XX teaching for Leicester medical students**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
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<tbody>
<tr>
<td>☐</td>
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</table>

I have received information about this teaching session

I agree to tell you how many sessions I can attend

I know that students will be briefed before the session

I am happy to talk with the students about my health problems

I am aware that students will engage in asking me questions

I am aware that my in-put will be used anonymously

I am aware that all information will be treated strictly confidentially

I understand that my consent and this written information will be stored in accordance with the data protection act

I agree to participate

I am aware that I can withdraw from the programme at any time and I know who to inform to do so

I know how to contact the tutor if I have any queries or concerns

Patient Signature……………………………………………………………………

Patient name (please PRINT)…………………………………………………………

Date:……………………………………………………………………………………

Tutor Signature…………………………………………………………………………

Tutor name (please PRINT)…………………………………………………………

Date:……………………………………………………………………………………
# Contract to participate in XXX medical education in XXX

*(to be modified for each teaching event)*

<table>
<thead>
<tr>
<th>Patient Contract to the University</th>
<th>University contract to the Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>I <em>(the patient/service user/carer)</em> agree to:</td>
<td><em>We (the University) agree to:</em></td>
</tr>
<tr>
<td>- Host an interview with health and social care students</td>
<td>- Support you in your teaching role</td>
</tr>
<tr>
<td>- Sign a consent form</td>
<td>- Identify suitable times and dates convenient to you for the interview</td>
</tr>
<tr>
<td>- Be available on the date and time agreed with the tutor</td>
<td>- Enable you to be informed about the teaching and understand how the students are briefed</td>
</tr>
<tr>
<td>- Be in a stated venue or at home for the interview</td>
<td>- Confirm to you how your confidentiality will be maintained</td>
</tr>
<tr>
<td>- Respond to the student questions, as I feel able</td>
<td>- Ensure students act professionally</td>
</tr>
<tr>
<td>- I am aware that I do not have to divulge personal details</td>
<td>- Brief students about not divulging your personal confidences</td>
</tr>
<tr>
<td>- To inform the tutor if there are any concerns about the interview</td>
<td>- Where possible, provide access to the students, at the end of the course, to thank you and inform you about what they have learnt</td>
</tr>
<tr>
<td>- Where possible let the administrator know if I can no longer keep this agreement</td>
<td>- Ensure you understand how to exit the course at any time</td>
</tr>
<tr>
<td>- I know how to withdraw from the programme</td>
<td></td>
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<tr>
<td>Date .................................................</td>
<td>Date .................................................</td>
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<tr>
<td>Signature .........................................</td>
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Payment Algorithm

The level of reward will be given according to the type of participation and job description

**Level One**
Travel Costs

Telling stories and sharing experiences of receiving treatment within the NHS. All participants will be offered reasonable travel costs. We are not able to cover caring costs for this work.

**Level Two**
Vouchers £20

Sharing experiences relating to a particular clinical condition. Here patients will be required to support formal teaching on a clinical condition e.g. stroke, and after selection will be offered a voucher.

**Level Three**

*Payment hourly rates (scales):*
Committee: £12.98 – Grade 5
Teaching: £21.16 – Grade 8
Admissions: £16.72 Grade 7

Job descriptions identify the hourly rates. The teaching scale recognises training and engagement within the learning process, such as offering student feedback, participating in oral presentations, patients co-tutoring with faculty members or leading sessions. The admissions work similarly requires training.

**Training**
Travel Costs

Where patients/carers receive formal or mandatory training they will be offered this as part of their personal development. There will be no payment but those who require help with transport will receive this.
Generic Form for Data Protection

If you are happy to take part in the training sessions please read and sign this form

For the purposes of the Data Protection Act 1998, the University of Leicester is a Data Controller. This means that the University of Leicester is responsible for how your personal information can be used. The Academic Unit of Medical Education, within the School of Medicine, University of Leicester may hold information about your medical condition as long as you are involved in the teaching of medical students. If you no longer wish to be involved with the training of medical students we will remove all of your information from our computer files and any paperwork relating to you will be shredded.

The information we collect may be used in one or more of three ways. We need your written permission in order for us to be able to use the information we collect. Below are three statements. Please tick the boxes to show you are happy for us to use your information. You can tick all or only one, or two of them the choice is yours. Once you have read and ticked these statements please sign and date the form.

I understand and am happy that the information you collect about me and my condition may be used:

- To teach or assess medical students within the School of Medicine, Leicester
- To support research projects, where my identity will be anonymous
- In published materials, where my identity will be anonymous
- On the University of Leicester's managed learning network and will only be available to medical students and teaching staff

Every care will be taken to ensure that your personal information is held securely and according to the data protection policies of the University of Leicester and will only be accessed by authorised staff.

Signing this form gives us permission to use your information in the way described above. If you are not entirely happy for us to do so, do not sign this form but discuss your concerns with XXXXX XXXXXX

Your signature:  
Print name:  
Date: 

...
**Code of conduct commitment charter**

The Medical School Commitment To You
- Support
- A point of contact to provide you with further information and answer any questions you may have
- Opportunities for training to help you take part in certain roles and activities
- Appropriate assistance with travel costs
- Information concerning roles and activities within a reasonable time frame
- Confirmation of your involvement by email and provide you with details of the role/activity
- Maintenance of all information about you with strict confidentiality in accordance with Leicester University’s Data Protection policy
- To treat you with respect and acknowledge your individual needs
- To provide you with updates about the group at least once a year

Your Commitment to Us
- Behave respectfully and inclusively at all times
- Be professional
- Be responsible for paperwork that needs to be read/returned relating to your role/involvement
- Notify us of any change in the information that you have provided to us (e.g. change in clinical condition, change of address etc.)
Job Descriptions/pay rates

(Awaiting from Alison Powell- meeting in September)

a) Committee work:
b) Teaching roles:
c) Admissions

Exemplar (b)

<table>
<thead>
<tr>
<th>Teaching Key Responsibilities</th>
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<tbody>
<tr>
<td>on dates agreed in advance</td>
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<tr>
<td>This role is based on experience of the NHS as a patient and/or carer</td>
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<tr>
<td>Able to work in a team with faculty members./clinical teachers</td>
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<tr>
<td>Can lead a small group of students following training</td>
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<tr>
<td>Explain the meaning of the learning outcomes</td>
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<tr>
<td>Monitor and support students</td>
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<tr>
<td>Facilitate student discussions and student feedback - be able to empathise and</td>
</tr>
<tr>
<td>establish a climate to encourage active engagement within boundaries</td>
</tr>
<tr>
<td>Positive attitude to professionalism</td>
</tr>
<tr>
<td>Ensure that the teaching runs smoothly</td>
</tr>
<tr>
<td>Basic knowledge of students and their courses</td>
</tr>
<tr>
<td>Assist with record keeping</td>
</tr>
</tbody>
</table>

Criteria

- Enthusiastic and committed to student learning
- Able to build a rapport with others
- Prepared to undertake some training/support/workshop e.g. shadow a tutor
- Reliability - I attend as agreed or let the lead tutor know if you cannot attend
- Develop the professionalism of being a teacher/facilitator
- To gain, build on the experience of healthcare education as a patient/service users/carer
- Positive attitude and empathy towards students.
  - Willing to extend knowledge
- Being impartial and promoting equality
- Develop skills in structure and organisation of teaching