# 

 School of Medicine

# Year 1

# Foundations of Clinical Practice

# First Clinical Attachment

# 2012-13

# STUDENT COURSE GUIDE

Academic co-ordinator: **Dr Rosalind Herbert** r.herbert@imperial.ac.uk

Course administrators: **Tom Durley** t.durley@imperial.ac.uk

**Anthony Khaseria** a.khaseria@ic.ac.uk

Please see the intranet for further information:

<https://education.med.imperial.ac.uk>

### Contents

[Introduction 1](#_Toc334450289)

[Overall Learning Objectives for FCA 2](#_Toc334450290)

[Assessment 3](#_Toc334450291)

[Professional Behaviour at Placements and Patient Visits 5](#_Toc334450292)

[Module 1: Illness, Health and Disease 7](#_Toc334450293)

[Learning Objectives for Module 1 8](#_Toc334450294)

[Logging on to e-portfolio 9](#_Toc334450295)

[Patient/Family Visit One: Introductory visit 11](#_Toc334450296)

[Patient/Family Visit Two: Symptoms, disease and illness 12](#_Toc334450297)

[Example e-portfolio 13](#_Toc334450298)

[Health Talk online task 15](#_Toc334450299)

[Module 1 Presentation 16](#_Toc334450300)

[Background Information 17](#_Toc334450301)

[Reading List 21](#_Toc334450302)

[Module 2: The experience of health and social care 22](#_Toc334450303)

[Learning Objectives for Module 2 23](#_Toc334450304)

[Society & Health Essay 24](#_Toc334450305)

[Patient/Family Visit Three: Experiences of health and social care 27](#_Toc334450306)

[Patient Satisfaction Survey 28](#_Toc334450307)

[Background Information 29](#_Toc334450308)

[Reading List 30](#_Toc334450309)

[Module 3: Living with a long term condition 31](#_Toc334450310)

[Learning Objectives for Module 3 32](#_Toc334450311)

[Outline of Module 3 32](#_Toc334450312)

[e-Poster Presentation 33](#_Toc334450313)

[Patient/Family Visit Four: Living with a long-term condition 36](#_Toc334450314)

[Background Information 37](#_Toc334450315)

[Reading/Viewing List 40](#_Toc334450316)

# Introduction

The First Clinical Attachment (FCA) is your first opportunity to meet patients as a medical student. During the year you will be visiting a patient and his or her family to learn how people manage to live with long term illnesses.

The aim of the course is to give you the experience of listening and talking to patients and to help you to find out what is important to people who use health care services. Through interviewing people yourself and taking part in group work you will find out why people come and see a health professional, what people expect from health care professionals and what it is like for a person to live with a chronic illness or disability. There is some overlap between this course and society and health, ethics, epidemiology & public health, problem-based learning and the communication programme. The FCA is an opportunity to see some of the theory from those courses applied to the lives of individuals.

The course is delivered in three modules over the first year. Each module covers a different aspect of the experience of health and healthcare.

**Module 1: Illness, health and disease**

**Module 2: The experience of health and social care**

**Module 3: Living with a long term condition**

In each module you will visit your allocated patient and produce a portfolio from your visit material and other course work. You will have two tutorials/term and also one-to-one time with your tutor. In module 2 there will be a ‘consultation’ placement in a GP clinic where you will have the opportunity to observe consultations taking place. There are designated study sessions for FCA which you are expected to use to do background reading, visit your patient, produce your portfolio and to prepare for essays and presentations.

# Overall learning objectives for FCA

* Practise communication skills learnt in the clinical communication course and begin to build up a toolbox of different techniques
* Observe, discuss and reflect on the experience of long-term illness from the patient’s perspective in order to develop holistic attitudes and encourage empathy development
* Begin the process of reflection on patient encounters in order to develop self-awareness.
* Essay writing/poster design/group work/presentation skills/survey design skills. Specific objectives for each of these tasks.

Attendance at tutorials and placements is compulsory

Allowance is made for absences due to illness and other extenuating circumstances. If you are unavoidably prevented from attending a session, you must **inform your Tutor** and the FEO. Please give notification as soon as possible and in advance if you have to miss an appointment to interview any patients.

# Assessment

# The First Clinical Attachment forms part of the Foundations of Clinical Practice theme of the core curriculum. The course is assessed by a series of in-course assessment tasks which make up a coursework mark out of 50. This will be 25% of the FOCP exam total mark.

The marks are made up as follows:

Reflective e-portfolio 21

Satisfaction survey 8

Module 2 essay 13

Module 3 poster presentation 8

# The essay deadline is 5pm on Friday 22nd March 2013

# You must fill in the relevant sections of your eportfolio by the last day of term otherwise you will receive no marks.

# If you miss the deadline without an extension given by the course lead, 5 marks will be subtracted per day, thus if it 4 days late or more you will receive zero marks.

# If you miss the presentation and survey due to illness you need to contact your tutor to arrange an alternative time to present.

### Personal and Professional Behaviour

You are expected to attend all the sessions. This means you need to be punctual and not leave early, prepare for the sessions, participate actively in discussions and show respect for the opinions of others, especially your patients. Failure to do so will mean that you will be referred to the Faculty Education Office.

### Presentations

You will be required to make presentations to your group in all three terms. The first one will be formative, however the marks from the other presentations will count towards your end of year mark.

### Written assignment

You will be asked to submit an essay at the end of Module two. The titles and requirements for the essays are in the relevant section of this guide and on the intranet. You will be given feedback by your group leader on your essays. This essay will be double marked. If you miss the deadline, without an extension from the course lead, 5 marks will be subtracted per day that it is late, thus if it is 4 days late or more you will receive zero marks.

### e-portfolio

****You will need to complete this on the e-portfolio. After each visit please log in and document the information you have found out and your reflections on the visit, the questions will link in with the taught material.

You must fill in the relevant sections of their e-portfolio by the last day of term otherwise you will not receive any marks

**Term 1** Visit1, Visit 2 and the health talk on line task

**Term 2** Visit 3, GP placement, patient journey section

**Term 3** Visit 4

### Plagiarism

You are reminded that all work submitted as part of the requirements for any examination (including course work) of Imperial College London must be expressed in your own words and incorporate your own ideas and judgements.

Plagiarism, that is the presentation of another person’s thoughts or words as though they were your own, must be avoided, with particular care in course work, essays and reports written in your own time. You are encouraged to read and criticise the work of others as much as possible. You are expected to incorporate this in your thinking and in your course work and assessments, but you must acknowledge and label your sources.

Direct quotations from the published or unpublished work of others, from the internet, or from any other source must always be clearly identified as such. A full reference to the source must be provided in the proper form and quotation marks used. Remember that a series of short quotations from several different sources, if not clearly identified as such, constitutes plagiarism just as much as a single unacknowledged long quotation from a single source. Equally, if you summarise another person’s ideas, judgements, figures, diagrams or software, you must refer to that person in your text, and include the work referred to in your bibliography. Please do not quote your course guide, you need to read the original work and quote the original authors. The use of the work of another student, past or present, constitutes plagiarism. When you submit your essay to BLACKBOARD it will automatically be run through anti-plagiarism software. Cases of suspected plagiarism will be dealt with under the College’s Procedure for Dealing with Examination Offences and may result in action being taken. Advice on correct referencing and avoidance of plagiarism is available here: <http://www3.imperial.ac.uk/library/subjectsandsupport/plagiarism/undergrads>

**Students re-sitting the year**

If you are retaking the year you are expected to submit an original piece of work for each module. Resubmission of work that is largely based on a previous submission will not be acceptable and you will be asked to resubmit.

**How to cite references**

When choosing references it is essential to ensure that the work is from a high quality academic source. For journal articles this will normally mean restricting references to peer reviewed reputable journals. Using the references in the course guide as a starting point will help. Please note that using a Google search and Wikipedia is not sufficient!

When referencing we would like you to use the Vancouver system. Please ensure that you are familiar with the library referencing guide which can be found using the following link.

<http://www3.imperial.ac.uk/library/subjectsandsupport/referencemanagement/vancouver>

# Professional behaviour at placements and patient visits

### Guidelines for home visits

* Visit in pairs
* Wear your identification label prominently.
* Telephone in advance for visits to people’s homes.
* Give the volunteer patient your contact details in case they need to rearrange.
* Arrive at the time agreed.
* Discuss the duration of the visit.

#### This may be your first experience of meeting patients as a medical student. It is therefore important that you take time consider some ground rules.

**Making arrangements**

Do ring and arrange a mutually convenient time

Leave your number with the patient in case they become unwell and need to rearrange

Please be punctual, your patient is giving up their time for your benefit.

**Starting the interview**

Thank your patient for there time and explain your purpose to being there

Discuss how long the interview will take and ask permission for one of you to take notes

**During the interview**

If your patient appears to find a topic distressing, stop and ask if they would prefer if you talked about something else

**Do not under any circumstances allow yourself to give advice or a medical opinion to patients, however simple the explanation might seem to be. You can helpfully suggest the most appropriately qualified person who may be able to give advice or an opinion. This may be the patient’s GP or hospital consultant.**

If, during your interviews, anything occurs that concerns or puzzles you, make a note of it to discuss later with your tutor.

Confidentiality

It is essential that you regard all information that you obtain from patients of whatever nature as strictly confidential.

In your notes and presentation use only the initials of people you have been interviewing to preserve their anonymity.

**Never store your patient’s number in your mobile phone, safety of confidential patient details is vital**

Consent

It is important to appreciate and respect the patient’s right to refuse consent. Patients have a right to decide whether or not they wish to talk to students. Many patients attending the doctor may be distressed, frightened or anxious. Under these circumstances, they may not feel willing to discuss their problems with others. Please be sensitive to this possibility and offer people the opportunity to say “no thank you”.

Dress

Please ensure that you wear identification badges to all sessions. You should dress smartly and appropriately when with patients on this course. This is both courteous and important to your relationship. Remember you will be meeting a variety of people from different cultures and representing the medical school. If unsure what to wear remember that you cannot go wrong by dressing more formally.

Punctuality

Professionalism entails turning up on time to meetings with health professionals and patients. Many will have made specific arrangements to be available to talk to you, maybe taking time off work.

# Module 1:

# Illness, Health and Disease

What makes us define ourselves as ‘healthy’   
or ‘unhealthy’?

Different perspectives on illness

How do people behave when they experience   
a symptom?

How do we decide whether we need to see a doctor   
or not

How to begin interviewing patients

## Learning objectives for Module 1

We can think about patients and their health problems in terms of a journey. Patients initially notice that something is wrong but do not necessarily immediately seek medical advice. During this module of the First Clinical Attachment (FCA) you will consider how health and illness are defined, what happens when people get symptoms and how they decide to visit a health professional. In Communication Skills you will learn some ways of approaching and talking to patients and will have the opportunity to talk with volunteers from the local community who act as though they are real patients (simulated patients). In FCA you will have the opportunity to practise these skills further with real patients, to feedback to each other and the group with a clinical tutor to guide you through the process. You have five designated FCA sessions this term, use this time to visit your patient, complete the health talk on line task, complete your e-portfolio and do the essential reading. **If you have a FCA session timetabled before tutorial 1, please use it to complete the health talk online task.** Details of your tutor and where to meet them will be on the intranet. You will be given information regarding your patient visits at your first tutorial. There is no need to contact the patient until after the tutorial.

### Objectives

* Understood and applied theoretical sociological concepts to individuals both in your families and that you visit as part of the course
* Understood the implications to society and to the medical profession of different definitions of health
* To interview a patient and reflect on the communication skills used and the impact the patient’s story has on you

**Essential pre-tutorial reading**

*How should we define health?* *BMJ 2011;343:doi:10.1136/bmj.d4163 (Published 26 July 2011)*

What is health? The ability to adapt[editorial]. Lancet 2009;373:781

Scambler, Graham. Sociology as applied to medicine. 5th Edition 2003. *Health and Illness behaviour* Ch 3 pp37-48 W B Saunders. London

**E-portfolio**

You should record your observations and thoughts in your e-portfolio after each visit. You will have to complete portfolios for assessment throughout your medical career, right from Foundation level to GP Principal/Consultant level, so it is a good idea to get into the habit.

In each visit there are questions relating to the interview and the material from the module. Please answer these questions succinctly but with thought as your portfolio work will be marked and will make up a large part of the assessment of this course. An example e-portfolio entry completed by a student from last year has been included on page 11.

## 

## Logging on to e-portfolio

**Please Note: The system will time-out (log out) if there is no activity for**

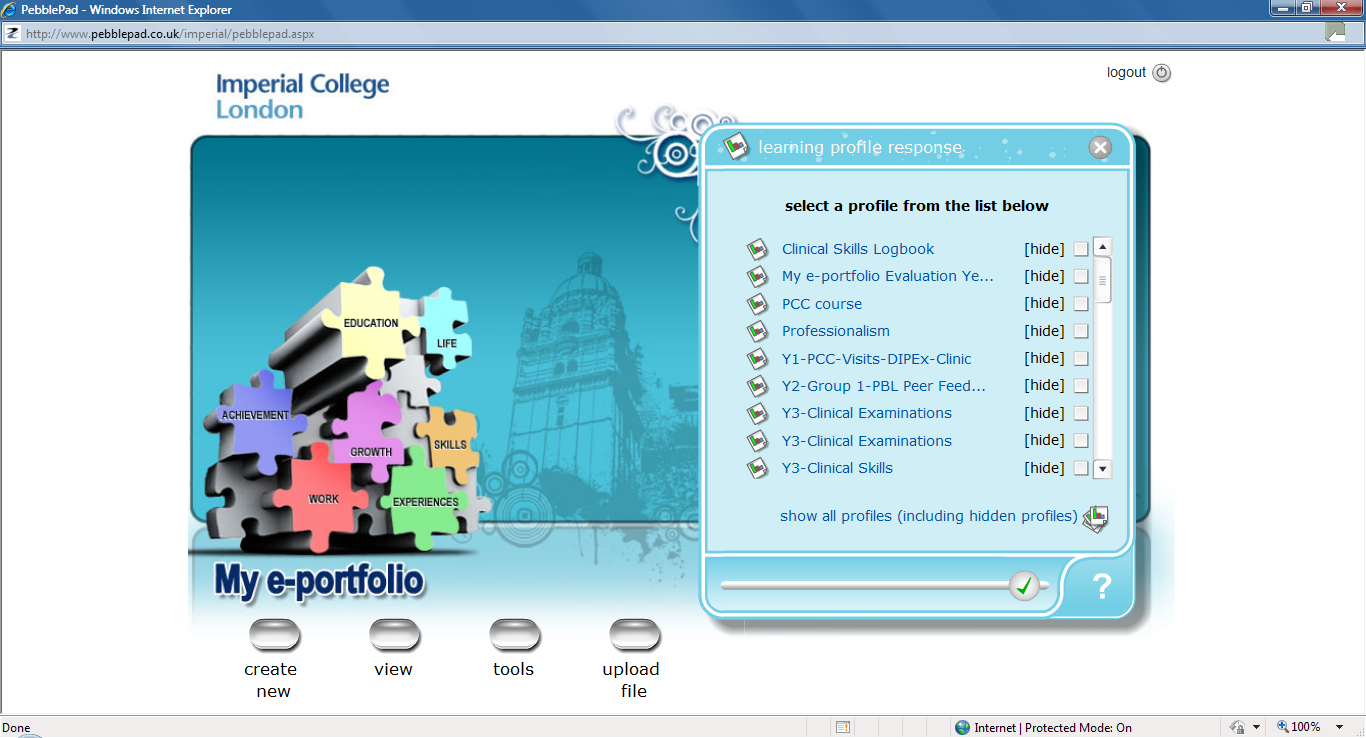
**one hour. We strongly suggest that you compose any text in Microsoft Word and then paste it into My e-portfolio, especially if you need more time to complete your work. Also, "Save Changes" at regular intervals to avoid losing any work.**

**Logging in:**

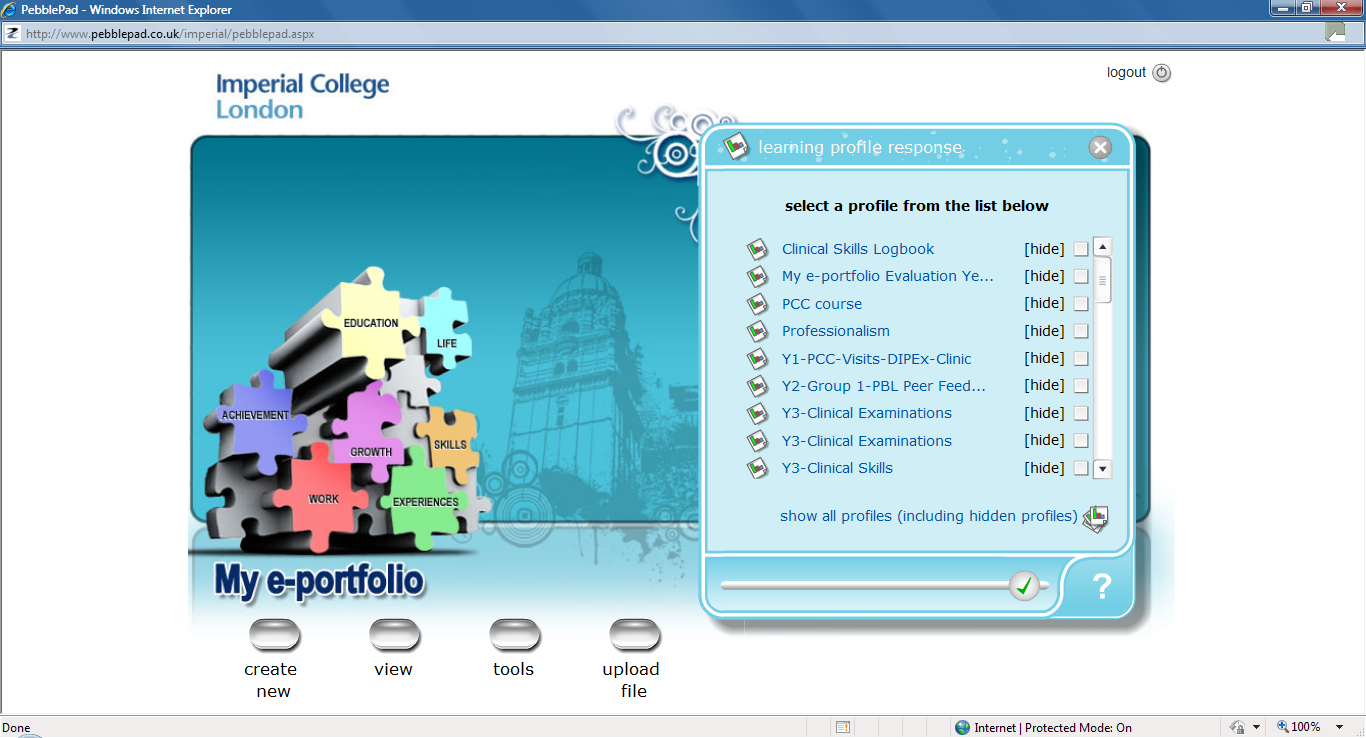
1. Access **My e-portfolio** at <http://www.pebblepad.co.uk/imperial>
2. Be sure to select **I am from Imperial College** (I have an ‘imperial.ac.uk’ account)” and then log in normally using your College username and password.

**Video tutorials:** *How to log-in* – <http://tinyurl.com/36kyknh>

**Filling in and Submitting the Profiler:**

1. Click on create new > more … > **Profile**
2. Select **Y1-FCA-Portfolio** and click on the **tick** 
3. Fill-in the profiler.

***To submit the profiler to the gateway:***

1. From the home page, click view > **my assets**
2. Click on your profile (Y1-FCA-Portfolio)
3. On the window that appears on the right, click send to … > **gateway**
4. Click on your gateway – **FCA – *Your Tutor’s Name*** (e.g. FCA – Ros Herbert) and click the tick button 
5. Click **Publish**. Your activity has been published.

**Video tutorials:** *How to complete and publish a profiler tutorial* – <http://tinyurl.com/35wcjd6>

**Editing the Profiler:**

1. From the home page, click view > **my assets**
2. Click on your profile (Y1-FCA-Portfolio)
3. On the window that appears on the right, click **edit this asset**
4. When you’re done, click **Save & Close**

**Please note that any changes that are saved are automatically reflected on the gateway.**

**Further Information**

There is a dedicated e-portfolio website at [www.imperial.ac.uk/medicine/elearning/eportfolio/](http://www.imperial.ac.uk/medicine/elearning/eportfolio/) where starter guides and video tutorials on **My e-portfolio** are available.

Please forward any queries or feedback to [webmaster.feo@imperial.ac.uk](mailto:webmaster.feo@imperial.ac.uk)

**Mark Scheme for the e-portfolio**

Each e-portfolio entry is marked out of 3

**Excellent = 3** All answers at a deep level. Good reflection on visits has thought about teaching from FCA and sociology courses and analysed them at an individual (patient) level. Also analysis level of thought about communication skills

**Good = 2** Some answers at analytical level

**Poor = 1**  Task done, but answers at surface level only. No real grasp of material, repetition only.

**Not done by the last day of term = 0**

## Patient/Family Visit One: Introductory visit

This will be your introductory visit to the patient/family. After introducing yourselves you will need to explain the purpose of your visits and your role. Agree how long the visit should last (generally this will be between 1-2 hours), and explain that the information given to you will remain confidential. The purpose of this visit is to build up a picture of the patient, the patient’s family, wider community, culture and support systems.

**Learning Objectives**

**By the end of this visit you will have**

1. Gained experience in interviewing patients and their family members
2. Learned about the structure of the patient’s family
3. Practised obtaining information about a patient’s medical condition in the patient’s own words
4. Considered the sources of social, psychological, medical, family and other practical support available to an individual or family with medical needs

**Areas to explore during the visit – NB this is a suggested structure – however be sensitive to the patient’s wishes. For example a person who has lost all his or her relatives may not wish to discuss this at length – as with all tasks, check first that the individual is happy to complete the exercise.**

1. Introduction
2. Description of family
3. Initial information regarding the patient’s condition

Ask the person or parent to describe the condition in his or her own words.

* How and when did he/she become aware that there was a problem?
* What was the experience at the time of diagnosis?
* How has it affected the individual and the family?
* What support from other people or agencies is required? (social/medical/voluntary)?

Ask the person about the way that the diagnosis was conveyed.

* How and when was the diagnosis discovered?
* How was information given?
* How did the patient feel about the way that the diagnosis was given?

1. Examine the geographical location of different health services to the home, including the location of the GP surgery, the local hospital, pharmacy, NHS walk in centre, dentist, and other health services that the patient uses. You may wish to print out a map from [maps.google.com](http://maps.google.com) prior to the visit.
2. Wider cultural aspects:

* What is the role of the extended family – e.g. in the case of a child how involved are grandparents in day to day care?
* How far are family members dispersed geographically and what degree of contact is there beyond the nuclear family? The geographical location of family members should be charted on the family tree.
* How do they spend their time, what sort of social support networks do they have outside of the family?
* Do they have religious beliefs, how important are they to them?

## Patient/Family Visit Two: Symptoms, disease and illness

This visit ties in with the themes of Module 1 of the course and deals with the patient’s own perspectives on health and illness (not necessarily related directly to the current condition).

**Learning Objectives**

**By the end of the visit you will have**

1. Considered the types of responses that individuals demonstrate when faced with symptoms of ill health
2. Examined the types of health beliefs that individuals or families may hold
3. Considered the triggers to and factors that may inhibit seeking medical help or advice
4. Gained an understanding of the range of conventional, complementary and lay sources of medical advice and treatment

**Areas to explore during the visit**

How do individuals within the family respond when they are ill or have symptoms?

Consider a minor illness and how people within the family respond?

Is there someone in the family to whom people turn?

How is a decision made to turn for medical help? What are the triggers to seeking help?

What steps are taken to resolve the problem before seeking medical advice?

Are there other sources of advice outside the family?

Are complementary therapies ever used?

Ask your patient how ‘unwell’ they consider themselves. Try to gauge what is that makes them feel this way.

How is illness explained? Ask about a recent illness within the family and explore how the family or individual explain what happened in terms of the causes of the illness

Are there particular health beliefs, sources of help or types of treatment that seem to be special to this family or have been passed down from the previous generation?

How do these differ from your own health beliefs?

**Social and economic support**

Sensitively explore financial, social and individual resources

How many family members are in employment?

How many dependants are there?

Observe the type of accommodation. How adequate is it? Is it owned/ rented/ local authority/ housing association or other?

Recreation, interests holidays.

Which aspects of life are most enjoyed and which aspects are most difficult or challenging?

## Example e-portfolio

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **1. Describe your patient’s health problems**  The patient has Crohn’s Disease which is a kind of Inflammatory Bowel Disease.  She first developed symptoms of the disease around Christmas Eve 2006, although at that time she did not think it was indicative of anything. On admission to hospital during her second pregnancy on 2nd February 2007, there were many complications, resulting in a Caesarean Section to deliver her daughter 7 weeks prematurely, this was when she was the diagnosis was made. In May 2008, her bowel was surgically removed. More treatment was required in January 2009 to treat infection of the surgical staples used. Currently, she lives with the illness, which causes sudden episodes of pain (not as severe as before treatment) that she has learned to cope with in different ways over time. | |  |  |  | | --- | --- | --- | |  | Report Icon | [http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/NotYetValidated.png](javascript:;) | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **2. Geographical location of different health services**  The patient is still referred to the hospital which treated her during her second pregnancy while she was at her first place of residence. She recently moved to her current place of residence, from where her GP is "around 5 minutes" of travel time away. According to the patient, the Pharmacist is also conveniently located. | |  |  |  | | --- | --- | --- | |  | http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/text_h.png | [http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/NotYetValidated.png](javascript:;) | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **3. What wider cultural aspects did you observe**  The patient grew up in a very close-knit family environment where many families and successive generations live together in a single house-hold or live nearby each other. She is a staunch believer in the role of the family as a support net for the individual, and extends this view to society in general, where each member of the society forms part of a collective "family" in which members look after each other. When she moved, she wanted to live closer to her mother. Also, despite only having lived in her current residence for a short while, she has already garnered a strong social network of friends. Her cultural identity is analogous to a "spider-web" model: she defines herself by her relationships and social connections (the web is strengthened with each new link). | |  |  |  | | --- | --- | --- | |  | http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/text_h.png | [http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/NotYetValidated.png](javascript:;) | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **4. Describe the family**  She lives with her male partner and her sister (who has lived with her since her 3rd pregnancy). Her mother occasionally lives with her as well. She has 3 children: Her eldest son is 5 years old, her daughter is 4 years old and her youngest son is 6 months old. The rest of her family lives primarily in her previous area of residence. She has an aunt (maternal) who also suffers from Crohn's disease and another aunt (maternal) with diabetes. | |  |  |  | | --- | --- | --- | |  | Report Icon | [http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/NotYetValidated.png](javascript:;) | |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **5. How did you find interviewing your patient?**  Interviewing the patient was thoroughly enjoyable, mainly because she was so welcoming and cheerful. Personally, the interview was very significant to me, because the patient was around my age when she first developed symptoms of the disease, and even today (being not much older than I am) she lives with a chronic illness while caring for 3 young children. Being confronted with this, I was forced into a deeper realisation of the kind of pressures and uncertainties she must have faced when she first was given the diagnosis of the disease (by extrapolating on how I myself would feel in that situation). I was truly astonished at how she was able to keep hold of herself for all this time, and my respect for her and for the willpower of patients with chronic diseases in general, deepened remarkably. Hence, despite the cheery nature of the interview, it was also tinged with an undercurrent of sadness at the reality of the situation, which hopefully I will be able to come to terms with. | |  |  |  | | --- | --- | --- | |  | http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/text_h.png | [http://www.pebblepad.co.uk/sharedprofiler/images/icon/report/NotYetValidated.png](javascript:;) | |

|  |  |
| --- | --- |
|  | **6. Give examples of Communication skills you used well and the context in which it was effective?**  I believe the most important skills that were relevant to this interview are the skills of Active Listening and Making Empathic Statements. As mentioned previously, the patient was very forthcoming in her opinions when answering our questions. Hence, the most important thing was to elicit further and deeper responses from her, which was achieved by subtly letting her know that I was listening intently and that I was taking in everything she was saying. I displayed active listening with various non-verbal (such as maintaining eye-contact and nodding every once in a while) and verbal (summarising her opinions in short sentences and reemphasising the important points) means of communication.  Showing empathy was also very important because I could sense that despite her very pragmatic outlook, she was nevertheless deeply conscious about her condition and how she was perceived by others. She had also had a previous negative experience with a midwife who was not very empathetic to her situation. Hence I put much effort into making sure I showed empathy in my statements and actions, and I believed this paid dividends. |

## Health Talk online task

Learning from the stories or narratives of patients enables doctors to gain an understanding of their patients. The patient's story puts his or her medical condition in a wider context, providing meaning and perspective to the patient's predicament (Greenhalgh T and Hurwicz B. 1998). In clinical practice, encouraging patients to tell their ‘story’ may encourage empathy and promote understanding between clinician and patient, and may in itself be of therapeutic value to the patient. Watching and listening to interviews from a website gives access to a wider range of conditions and numbers of patients than can be provided in the placements alone.

The website [www.healthtalkonline.org](http://www.healthtalkonline.org) contains a database of patient narratives in the form of transcripts, audio recordings and video recordings. This session requires access to the internet with broadband and preferably speakers/audio. It is suggested that you spend 1.5 – 2 hours on this task. The session needs to be completed before your second tutorial. You may decide to complete this task singly or in pairs. There are a range of patients with different conditions, including interviews with parents, antenatal patients and adult patients. Follow the link above and you will immediately see a list of different conditions on the left hand side of the page. If you know what your FCA patient has you may want to look into this condition further otherwise choose something that interests you. After selecting a condition, click on the ‘talking about’ link. This takes you to different topics. In order to answer the questions below you will need to choose topics that deal mainly with the initial experience of symptoms and discussions with medical professionals. These interviews are to be found under headings such as ‘discovery’, ‘first contact with services’, ‘getting the diagnosis’ etc. However, to get a fuller picture you may wish to look at other aspects of the patients’ experiences.

Consider the answers to the following questions. Record your answers in your portfolio on pebblepad, there are in-course assessment marks for having completed this task.

* Describe how the individuals who are interviewed first begin to experience signs of ill health
* To what extent are different individuals similar and in what ways do they differ in the way they perceive initial symptoms?
* What factors prompted different individuals to seek medical attention?
* Whom if anyone did people speak to or consult before seeking medical advice?
* The patients are describing events that have taken place during the course of their illness or treatment. Consider what questions the interviewer might have asked to elicit these responses from the patients
* Describe what happened when individuals consulted a health professional about their symptoms. How was the diagnosis given to them? How did they react to the diagnosis that they were given? What were the main difficulties that people faced?
* What other steps either in addition to or instead of conventional medical treatment did people take to treat their condition?
* What are the possible benefits for patient and doctor of patients telling their ‘story’ or ‘narrative’?
* What are your personal thoughts and feelings having listened to and watched people talking about serious health problems? How will this exercise impact on the way that you interview patients in the future?
* Make a list of questions that you would like to ask your own patient at a visit

## Module 1 Presentation

Prepare a brief presentation (no more than 10 minutes per pair). The presentation must be related to an aspect of the patient’s journey that you have encountered but you can choose your own topic or something that has interested you from health talk on line.

Examples from previous years include topics such as the organisation of health care, working in teams, media representations of nurses and doctors, funding of health services, alternative therapies, translation services, impact of religious beliefs on health, NHS changes, the doctor as a patient and cultural aspects of illness. The presentation may also include some material related to the patient you are visiting. You will have received instruction in the Communication Programme about delivering presentations. Your group leader will give you additional guidance.

The idea is to be inventive in the way that you present. If everyone does PowerPoint presentations your next tutorial will be very repetitive, so you are invited to be as creative as possible!

After each presentation the Group Leader will lead the group in giving constructive feedback and award a grade.

If you are unable to attend the presentation session and there are extenuating circumstances, you must inform your group leader PRIOR to the session.

This presentation is **formative** and an opportunity for you to practice your presentation skills. You will also have to give presentations in modules 2 and 3, these will count towards your FCA mark.

MARKING SCHEME FOR PRESENTATIONS

**Merit** Appropriate balance between style and content of presentation.

Successful use of alternative/innovative methods of presentation.

**Satisfactory** Presentation has structure with beginning, middle and end. Presentation delivered adequately to audience.

**Unsatisfactory** Presentation inadequately prepared. Presentation lacking in structure with too much/too little material.

## Background Information

Illness, health and disease – these are concepts which are at the very foundation of our role as doctors and yet they are open to interpretation. Some definitions are considered controversial. Health care costs billions and lay and political attitudes can be influenced by the way such words are used with huge consequences nationally and internationally.

Definitions

In 1948 the World Health Organisation defined **Health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity**.

This was supposed to provide a transformative vision of “health for all”, one that went beyond the prevailing negative conception of health based on an “absence” of pathology.

The achievability and appropriateness of this definition has been challenged many times though. Please read the 1997 BMJ article by Saracci in 1997 and the 2009 Lancet review

Then read the recent BMJ editorial which states that this definition is no longer fir for purpose. The emphasis is being changed toward **the ability to adapt and self-manage in the face of social, physical and emotional challenges.**

Symptoms

People who are unwell have symptoms. In other words they notice a change in their body or its function which may indicate the possibility of injury or disease. Symptoms are very common; some people notice as many as one symptom a day*.* Not all symptoms however, have the same significance. The symptom of chest pain is likely to be of more serious significance than a sore throat, but this is not inevitably the case. People must make a judgement about the significance of their symptoms in deciding what to do about them.

### The Symptom Iceberg

The symptom iceberg describes the fact that what doctors see is only the tip of the number of symptoms people in the community suffer from. The figures in this diagram are from a study that was done 40 years ago, but give a good example of the distribution of symptoms in the community.

Only a minority of all people with a symptom will see a doctor, usually in primary care. Of this group a further very small proportion will be suffering from a significant disorder. Only a few of those may be referred on for a specialist opinion in secondary care, and even fewer will find their way to the super-specialities of tertiary care, at the tip of The Symptom Iceberg.

*Prevalence of illness and utilization of medical resources among 1000 adults in US and Great Britain (White, Williams and Greenberg NEJM 1961)*

1000

Adult population at risk

750

Number reporting a symptom (per month)

250

Number consulting a doctor

(per month)

number admitted to hospital ↑

(per month)

9

1

|  |  |
| --- | --- |
| Number admitted to **🡩**  hospital (per month) | **🡩** Number admitted to university  medical care (per month) |

More recent studies have looked at particular symptoms; comparing their prevalence in the community to how often people consult. Not all people will perceive their symptoms to be abnormal. As the figures below show many more people with dizziness and rectal bleeding consult a GP than people with prostate symptoms. Why do you think this is?

*Symptom Number in the community No. reporting No. consulted GP References*

*sample symptom*

Dizziness 2064 480 192 Yardley et al 1998

Rectal bleeding 1200 287 118 Crossland et al 1995

Prostate symptoms 1610 364 40 Simpson et al 1994

### Important concepts regarding illness, health and disease

### Models of Illness

What does the term ‘a model of illness’ mean?

The term a ‘model of illness’ is a useful way to understand how people think about illness. The term ‘model of illness’ implies that people have ideas about illness, and illness’s causes and consequences. We all carry these ‘models of illness’ but usually do not think about them much. There are medical ‘models of illness’ and lay ‘models of illness’. A lay model of illness in the UK might be that colds are caused by getting wet when it rains and that to treat colds you need to sweat a lot and eat a lot (‘feed a cold, starve a fever’). These models can be very specific to cultures and even within families.

**1 Biomedical model of illness**

The biomedical model of illness is the model on which much of modern medicine is based. In its simplest form it asserts that illness is caused by a pathological change in the body that may be investigated, identified and addressed.

**2 Bio-psycho-social model of illness**

The bio-psychosocial model of illness includes psychological and social aspects of illness as well as biological aspects. It recognises that an individual has psychological and social aspects to their lives and these influence health and illness. These are not separate aspects but have a dynamic interrelationship. Cultural and environmental factors also influence models of illness.

A holistic approach to patient care is one which recognises the influence of these factors and their importance in the experience of each patient. The Holistic model includes cultural and environmental factors as well as bio-psychosocial factors.

**3 ‘Folk models’ of illness (Helman 1981)**

When faced with misfortune, such as ill health, individuals try to find ways of explaining what has happened. According to Cecil Helman, a doctor and anthropologist, the way that illness is perceived and responded to will depend on the answers to 6 questions:

1. *What has happened?*

This involves giving the condition an identity e.g. ‘I have picked up a cold’. The name may be couched in lay terms, or where medical terminology is used the meaning may be different from the medical conceptualisation.

1. *Why has it happened?*
2. *Why to me?*
3. *Why now?*

Questions 2, 3 and 4 will have answers that rest on folk or lay beliefs about the body and the causation of illness. Answers may include ‘because I went outside with wet hair’ or ‘because I am under stress at work’ or ‘because I wasn’t getting enough sleep’.

1. *What would happen if nothing was done about it?*

For example ‘it might go to my chest’. Again folk beliefs about the aetiology (cause), significance, natural history and prognosis are important in formulating the answer.

1. *What should I do about it – or whom should I consult?*

The possible courses of action include self-medication, consultation with family members, friends, lay referral and professional referral.

### Illness Behaviour

Illness behaviour is the term used to describe how people consider and act upon any symptoms they may have. You will see that many people have symptoms, but not all consult a health professional. The questions that people have to consider include - is this symptom normal? Will I go to the doctor? What else can I do?

Mechanic & Volkart's definition: "The ways in which symptoms are perceived, evaluated and acted upon by a person who recognises some pain, discomfort or other signal of organic malfunction".

Zola has described ‘triggers’ to consultation. These are social factors which influence people’s decision to consult a health professional. People can also ask advice from other people, including friends and family. They may be advised by one family member to consult another friend or family member who has more experience of a problem. This system is called the ‘lay referral system’.

Zola’s triggers include:

* Interpersonal crisis
* Interference with social or personal relations
* Sanctioning
* Interference with vocational or physical activity
* Temporalizing

## Reading list

How should we define health? *BMJ 2011;343:doi:10.1136/bmj.d4163 (Published 26 July 2011)*

Charon R. (2004) ‘Narrative and Medicine’ New England Journal of Medicine 350:9

Crossland A, Jones R. Rectal bleeding –prevalence and consultation behaviour 1995 BMJ

Greenhalgh T et al. *Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study*. BMJ, 1998 316, 978-83.

Helman, Cecil G. *Culture, health and illness.* 4th edition 2000. Butterworth Heinemann. Oxford.

Helman, C. *Disease versus illness in general practice*. Journal of the Royal College of General Practitioners 1981 31:548-552

Saracci R. *The World Health Organisation needs to reconsider its definition of health*. BMJ 1997. 314, 1409-1410. Available on line

Scambler, Graham. *Sociology as applied to medicine. 6th Edition 2008*. Health and Illness behaviour W B Saunders. London.

Tullock A. *What do we mean by health?* British Journal of General Practice. 2005. 320-323

*What is health? The ability to adapt [editorial]. Lancet 2009;373:781*

# Module 2:

# The experience of health and social care

What is it like to be a patient?

How well does the healthcare system serve patients?

Introducing ICE

Introducing the multidisciplinary team

What aspects of health care are most important to patients?

## Learning objectives for Module 2

* Observed and understood the importance of good doctor-patient communication
* Observed and then reflected on the difference that identifying patient’s ICE makes to patient care.
* Undertaken a team project, looking at survey design which ties in with our theme of patient satisfaction
* Continued to reflect on their personal interaction with their patient, the impact on themselves, the use of communication skills and then to evaluate the whole reflection process.

**Learning objectives of the essay**

1. Reflect on tasks and interviews completed for the First Clinical Attachment course and make conclusions from these about patient satisfaction

2. Consider one aspect of the Society & Health course in depth and how it impacts individuals.

3. Develop critical thinking by reading the relevant literature and writing about it

4. Improve on essay writing skills including developing an argument and referencing

**Essential pre-tutorial reading**

Pendleton et al. (1984) Around the consultation*.* In *The Consultation. An Approach to Learning and Teaching.* Oxford. Oxford Medical Publications pp30-44 (available from the Central and Charing Cross libraries)

**TUTORIAL 1**

* Discuss the meaning of patients’ ideas, concerns and expectations
* Discuss communication between health professionals and patients
* Discuss the roles of different health care professionals
* Prepare for placements
* Plan your satisfaction survey
* Discuss the essay, how to reference and deadline for submission

**Tasks to be completed:**

1. Satisfaction Survey
2. Joint Essay
3. Placement: Interviews with patients in a hospital clinic or GP surgery.
4. Patient Visit 3
5. Your e-portfolio

**TUTORIAL 2**

* Debrief about your placements and visits.
* Present findings of satisfaction survey
* Go through portfolio

## FCA and Society & Health Essay

**Instructions for writing**

Discuss experiences of health care and the factors that may influence patient satisfaction. Use your own experience, the experience of patients you have met on your placement and patient visits and the experiences of people you have spoken to in your satisfaction survey. You should relate this to relevant topics from FCA and Society & Health courses and to some of the relevant literature.

Your essay should include:

* An account of an actual experience of health care described by patients
* A consideration of the patient’s satisfaction:
  + The factors that influenced satisfaction or dissatisfaction with health care in your chosen example
  + Satisfaction survey:
    - A brief summary of your findings (supporting tables and graphs can also be included in the Appendix)
    - Similarities and differences between findings from different settings
    - How your findings compare with the literature on patient satisfaction
* A consideration of how your account of a patient’s experience relates to ONE of the following TWO sociological concepts:
  + EITHER health inequalities
  + OR deviance

**The sociological topic**

You will be asked to relate the account of patient experience to one of two sociological topics: heath inequalities or deviance. Below are some suggestions on these.

**Deviance:** Using your chosen example, you should discuss how the patient’s past or present behaviour could be classified as deviant. For instance, you could illustrate how the perception of risk by the patient may differ from that of their doctor, of society and/or from your own.

**OR**

**Health inequalities:** the largest gap in life expectancy between the most and least deprived deciles of the male population in England is found in the Borough of Chelsea & Westminster. Using your account of a patient’s experience, you should demonstrate how social inequalities in health are produced (see Bartley M and Blane D. Chapter 8: *Inequality and Social Class*. In: 'Scambler G (ed) (2008) Sociology as Applied to Medicine, 6th edition. London: Saunders.)

**Maximum word count**

2000 words, this does not include references or diagrams which should be put in an appendix. Penalties apply for excess words beyond 10% of the maximum.

**Marks**

The mark awarded for this essay will count 13% of the total FCA marks (which is 6.5% of the FOCP mark).

**Plagiarism**

Please read the section about plagiarism on page 3 carefully before you start your essay.

**Confidentiality**

All information that you obtain from patients, of whatever nature, is strictly confidential. Therefore, in your notes and final submission, please use only the initials of people you have been interviewing to preserve their anonymity.

### Marking scheme for essay

Essay includes factors from: Own experience

Patient experience

Clinic placement

Survey results

Essay contrasted findings from different settings

**(1 mark for each, total 5 marks)**

Essay includes More than 3 relevant pieces of literature quoted on patient satisfaction

The use of recent literature

Correct referencing (Vancouver Method)

**(3 marks total)**

Essay Well written, arguments flow well

At metacognitive level, has ability to reflect on material and make conclusions form it rather than just state it

**(2 marks)**

**Society and health part**

See FCA essay information on the intranet for how these 3 marks will be awarded.

**Total = 13 marks**

**Penalties**

The essay deadline is 5pm on 22nd March 2013.

# If you miss the deadline without an extension given by the course lead, 5 marks will be subtracted per day, thus if it 4 days late or more you will receive zero marks.

If the essay is 10% more than the word count a 2 mark penalty will be applied

### Clinic Placements

Your placements will be in GP surgeries. You will be working in pairs as previously. We recommend that, if possible, you talk to patients in turns.

* + You will talk to patients before and/or after the consultation to explore their ideas, concerns and expectations.
  + If possible you should sit in during consultations with the doctor, nurse/midwife or other health professional.

Plan which questions you will ask. Some ideas given below:

* Try and find out what the patient understands about what is happening to them and who is looking after them. What ideas about their condition, concerns about their health and expectations for the consultation do they have? What and who has helped them to understand things better? What has been confusing? How have they found the health care ‘system’? What has been good and what might be done better? Who has helped them and how? Let the patients tell their story in their own words.
* Ask which health professional the patient chooses to go to for different aspects of their care.
* Interview your patients **after** the consultations as well: ask if they felt that their ideas, concerns, expecations were explored? Were they satisfied? Why/ why not?
* Find out who are the members of the team of doctors, nurses and professions allied to medicine who care for the patient.
* Try to interview at least one of the members of the team (if this is possible). What is their role in looking after the patient? What do they think is the most important aspect of the patient’s care? If the health professional has time, ask him/her for views about the consultation - what went well, what was difficult/uncomfortable.
* On observing the consultation, notice who speaks the most during the consultation. Is it the doctor/nurse or the patient? What techniques does the doctor/nurse use to help the patient understand and remember the information? How do they put patients at ease if they need a physical examination.
* Use open questions, which enable people to tell their stories. Avoid questions which require a yes or no answer.
* Consider the physical factors e.g. waiting room and casualty room layout, decoration, noise, presence of clinical equipment, etc. Do these factors help or hinder the consultation?
* Consider how you might handle the consultation and explanation if you were the doctor/nurse. Note anything that you would have done/ said differently
* Complete records of your interview on the ePortfolio. You will need to refer to these notes for your essay.

In addition to the Module 2 GP Placement you will need to arrange your 3rd patient visit.

## Patient/Family Visit Three: Experiences of health and social care

**Learning Objectives**

**By the end of the visit you will have:**

1. Understood the importance of communication on the patient’s experience of health care
2. Understood what is meant by the terms ideas, concerns and expectations, in relation to the doctor patient consultation
3. Described a positive and less satisfactory experience of health care from the patient’s point of view
4. Outlined the journey of a patient during an episode of medical care

**Areas to explore during the visit**

* What has happened to the patient since your last visit?
* Ask the person to describe a recent consultation with a health care professional.
* What was considered to be important by the patient? What ideas did the patient have prior to the consultation? What did the person hope was going to happen as a result of the consultation, and were these expectations met? Did the patient have any specific areas that he/she had wanted to explore, including any concerns, and were these aired during the consultation?
* What was it about the way that the consultation was conducted that helped or hindered the experience?
* What could have improved the consultation?
* What other factors more generally in relation to the health services are important? Consider waiting times, experience of inpatient or outpatient or GP care.
* If the patient has been referred to a specialist by their GP, what was the process like? Were they given a choice of hospital and did the process work smoothly? What was communication like between the hospital consultant and GP?
* Ask the patient/parent to describe in detail 2 specific instances, firstly one which demonstrated a positive experience of receiving health care, and the other where the experience was less satisfactory. Identify specific components that led to the experience being satisfactory on the one hand or unsatisfactory on the other.
* Ask the patient whether they generally trust doctors to tell the truth. What factors do they believe help to maintain trust in the profession as a whole? How does the media portray doctors and has this influenced their view of the profession in any way?
* Ask the person to describe a previous hospital admission and to outline every health care professional, with whom they had contact along the way, including the role of the professional and their involvement. If there have never been any previous hospital admissions ask them to describe the admission of a family member or friend.

## Patient Satisfaction Survey

Between tutorials one and two you will be required to conduct a patient satisfaction survey.

We would like you to do this in 2 teams with 5–6 students on them. You will have an opportunity in your tutorial to begin to design your questionnaire in your team and then decide how you are going to implement it, analyse it and present the data. Please see the intranet for two papers on how to undergo satisfaction surveys.

Each team will present their findings in tutorial 2. You will be marked for your contribution to the team as well as the final presentation. Your tuor will ask you which part of the team task you contributed to.

**Mark scheme**

Survey design Good sample size 1

Good variability in sample 1

Appropriate use of questions 1

Presentation Results clearly demonstrated 1

Good presentation skills 1

Ability to deal with questions 1

Group work- Can state clearly what they contributed 1

Shows evidence of good team working 1

**Total = 8 marks**

*Below is an exmaple of a survey done by last year’s students.*



## Background Information

##### IDEAS, CONCERNS AND EXPECTATIONS (ICE)

In Module 1 and in your sociology lectures you will have learnt that people do not always go to see a health professional when they have a symptom. People may choose to do nothing or they may talk to family and friends. People may have looked up information on the web or know of other people with similar symptoms. They may have consulted a doctor in the past. By the time people do see a health professional they will have thought about their problems. They are likely to have specific ideas about what the problem is, or what it might be, specific concerns about the problem and how it is affecting them and expectations about their problem and about the help they need or want. There is research evidence that if patients perceive that the doctor understands them and the effect of their problem that their health outcomes are better.

For a more detailed explanation of exploring patient ideas, concerns and expectations in a consultation refer to the Pendleton reference in the reading list.

### Patient satisfaction

You will have learnt about hospital patient satisfaction data in Sociology.

See below a 2005 general practice satisfaction survey, how to the two differ? Do any of things below surprise you.

Health care funding is now in part dependent upon patient satisfaction levels and both hospital trusts and GP practices have to demonstrate the ‘satisfaction’ level of their patients.

An observation study by Little et al (2001) concluded that patient satisfaction was dependent on a positive patient centred approach from the doctor.

A 2005 patient survey found that the general public rated the following as most important in primary care (Coutler 2005 BMJ 331 editorial)

**Healthcare aspirations of patients and citizens**

**Patients**

Fast access to reliable health advice

Effective treatment delivered by trusted professionals

Participation in decisions and respect for preferences

Clear, comprehensible information and support for self care

Attention to physical and environmental needs

Emotional support, empathy, and respect

Involvement of, and support for, family and carers

Continuity of care and smooth transitions

**Citizens**

Affordable treatment and care, free at the point of use

Safety and quality

Health protection and disease prevention

Accessible local services and national centres of excellence

Universal coverage; geographical and social equity

Responsiveness, flexibility, and choice

Participation in service developments

Transparency, accountability, and opportunity to influence policy decisions

It will be interesting to see how this compares with your satisfaction survey.

## Reading list

Barry et al. *Patient’s unvoiced agendas in general practice consultations: qualitative study*. BMJ 320, 1245-1250.

Coulter A. *What do patients and the public want from primary care?* BMJ 2005, 331, 1199-200

Jung, H. Wensing, M. Mainz,J. Olesen, F. & Grol, R (1998): A systematic review of the literature on patient priorities for general practice care. Soc Sci Med 47: 1573-88.

Kinnersley et al. *Randomised controlled trial of nurse practitioner versus general practitioner care for patients requesting ‘same day’ consultations in primary care*. BMJ 2000, 320, 1043-8

**Conducting a survey: Wai-Ching Leung** explains how to conduct a good survey.

Student BMJ 2001;09:129–170

Little, P et al. *Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations*. BMJ 2001, Vol. 323, 908-911.

McKinley R, Middleton, J. *What do patients want from doctors? Content analysis of written patient agendas for the consultation.* British Journal of General Practice 1999, 49, 796-800

Pendleton et al. (1984) Around the consultation*.* In *The Consultation. An Approach to Learning and Teaching.* Oxford. Oxford Medical Publications pp30-44

Stevenson et al. *Doctor-patient communication about drugs: the evidence for shared decision making*. Social Science and Medicine. 2000, Vol. 50, 829-840.

Williams, S and Calnan, M. *Key determinants of Consumer Satisfaction with General Practice.* Family Practice 1991 Vol8, p 237-242

Williams S, John Weinman, Jeremy Dale and Stanton Newman. Patient expectations: What do primary care patients want from the GP and how far does meeting expectations affect patient satisfaction? Family Practice 1995, Vol. 12, No. 2

# Module 3:

# Living with a long term condition

What are chronic diseases?

What is disability? Are there different ways of explaining disability?

How are people affected by medical conditions that result in the need for long term care?

What do we mean by a ‘web of care’ in the community?

Why are some conditions stigmatising?

## Learning objectives for Module 3

In the previous two modules you considered the patient’s journey from initial symptoms into the health care system. During this module you will be considering the factors that affect those with long-term problems – chronic diseases and disabilities. Many of you will already have had a chance to consider some of the problems encountered by those with long term illnesses through your patient visits.

The aims of Module 3are for you to develop your understanding of how people are affected by medical conditions that result in the need long term care and to explore the complex web of support that is available in the community for these people. There is overlap between this module and your sociology course regarding concepts such as stigma.

### Objectives

* To understand and reflect on the implications of different models of disability
* To look at the WHO model with regard to individuals and see how it can be used to benefit patient care
* To begin to look at communication tools when sharing difficult news
* To research the role of the charity sector in long term illness and then produce a patient leaflet/poster with this information.

## Outline of Module 3

**Essential pre-tutorial reading**

Scambler, Graham. *Sociology as applied to medicine. 6th Edition 2008* ‘Living with chronic disease’ Ch 6 W B Saunders. London.

Silverman, J, Kurtz, S. *Skills for communicating with patients*. ‘Breaking Bad News’2nd Edition 2004.pp208-215 Abingdon. Radcliffe Medical.

**TUTORIAL 1**

* Explore the communication around sharing difficult information
* Discuss different models of disability including the medical model, the social model and the WHO model
* Explore attitudes and behaviour towards people with diseases or disabilities
* Prepare to visit your patient
* Discuss poster presentations.

**Tasks to be completed**

1. Poster presentation: The voluntary sector and patient support organisations
2. Patient/Family visit 4: Living with a long term condition
3. E-Portfolio reflections

TUTORIAL 2

* Poster presentations
* Debrief on the course

## e-Poster Presentation

Final tutorial, Module 3

The voluntary sector and resources for patients

Apart from the medical care that patients receive from the NHS, for many chronic conditions there are sources of advice, support and care from which patients derive enormous benefit.

In fact for almost any medical condition imaginable there is likely to be a network of organisations and self-help groups. These may provide a range of important functions including practical and financial support, publications, counselling, complementary therapies, research funding, advice forums, access to day centres, respite care and support for carers.

**The Task**

We realise that the tutorials in module 3 arrive at a busy time for you during your revision for examinations. We would like you to spend a short amount of time researching the resources available outside of the NHS for patients. We would like this to be a fun and stimulating exercise and for you to be creative in your approach to this task.

You should use the patient(s) who you have visited over the year as a starting point, and to research the resources that are available for patients with that particular condition. If possible we would like you to visit such an organisation and talk to the people who run it.

A useful starting point is the Internet. The following sites have links to patient organisations:

patient.co.uk [**http://www.patient.co.uk/selfhelp.asp**](http://www.patient.co.uk/selfhelp.asp)

Prodigy [**http://www.prodigy.nhs.uk/Portal/PatientInformation/SelfHelpList.aspx**](http://www.prodigy.nhs.uk/Portal/PatientInformation/SelfHelpList.aspx)

DIPEx: [**http://www.dipex.org/DesktopDefault.aspx**](http://www.dipex.org/DesktopDefault.aspx)

For this exercise we would like you to work in pairs to research voluntary sector organisations and develop an educational tool for patients about this. This could summarise the key activities of a single organisation or signpost a variety of services for people with a certain disease or disability.

This could include a poster presentation (which might be interactive), an information video or patient leaflet. An interactive information tool might be particularly appropriate for those with a disability, for example. You can find examples of previous posters on the intranet.

**Presentation**

The final tutorial in Module 3 will take the form of presentations which will be carried out in pairs to your group. You should introduce and present your information tool (be it a poster, patient leaflet, video) and be ready to answer questions from your colleagues and the group leader.

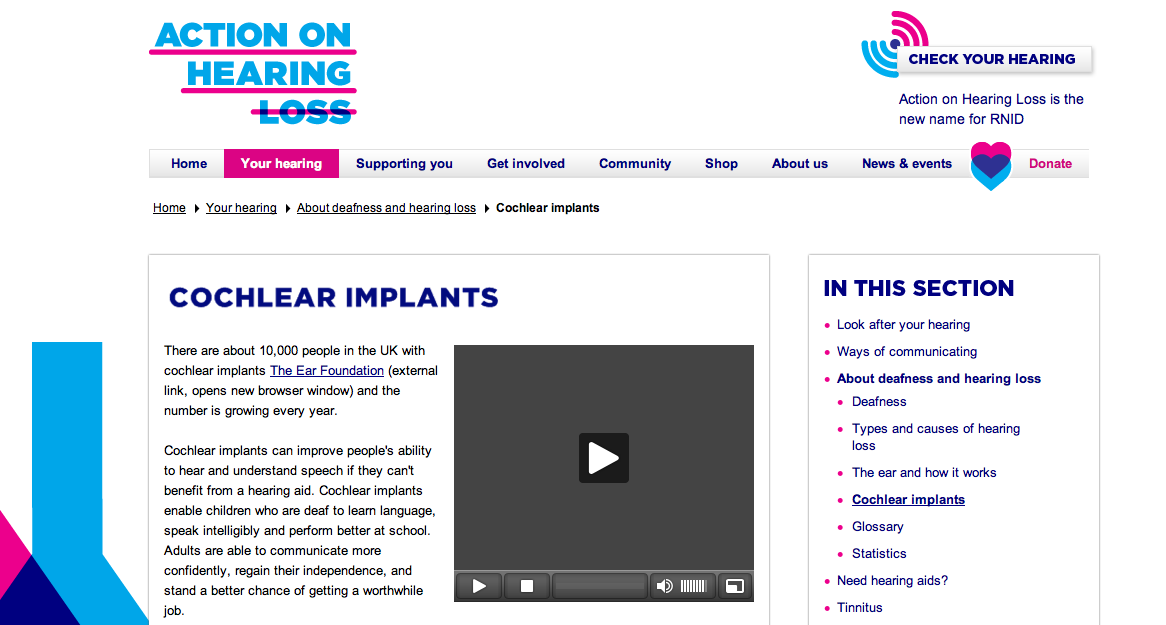
**Content**

Consider the objectives of your resource, and the message that you wish to convey.

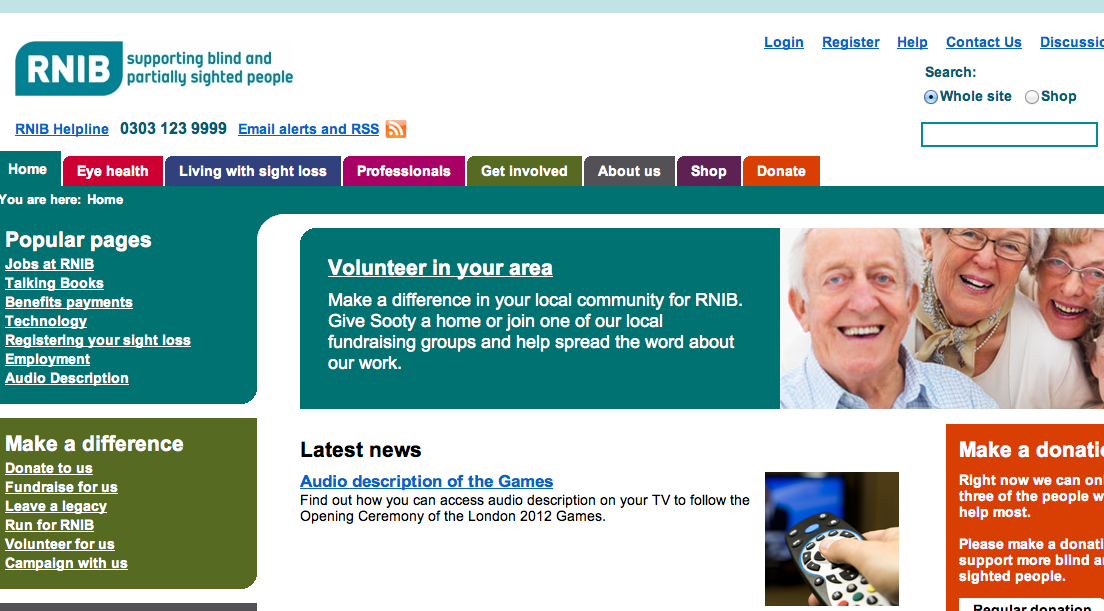
Present your findings and how you went about your research. You should also focus on a few areas of interest, which illustrate the most important aspects of the organisation(s) in some detail.

**Target Audience**

The mark scheme will take into account the sensitivity of the way the information is presented to the target audience’s needs. Professional charitable bodies go to great lengths to ensure that their information is accessible. An example is the website by Action on Hearing Loss (previously the Royal National Institute for the Deaf), which includes many explanatory videos which facilitate understanding in those with hearing impairment.



Similarly, the website by the Royal National Institute for the Blind uses large, clear bold images and fonts which are suitable for partially-sited people:



**Marking Scheme**

**The Group Leader will be observing the following:**

|  |  |
| --- | --- |
| **Domain** | **Mark** |
| Clarity of aims and objectives (max 1 marks) | Clear statement of aims and objectives – 1  Unclear aims/objectives – 0 |
| Artistic quality of information (max 2 marks) | Excellent artistic quality to information – 2  Acceptable presentation of information -1  Poorly presented, lacks artistic quality – 0 |
| Concise and coherent presentation of information resource (max 2 marks) | Excellent coherent presentation – 2  Acceptable presentation – 1  Poorly presented -0 |
| Sensitivity to target audience of information resource (max 2 marks) | Information resource displays excellent sensitivity to target audience -2  Resource displays partial sensitivity -1  No sensitivity to target audience -0 |
| Ability to deal with any questions asked by colleagues (max 1 marks) | Excellent responses to questions by colleagues – 1  Unable to answer questions or consider view of colleagues - 0 |
| **TOTAL** | **/8** |

## Patient/Family Visit Four: Living with a long-term condition

**Learning Objectives**

**By the end of the visit you will have**

1. Re-established the relationship and obtain an update regarding the current circumstances
2. Considered the adaptations that are made by the individual and his or her family, to a long term illness
3. Considered the effect on patients and carers of the way in which a medical diagnosis/ test results are shared
4. Deepened an awareness of the different ways in which individuals may respond or cope with long term illness or a life event

**Things to cover:-**

What adaptations have been made to cope with the changes that come with a long term illness in terms of:

* Physical adaptations
* Psychological adaptations – how has the individual had to come to terms with the circumstances
* Social – effect on employment, or social or leisure activities, housing, economic, need for social services, state benefits or other social consequences

What have been the reactions of others? Is there any evidence of experiencing **stigma**?

In the case of a disability, what is their experience of day to day living? What activities of daily living are difficult or require assistance from another person. Consider dressing, cooking, eating, washing/ bathing, use of toilet, housework, walking, driving etc.

What is the person’s daily routine?

Are there any activities that the person would like to be able to undertake but is unable to?

What are the person’s current interests or hobbies and plans for the future?

Examples of areas to explore:

* How does someone with a walking frame get upstairs?
* What tests and treatment do people with diabetes/cystic fibrosis etc have to perform for themselves? (Ask them to show you).
* How does a child in a wheelchair change classrooms at a school which is built on more than one floor?
* How does someone who has dialysis three times a week go away on holiday?
* How does someone with both legs paralysed drive a car?
* What is a typical day like for someone with their chronic health condition?

How dependent or independent is the person on others? Examples of questions.

* What support do you need? Does anyone help you?
* Do you feel people could do more to help you? What would you like help with? e.g. has the spouse/parent had to give up work to do the caring?
* Who comes to visit – is it friends? Do the strangers in the home care team become friends?
* Who does the shopping/washing/cooking/gives the injections/changes the urine or colostomy bags or nappies?

## Background information

The aims of the third moduleare for you to develop your understanding of how people are affected by medical conditions that need long term care and to explore the complex web of support that is available in the community for these people. Physical problems have repercussions for people in social and psychological terms as well as on practical problems of daily living. When you meet people with problems remember to consider these factors both in terms of how they affect people, but also how social and psychological factors can influence how people cope. Some of the patients you are visiting will have a chronic illness, some will have a ‘disability’. Both may have experienced stigma and the models below can be useful to both on how to view the ‘problem’.

**The Medical (Individual) and Social Models of Disability**

**Adapted From The Disability Rights Commission**

In addition to understanding the conventional definition of disability, it is important to be aware of the fact that there is an on-going debate as to whether a disability should be regarded as something that an individual ‘has’ as opposed to something that is a function of the way society accommodates people with impairments. This may be expressed in the two ‘models’ of disability.



**The ‘Medical Model’ of Disability**

According to the medical model, disability is seen as a product of a biological abnormality. This model sees disablement as a medical problem, which affects only a small proportion of the population. Recent studies in Britain, however, conclude that four out of every ten adult women and men have a longstanding illness or disability. Other studies show that internationally there are around 50 million disabled people in Europe and approximately 500 million worldwide The medical notion of disability, seeing disability as a cause of a limitation within the individual, cannot account for the fact that not all people with losses, diseases, illnesses etc. experience disablement.



**The Social Model of Disability**

Advocates for the social model maintain that disability is a complex problem which has social and political dimensions. It is therefore seen as a product of organisation and culture rather than a personal limitation due to a person’s impairment. Such a view implies that social barriers, norms and values, rather than impairments, should be analysed in determining quality of life. It is even possible for disabled people to report that their lives have changed for the better following disablement. Of course the social models do not deny that impairments can affect quality of life but they deny assumptions, on which, for example, the practice of antenatal screening for abnormality rests.

**2001 definitions**

In 2001 the WHO modified the classification of disability, to produce a more dynamic model, which focussed more on abilities and function rather than disability and impairment. The model also recognises the important interaction between envirionmental factors, personal factors, the effects of the limitations on activity, and the person’s health condition.

* Learning & Applying Knowledge
* General Tasks and Demands
* Communication
* Movement
* Self Care
* Domestic Life Areas
* Interpersonal Interactions
* Major Life Areas
* Community, Social & Civic Life



Person

gender

age

other health conditions

coping style

social background

education

profession

past experience

character style



Environment

Products and technology

Natural environment and human-made changes to the environment

Support and relationships

Attitudes

Services, systems and policies

**ATTITUDES AND BEHAVIOUR**

One of the important aspects of living with a long term problem is coping with how other people see you. Some disabilities can be disfiguring, others can become obvious when walking or talking, and others can be hidden more easily if the patient wishes. Revisit your sociology lectures regarding ‘stigma’. Almost all people will have some reaction to those who are different from us - we may be curious, frightened, worried about what to say (look at the changing faces website - see references). The reference list includes recent research regarding how people with lung cancer feel they are stigmatised.

As health professionals it is important that we recognise these feelings and behaviours in ourselves. They may influence how we talk to and treat patients. Our nervousness may make us clumsy when talking to someone. A patient may remind us of someone in our family - we may presume we know all about their problem without asking them! As part of this module we will consider our past experience of people with long term problems - both people we know personally and public figures and consider our responses and those of society.

SHARING A DIAGNOSIS

Doctors tend to take a history, perform an examination and then organise a series of tests to confirm a suspected diagnosis. The time of waiting for results may be worrying for the patient. You may like to explore what this time of waiting was like for your patient.

The way in which information is shared has been shown to affect how well people cope and how they benefit from medical services in the future. Patient distress may be increased when: information is shared with someone when they are unsupported or lack privacy, is given in a rushed, impersonal and negative way and where no time is being made for a follow-up appointment in order to repeat the information and answer questions. In your tutorials you will have an opportunity to explore how best to communicate such information with patients.

Further reading

There is a section on ‘breaking bad news in Silverman and Kurtz ‘Skills for Communicating with Patients’.

## Reading/viewing list

Chapple, A, Ziebland, S and McPherson, A. ***Stigma, shame, and blame experienced by patients with lung cancer: qualitative study*** BMJ, Jun **2004**; 328: 1470

Ferriman Annabell, The Stigma of Schizophrenia *BMJ* 320 : 522 doi:10.1136/bmj.320.7233.522

Scambler, Graham. *Sociology as applied to medicine. 6th Edition 200*8 ‘Living with chronic disease’ Ch 6 pp 79-91 W B Saunders. London.

Silverman, J, Kurtz, S. *Skills for communicating with patients*. ‘Breaking Bad News’2nd Edition 2004.pp208-215 Abingdon. Radcliffe Medical.

<http://www.changingfaces.co.uk/> – website of Changing Faces

Films