Part C

Views about user involvement

Introduction

A summary of Part C

Why is Part C important?

There are many different opinions about what doing user involvement work means. As a user consultant do you present your individual view - issues unique to your own experience and opinions? Do you represent other people - issues frequently shared with other users, carers and members of the public? Doing both is important, but you need to decide what fits best with your user involvement role. In this part you learn about 'user perspective,' which helps you work these issues out. You will also think about how to talk about differences among people. This is very important, as you have to think about the many different people who use health and social services. Learning about user perspective will help you think about the experiences of user involvement you have had already and other skills that you bring to user involvement work.

What will you learn by doing Part C?

At the end of this part you will be able to:

▪ Explain differences between personal and user perspective – Activity 1

Introduction

- Discuss respectful ways or talking about different groups of people – Activity 2

- Identify what knowledge, skills and attitudes you bring to user involvement work – Activity 3

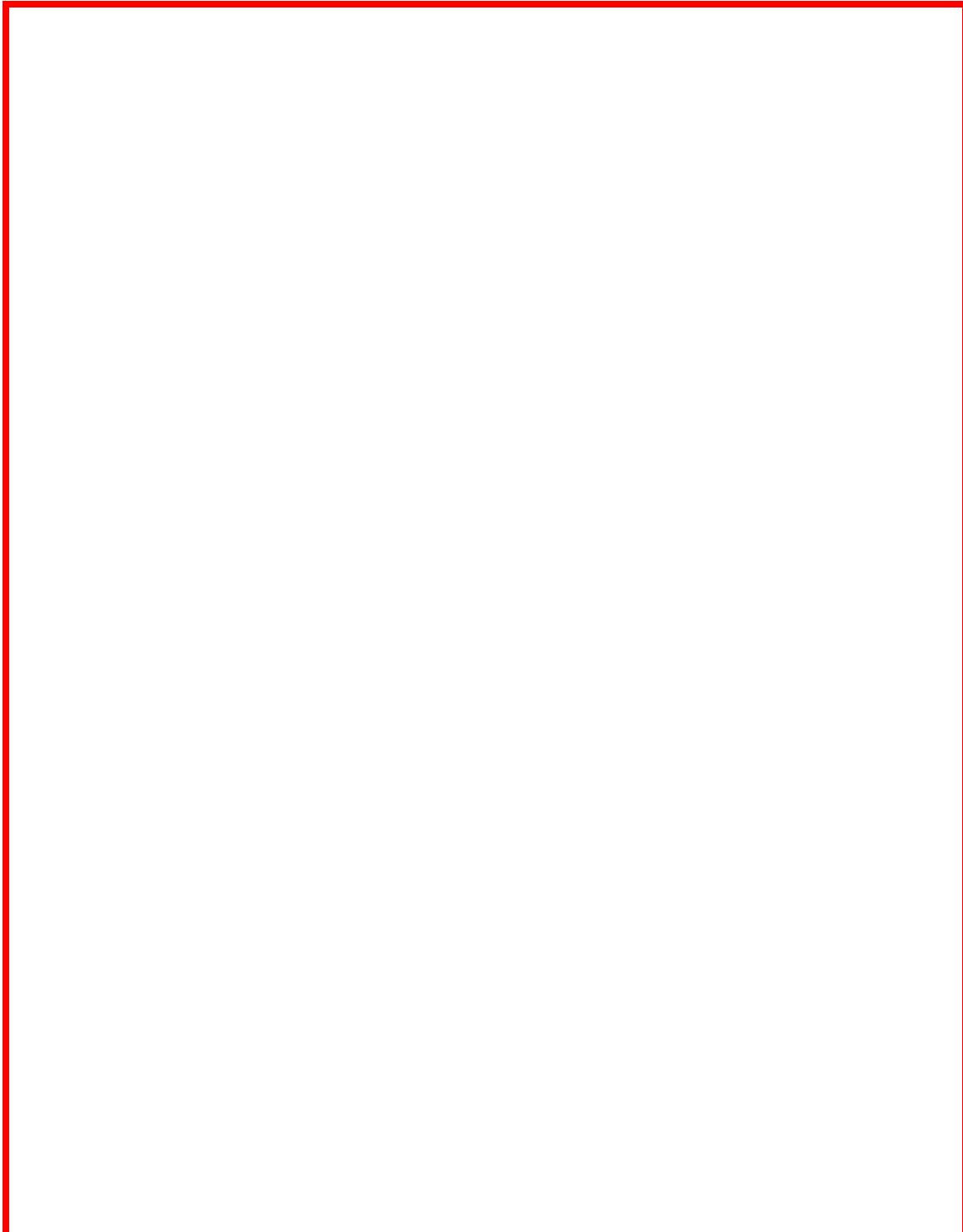## Skills you will strengthen or develop

Skills that you will strengthen or develop include:

- Level 1: Develop the ability to think about issues

- Level 1: Learn to develop and present an argument

- Level 1: Develop the ability to think about case examples

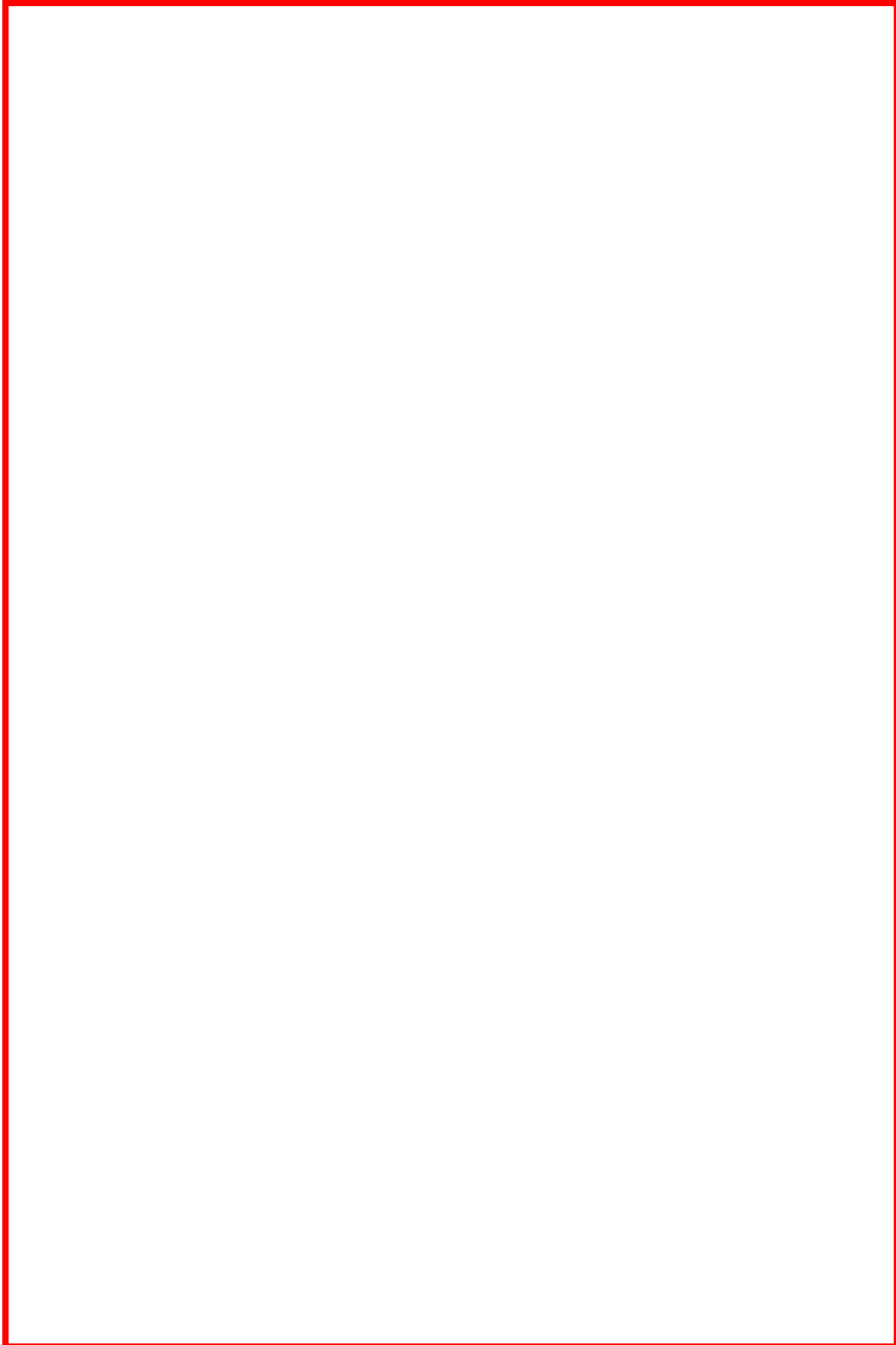- Level 1: Develop the ability to do personal reflection

Activity 1

Whose view do you represent?
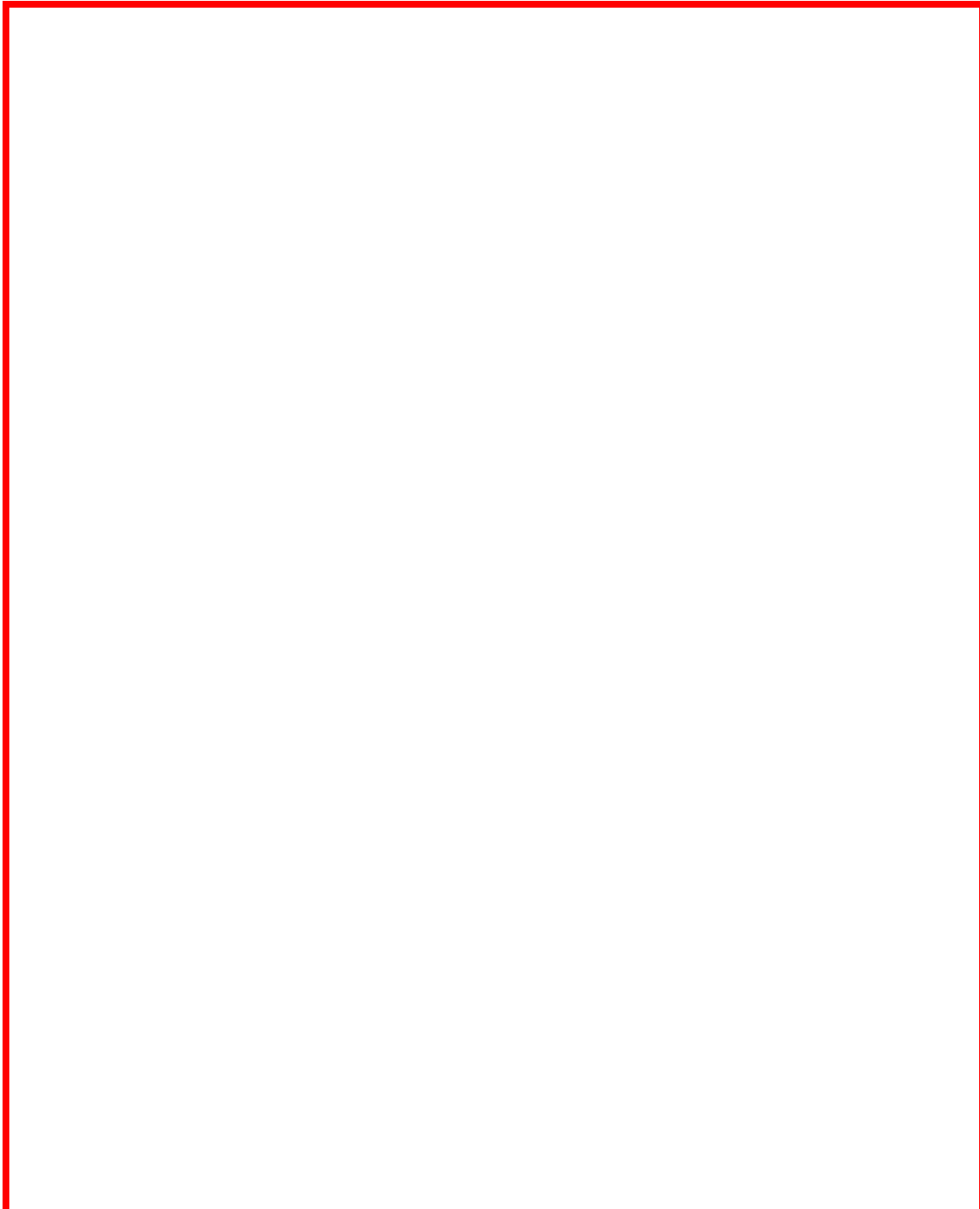
Thinking about individual and user perspective

Activities

What is user perspective?

Activities

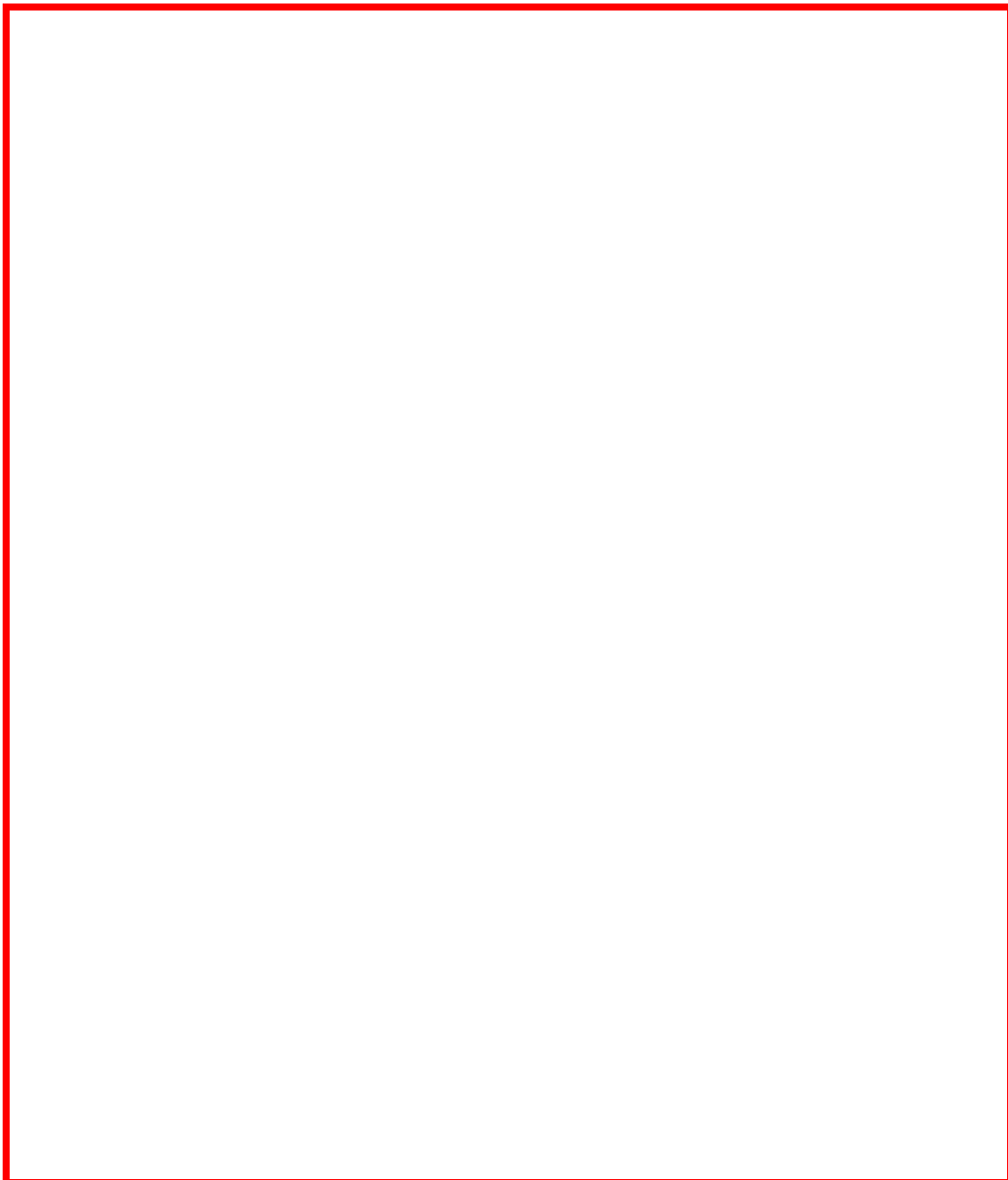# Activity 2

Language for talking about difference

Language for talking about difference – what is politically correct?

Activities

Activity 3

What have I done and what do I bring to user involvement?

What have I done and what do I bring to user involvement?

Personal exercises

Here is an exercise to help you think about the ideas in Part C.

User and individual perspective

- How will you keep a check on whether you are talking from an individual perspective or user perspective?

- What can you do to help yourself with keeping a balance?

Personal exercises

Case examples

1. MIND

http://www.mind.org.uk/About+Mind

Mind Infoline: 0845 766 0163

MIND is the leading mental health charity in England and Wales, and is an example of a user-led organisation that promotes user perspective. There are several local branches of MIND around the country, such as Solihull MIND. Each branch provides it own services according to needs in their local area. It works for a better life for everyone with experience of mental distress by:

- advancing the views, needs and ambitions of people who have experienced mental distress

- promoting inclusion by challenging discrimination;

- influencing policy through campaigning and education;

- inspiring the development of quality services, which reflect users and carers need and diversity;

- achieving equal civil and legal rights through campaigning and education

Case examples

2. Involving and empowering patients from Ethnic Minorities and Cultural Groups

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The Black & Minority Ethnic Advisory Group (B&MEAG) was set up in 1995 by Gillian Waterhouse, Quality Manager for the Trust, with the help of the local community and voluntary groups. Examples of their work include:

- **Dietary needs** - B&MEAG identified the need for appropriate diet provision for Muslim patients i.e. Halal food. Together with Trust staff they visited meat suppliers and abattoirs to check religious and hygiene standards. The Trust appointed a Muslim chef and religious leaders were invited for food tasting sessions. The halal food has become part of the hospital menu and is well publicised. The Muslim chef visits the wards regularly to speak to the Muslim patients about the halal food provision.

- A **multi-faith prayer facility** was established at the Trust in response to the needs of the local community. B&MEAG

Case examples

advised the Trust about the provision of Holy Scriptures, prayer timings, methods of prayer, worship and meditation, washing facilities and the importance of maintaining a neutral environment. The facility will be moved near the chapel and become part of a purpose built multi-faith centre. The facility is used regularly by patients, carers, visitors and staff of different faith groups.

- **Interpreting and translation services** – The B&MEAG guided the Trust to set up a full-time and Trust-wide interpreting and translation service in five South Asian languages. This ensured that the non-English speaking patients and carer's communication needs were met appropriately so they could make informed choices and give informed consent about their treatment. The interpreters provide face-to-face interpreting on request of patients, carers or staff and also culturally sensitive bereavement services to families and staff.

- **Cultural awareness sessions for staff** - Regular sessions are held for staff to provide and introduction to the cultural diversity and it's implications for providing quality health care service to the communities the Trust serves. This initiative was developed in conjunction with the B&MEAG based on user and staff feedback.

Case examples

Useful information for participants

Useful reading

SPICE Consulting (1998). *The Kit: A guide to the advocacy we choose to do. A resource kit for consumers of mental health services and family carers*. (Australian) Commonwealth Department of Health and Family Services: Canberra. Available online at: http://www.mhca.com.au. Click on their 'Projects' section and follow the links to view or download all or sections of the kit.

> If possible, gain access to the Internet through your organisation and take a look at this resource. It was developed in Australia to support user consultants in the mental health field to learn more about advocacy to help them in doing user involvement work. There are many sections you will find helpful in understanding user perspective and how to represent yourself and other people as a user consultant.
>
> **Ease of reading**: Good

Useful information

Useful information

Sources used for the material in this part

Epstein, M. & Shaw, J. (1997). *Developing effective consumer participation in mental health services: The report of the Lemon Tree Learning Project*. Melbourne: Victorian Mental Illness Awareness Council. Available online at:

http://home.vicnet.net.au/~vmiac/home.htm

Wilson, J. (1999). Acknowledging the expertise of patients and their organisations. *British Medical Journal*, 319, 771-774.