

SIGN 100 – *A Handbook for Patient and Carer Representatives*



SUMMARY

SIGN 100 is a handbook for patient and carer representatives who have become involved in the work of SIGN. It is a helpful resource for people who are interested in the process of developing clinical guidelines for the NHS in Scotland.

SIGN 100 is a companion to SIGN 50, our methodology handbook.

SIGN 100 has three main objectives:

- to explain the process used to develop clinical guidelines
- to show how one can become involved in developing guidelines
- to provide understanding of the role of a patient and/or carer representative

Throughout SIGN 100, the term ‘patients and carers’ is used to cover the groups of people who are involved in SIGN’s work. This includes people who have a medical condition, people who are caring for someone, a patient’s family and friends, or people who work for voluntary organisations that represent patients. These ‘representatives’ are not medical staff.

SIGN 100 aims to be a tool in the promotion of patient and carer representation in guideline development process.

KEY POINTS

Patient and Carer Involvement:

It is very important for patients and carers to be involved in the decisions that are made about their care.

By involving patients and carers in the guideline development process, the guideline group can identify patients and carers concerns and use their views and experiences to supplement scientific research and the knowledge and experience of healthcare professionals.

Patients and carers help guideline development groups to understand what it is like to live with a medical condition and how different forms of treatments can affect individual lives.

SIGN 100 gives a thorough explanation of research and the process of reviewing papers. Terms are defined and practices are explained in a way that someone without a research background can understand.

Expectations of Patient and Carers:

The role of patient and carers throughout the development process is clarified in SIGN 100. We hope it will help patient or carer representatives see that formal qualifications are not necessary to participate in guideline development.



PUBLICATION

SIGN 100 will be launched on September 3rd 2008, as part of the celebrations of SIGN's 15th anniversary. It is an honour to provide a handbook to promote and encourage patient and carer involvement in SIGN's work.

We would like to take this opportunity to thank all of the patient and carer representatives who have worked with us over the last 15 years.

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