



# SCOTTISH EXECUTIVE

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Your ref:  
Our ref:

9 August 2004

## INTRODUCTION OF NHS CARER INFORMATION STRATEGIES: DRAFT GUIDANCE

**I am writing to request your comments on draft guidance and your help in disseminating the draft within and beyond your respective organisations. Please could comments on this draft guidance be returned by 29 October 2004.**

Section 12 of the Community Care and Health (Scotland) Act 2002 ("the 2002 Act") enables Scottish Ministers to require that all NHS Boards prepare and submit to them for their approval a "Carer Information Strategy" and to prescribe the format and content of such Strategies. Ministers sought recommendations on the format and content of such strategies from an independent Working Group which included carer, NHS, local authority and Scottish Executive representation. **The Group's recommendations are set out in the attached draft guidance.** The guidance proposes the minimum requirements that any Strategy should meet. Strategies are to be developed jointly with local authorities, carers, carers' organisations and the wider voluntary sector. There is scope therefore for local flexibility and to build on these minimum requirements.

This draft guidance is the first step towards Scottish Executive Ministers formally exercising their power under Section 12 of the 2002 Act. **Before doing so they wish to seek your views on the proposed measures contained within the draft guidance and the potential resource implications.**

### Background

The introduction of NHS Carer Information Strategies builds on existing areas of activity within the NHS which are already starting to deliver outcomes for carers and those they care for. The Strategies and their associated guidance are aimed at quickening the pace of change and ensuring a reasonably standardised approach across all NHS Boards. As such, the development of an NHS Carer Information Strategy should dovetail with a range of practical steps which are already being undertaken in a range of policy areas. These include implementation of :-

- Patient Focus and Public Involvement
- Partnership for Care
- the development of Community Health Partnerships
- local carer strategies developed by local authorities and NHS Boards.

NHS Carer Information Strategies are aimed at building on this progress and delivering in all NHS Boards:-

- routine identification of carers as part of mainstream NHS activity
- the provision of targeted information to identified carers
- referrals of carers by NHS staff to sources of support/advice
- improved carer awareness amongst health practitioners
- better partnership working with carers in relation to care management/discharge
- mainstreaming of support for carers into the day-to-day functions of the NHS.

### **Consultation audience**

Within the statutory sector there are many people with an interest in supporting carers or whose actions can affect them. Clearly it is up to NHS Boards and local authorities how they prepare their corporate responses, but I would be very grateful if colleagues could arrange for the draft guidance to be copied to and considered by:-

- senior and frontline managers in NHS Boards working in acute care, primary care and community based settings, including independent contractors ie GPs and pharmacists
- dedicated NHS Board staff involved in supporting carers
- NHS managers involved at a strategic level in delivering Community Health Partnerships, Patient Focus and Public Involvement, and Partnership for Care
- local authority managers involved in supporting unpaid carers, including young carers.
- local authority teams involved in supporting children and families as well as adults and older people

**We would be very interested in receiving views direct from managers and staff as well as receiving their input through corporate responses.**

National organisations working in the voluntary sector and supporting carers and service users are being directly consulted on this draft guidance by the Scottish Executive. The draft guidance stresses the need for a bottom-up consultative approach with carers and other key stakeholders in developing NHS Carer Information Strategies. **Please could NHS Boards, in partnership with local authorities, ensure that local groups involved in supporting carers are made aware of this guidance and given the opportunity to respond directly to the Executive.**

### **Good Practice Examples**

Section 4 of the draft guidance has not been drafted. In the final version of this guidance Section 4 will contain good practice examples of how carers within NHS settings are already being identified, provided with targeted information and referred on to other sources of support and information. The existing good practice we know about is based on partnership working with carers, local authorities

and the voluntary sector. **As part of your response to this consultation, we would be interested in receiving examples of good practice within your area for inclusion in Section 4.**

### **Responding to this consultation document**

The consultation period closes on 29 October 2004. Responses should be e-mailed if possible to [elizabeth.mathison@scotland.gsi.gov.uk](mailto:elizabeth.mathison@scotland.gsi.gov.uk). Alternatively, hard copy responses can be sent to Elizabeth at the above address. Please also use the response information form to be found in Annex 1 to this letter when you are submitting your response.

We would be grateful if you could clearly indicate in your response which questions or parts of the consultation paper you are responding to as this will aid our analysis of the responses received. If you have any queries or would like additional copies of this document, please contact Angela McLachlan on 0131-244 4040.

### **Accessing this consultation document**

This consultation, and all other Scottish Executive consultation exercises can be viewed on line at: <http://www.scotland.gov.uk/consultations>. You can telephone Freephone 0800 77 1234 to find out where your nearest public internet access point is.

This consultation paper can also be made available in alternative formats and in various community languages. Please contact Angela McLachlan (Tel: 0131-244 4040) on this issue.

The Scottish Executive now has an e-mail alert system for its consultations (SEconsult). This system allows stakeholder individuals and organisations to register and receive a weekly e-mail containing details of new Scottish Executive consultations (including web links). SEconsult complements, but in no way replaces Scottish Executive distribution lists, and is designed to allow stakeholders to keep up to date with all Scottish Executive consultations and therefore be alerted at the earliest opportunity to those of most interest. We would encourage you to register. Details of how to do this are on <http://www.scotland.gov.uk/consultations>.

### **Access to consultation responses**

We will make all responses available to the public in the Scottish Executive Library, unless confidentiality is requested. All responses not marked confidential will be checked for any potentially defamatory material before being logged in the library or placed on the website. We draw your attention to the material in Annex 2 of this letter which sets out information on the consultation process used by the Scottish Executive.

Finally, thank you in advance for your responses to this consultation document.

*Adam Rennie*

**J A RENNIE**

## LIST OF CONSULTEES

Action for Sick Children  
Advocacy Safeguards Agency  
Advocating Together  
Age Concern Scotland  
Alzheimer Scotland  
Arthritis Care Scotland  
Assist (Scotland)  
Association for all Speech Impaired Children  
Association of Children's Hospices (CHAS)  
Association of Directors of Social Work

BAAF Scotland  
Barnardos (Scotland)  
Black & Minority Ethnic Elders Group  
Black & Minority Infrastructure in Scotland  
British Association of Social Workers  
British Deaf Association Scotland  
British Dietetic Association  
British Federation of Care Home Proprietors  
British Geriatrics Society  
British Institute of Learning Disabilities  
British Medical Association (Scottish Office)  
British Psychological Society (Scottish Division)

Camphill Scotland  
Capability Scotland  
Care Commission  
Care in the Community  
Carers Scotland  
Carr-Gomm Scotland  
CCETSW/TOPSS  
Childline Scotland  
Children 1<sup>st</sup>  
Children in Scotland  
Children's Head Injury Trust (Scotland)  
Choices  
Choices Community Centre Services  
Church of Scotland Board of Social Responsibility  
Citizen's Advice Scotland  
Coalition of Carers in Scotland  
Commission for Racial Equality  
Commissioner for Local Authorities in Scotland  
Communities Scotland  
Community and District Nursing Association

Community Care Providers Scotland  
Community Care Rights Adviser  
Community Integrated Care  
Community Mental Handicap Nurses Association  
Community Practitioners and Health Visitors Association  
Contact the Elderly in Scotland  
Cornerstones Community Care  
COSLA  
Crossroads Scotland  
Cruse Bereavement Care Scotland

Deaf Connections  
Deafblind Scotland  
Dementia Services Development Centre  
Depression Alliance  
Down's Syndrome Scotland

Edinvar Community Care  
Enable  
Epilepsy Action Scotland  
Equal Opportunities Commission  
Equal Say

Family Fund Trust

Glasgow Learning Disability Partnership  
Guide Dogs for the Blind Association

Hansel Alliance  
Headway  
Health Education Board (Scotland)  
Hear Here  
Help the Aged  
Homelink

Independent Health Care Association  
Information & Research Disability

Learning and Teaching Scotland  
Leonard Cheshire Scotland  
Lothian Centre for Integrated Living

Manic Depression Fellowship  
ME Association (Scotland)  
Men and Mind

Mental Health Foundation Scotland  
 Mental Health Nurses Association  
 Mental Welfare Commission for Scotland  
 Minority Ethnic Carers of Older People  
 Project  
 Momentum Scotland  
  
 National Association of Local Societies for  
 Visually Impaired People  
 National Association of Play Specialists  
 National Association of Special Educational  
 Needs  
 National Autistic Society  
 National Primary Centre Scotland  
 National Schizophrenia Fellowship (Scotland)  
 NCH Action for Children Scotland  
 NHS Quality Improvement Scotland  
 Nuffield Centre for Community Care  
  
 PAIN Association Scotland  
 PAMIS  
 Parent Network Scotland  
 Partners in Advocacy  
 Penumbra  
 People First  
 Play Scotland  
 Positive Steps  
 Princess Royal Trust for Carers  
  
 Rehab Scotland  
 Richmond Fellowship Scotland  
 Royal Blind School  
 Royal College of Nursing  
 Royal College of Psychiatrists  
 Royal Institute for Deaf People  
 Royal National Institute for the Blind  
  
 Samaritans  
 Scottish Accessible Information Forum  
 Scottish Alliance for Children's Rights  
 Scottish Association for Mental Health  
 Scottish Association for the Deaf  
 Scottish Association of Health Councils  
 Scottish Association of Sign Language  
 Scottish Carers Alliance  
 Scottish Churches Parliamentary Office  
 Scottish Consortium for Learning Disability  
 Scottish Council for Deafness  
 Scottish Council for Voluntary Organisations  
 Scottish Development Centre for Mental  
 Health  
 Scottish Disability Equality Forum  
 Scottish Early Years & Family Network

Scottish Eating Disorder Interest Group  
 Scottish Health Visitors Association  
 Scottish Human Services Trust  
 Scottish Huntington's Association  
 Scottish Independent Advocacy Alliance  
 Scottish Independent Special Schools Group  
 Scottish Intercollegiate Guidelines Network  
 (SIGN)  
 Scottish Older People's Advisory Group  
 Scottish Motor Neurone Disease Association  
 Scottish Pensioners Forum  
 Scottish Refugee Council  
 Scottish Social Services Council  
 Scottish Society for Autism  
 Scottish Society of the Mentally Handicapped  
 Scottish Spina Bifida Association  
 Scottish Throughcare and Aftercare Forum  
 Scottish Women's Convention  
 SENSE Scotland  
 Shared Care Scotland  
 Social Care Association  
 Social Firms Scotland  
 Solas-Waverley Care Trust  
 Spinal Injuries Scotland  
 Support for Ordinary Living  
  
 The Call Centre (Communication Aids for  
 Language and Learning)  
 The Child & Family Trust  
 The Community Psychiatric Nurses  
 Association  
 The District Nurses Association  
 The Equality Network  
 The Fostering Network  
 The Independent Federation of Nursing in  
 Scotland  
 The Joseph Rowntree Foundation  
 The National Association for Special Needs  
 The National Board for Nursing, Midwifery &  
 Health Visiting for Scotland  
 The National Commission for Social Care  
 The National Deaf Children's Society  
 The National Federation of Blind of the UK  
 The National League for the Blind and  
 Disabled  
 The NHS Confederation in Scotland  
 The Parkinson's Disease Society (Scotland)  
 The Patients Association  
 The Royal College of General Practitioners  
 The Royal College of Physicians of Edinburgh  
 The Royal College of Surgeons of Edinburgh  
 The Royal Pharmaceutical Society of Great  
 Britain (Scotland)

The Scottish Board of the College of Occupational Therapists  
The Scottish Child Psychotherapy Trust  
The Scottish Civil Forum  
The Scottish Community Care Forum  
The Scottish Council of Jewish Communities  
The Scottish Dyslexia Association  
The Scottish Gypsy Traveller's Association  
The Scottish Head Injuries Forum  
The Scottish Motor Neurone Disease Association  
The Scottish National Institute for the War Blinded  
The Scottish NHS Confederation

The Scottish Travellers Consortium  
The Thistle Foundation  
The Women's National Commission  
Together Opening Doors  
Trust a Carers Connection

Values in Action  
Visual Impairment Scotland

Who Cares?

Young Carers Alliance  
Young Scot  
Youth Scotland

**RESPONDEE INFORMATION FORM**

Please complete the details below and attach it with your response. This will help ensure we handle your response appropriately:

Name:

Postal Address:

Consultation title: NHS CARER INFORMATION STRATEGIES: DRAFT GUIDANCE

1. Are you responding as: (please tick one box)

- |     |   |                |
|-----|---|----------------|
| (a) | an individual                               | ÿ (go to 2a/b) |
| (b) | <b>on behalf of</b> a group or organisation | ÿ (go to 2c)   |

**2a. INDIVIDUALS:**

Do you agree to your response being made available to the public (in SE library and/or on SE website)?

- |                      |   |
|----------------------|---|
| Yes (go to 2b below) | ÿ |
| No, not at all       | ÿ |

**2b. Where *confidentiality is not requested*, we will make your response available to the public on the following basis (**please tick one** of the following boxes)**

- |  |   |
|--|---|
| Yes, make my response, name and address all available        | ÿ |
| Yes, make my response available, but not my name or address  | ÿ |
| Yes, make my response and name available, but not my address | ÿ |

**2c ON BEHALF OF GROUPS OR ORGANISATIONS:**

Your name and address as respondees **will be** made available to the public (in the SE library and/or on SE website). Are you content for your response to be made available also?

- |     |   |
|-----|---|
| Yes | ÿ |
| No  | ÿ |

**SHARING RESPONSES/FUTURE ENGAGEMENT**

3. We will share your response internally with other SE policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Executive to contact you again in the future in relation to this consultation response?

- |     |   |
|-----|---|
| Yes | ÿ |
| No  | ÿ |

## THE SCOTTISH EXECUTIVE CONSULTATION PROCESS

Consultation is an essential and important aspect of Scottish Executive working methods. Given the wide-ranging areas of work of the Scottish Executive, there are many varied types of consultation. However, in general Scottish Executive consultation exercises aim to provide opportunities for all those who wish to express their opinions on a proposed area of work to do so in ways which will inform and enhance that work.

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body. Consultation exercises may involve seeking views in a number of different ways, such as public meetings, focus groups or questionnaire exercises.

Typically, [Scottish Executive consultations](#) involve a written paper inviting answers to specific questions or more general views about the material presented. Written papers are distributed to organisations and individuals with an interest in the area of consultation, and they are also placed on the Scottish Executive web site enabling a wider audience to access the paper and submit their responses<sup>1</sup>. Copies of all the responses received to consultation exercises (except those where the individual or organisation requested confidentiality) are placed in the Scottish Executive library at Saughton House, Edinburgh (K Spur, Saughton House, Broomhouse Drive, Edinburgh, EH11 3XD, telephone 0131 244 4552).

The views and suggestions detailed in consultation responses are analysed and used as part of the decision making process. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

If you have any comment about how this consultation exercise has been conducted, please send them to:

Elizabeth Mathison  
 Community Care Division 2: Carers  
 Area 2ER  
 St Andrew's House  
 Edinburgh  
 EH1 3DG

e-mail: [elizabeth.mathison@scotland.gsi.gov.uk](mailto:elizabeth.mathison@scotland.gsi.gov.uk)

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<sup>1</sup> <http://www.scotland.gov.uk/consultations>

# **NHS CARER INFORMATION STRATEGY: DRAFT GUIDANCE**

## **SECTION 1**

### **1. INTRODUCTION**

#### **1.1 Who is the Guidance for?**

1.1.1 This guidance is designed as a tool for NHS Boards so that they will understand the new requirements being placed on them, and NHS staff at all levels, by Scottish Executive Ministers in terms of providing information to carers.

#### **1.2 What is the Guidance for?**

1.2.1 This document gives NHS Boards, working in collaboration with local authorities and the voluntary sector, guidance on implementing the provision contained in Section 12 of the Community Care and Health (Scotland) Act 2002 ('the 2002 Act') which provides Scottish Executive Ministers with the power to require that NHS Boards prepare and submit a 'Carer Information Strategy'.

#### **1.3 How the Guidance was produced**

1.3.1 This draft Guidance has been produced by the NHS Carer Information Strategy Working Group, set up by the Scottish Executive in January 2004. The Group's remit was to make recommendations to Ministers on the format and content that an NHS Carer Information Strategy should take. Such recommendations were to be made in the form of draft guidance.

1.3.2 The Group comprised representatives from the NHS, local authorities, carers' organisations, a carer, and Scottish Executive officials. It met monthly between January and June 2004. As part of its work, it considered the specific needs of young carers, carers from minority ethnic groups and mental health carers, as these groups were felt to have particular needs in terms of access to information. The Guidance contains references throughout to these groups.

1.3.3 The draft Guidance has been cleared by related policy bodies within the Scottish Executive.

#### **1.4 Format of the Guidance**

1.4.1 The draft Guidance is in 3 sections.

- Section 1 explains the purpose of the Guidance, the audience it is aimed at, and sets out the policy/legislative background to the requirement for NHS Carer Information Strategies.

- Section 2 sets out the policy context which now places the carers' agenda at the heart of the Scottish Executive's health and social care policies. It also looks at the invaluable contribution made by carers to health and social care and the vital role of the NHS in supporting carers effectively and working with carers in meaningful partnerships.
- Section 3 sets out the format and content of an NHS Carer Information Strategy, prescribing minimum requirements, a timetable for delivery, and monitoring arrangements.
- Section 4 of the final guidance will set out examples of good practice in identifying and informing carers within NHS settings and through effective partnership working with key stakeholders. As part of the consultation exercise on this draft guidance, we are asking NHS Boards, local authorities and the voluntary sector to provide good practice examples for inclusion in the final guidance (see the covering letter accompanying this guidance).

## 1.5 Links With Other Policies/Legislation/Guidance

1.5.1 Supporting carers is a key priority for the Executive under its '[Strategy for Carers in Scotland](#)' ('[Carers Strategy](#)') published in November 1999. The Carers Strategy provides a national framework for delivering improved support to carers, predominantly through the development of local services, the provision of improved information to carers, both at national and local level, and the introduction of new legislation to allow carers' needs to be met more directly. A further aim of the Carers Strategy is to give a new impetus to the way in which statutory agencies work with carers and involve carers as key partners in care management and service planning decisions.

1.5.2 The Carers Strategy has helped to deliver change through the development of local carer strategies, implemented by local authorities and NHS Boards, the creation of improved local infrastructures to support carers, and improved engagement with carers on care management and service planning. The extent to which carer support, engagement and participation happens however differs across local authority and NHS Board boundaries.

1.5.3 The legislative commitment contained in the Carers Strategy was fulfilled when [Sections 8-12 of the Community Care and Health \(Scotland\) Act 2002](#) ('the 2002 Act') came into force in September 2002. The 2002 Act introduced new provisions that enhanced existing legislative duties to help and support carers. The provisions in the 2002 Act:

- give 'substantial and regular' carers an independent right to have their support needs as carers assessed by local authorities, or other agencies under Single Shared Assessment, irrespective of whether or not the cared-for person chooses to be assessed (see Annex B for guidance on the way that 'substantial and regular' is interpreted)
- extend this right to an independent assessment to young carers, aged under 16
- require local authorities to notify those carers they encounter in their day-to-day duties of their potential right to an assessment
- require local authorities to take account of a carer's contribution and views before deciding what services to provide to the cared-for person

- provide Scottish Executive Ministers with the power to require NHS Boards to have an NHS Carer Information Strategy in place for informing carers of their potential right to an assessment.

1.5.4 Scottish Executive Circular CCD2/2003 gives local authorities, NHS bodies and the voluntary sector guidance on effective implementation of all the legislative provisions affecting carers contained in the 2002 Act. The Circular also sets out the background to the requirement for an NHS Carer Information Strategy.

**1.5.5 CCD2/2003 contains important messages for both local authority and NHS staff on effective engagement with carers, particularly in the areas of carer identification and the provision of information to carers. This Guidance must be read in conjunction with Circular CCD2/2003.**

1.5.6 Copies of CCD2/2003 were made available to NHS Boards and local authorities in March 2003. Additional copies can be obtained from:

Angela McLachlan  
 Carers Policy Branch  
 Scottish Executive Health Department  
 Area 2ER  
 St Andrew's House  
 Regent Road  
 EDINBURGH  
 EH1 3DG

Tel: 0131 244 4040

Email: [angela.mclachlan@scotland.gsi.gov.uk](mailto:angela.mclachlan@scotland.gsi.gov.uk)

1.5.7 In addition to the Carers Strategy, key health and social care policies implemented by the Executive in recent years recognise and support the important role played by carers. These include:

- joint working between local authorities, the NHS and the voluntary and private sectors under the Scottish Executive's Joint Future Agenda and the wider Community Planning context.
- the Scottish Executive's Health White Paper "Partnership for Care"
- Patient Focus and Public Involvement
- the development of Community Health Partnerships
- the Mental Health (Care and Treatment) (Scotland) Act 2003
- the Executive's development of new hospital discharge protocols
- integrated children's Social Care Services
- development of Home Care Services
- implementation of "Same as you?" – the Scottish Executive's Review of Social Care Services for People with Learning Disabilities
- free personal and nursing care
- improved access to independent advocacy
- the Scottish Executive's introduction of National Care Standards for Care Homes

- the introduction of Direct Payments for Parents of Children with Disabilities (from June 2003)
- Adults With Incapacity (Scotland) Act 2000
- the Scottish Executive's implementation of the Beattie Committee Report
- "Fair for All"
- The Right Medicine; a Strategy for Pharmaceutical Care in Scotland (2002)

## **1.6 Minority Ethnic Carers: A Policy and Legislative Background**

1.6.1 Two key areas of policy and legislation support and underpin work with minority ethnic carers: Community Care and Race Equality.

1.6.2 The Executive's Carers Strategy placed an expectation on local authorities to consider the needs of minority ethnic carers in the development of services, in accordance with statutory obligations under the Race Relations Act 1976. The passing of the Community Care and Health (Scotland) Act 2002, and its associated Guidance CCD2/2003, added considerable weight to this agenda. The Guidance requires local authorities to consider the different cultural backgrounds of carers, the provision of information in appropriate formats, the need for language and communication support and culturally- competent assessments. It also refers to the need to provide accessible services, to promote race equality and to monitor policies and services in line with the Race Relations (Amendment) Act 2000.

1.6.3 "Fair for All" (Scottish Executive 2002) requires that NHS Boards develop support for minority ethnic carers. An integrated equality and diversity strategy is currently being developed by the Scottish Executive to build on the work of "Fair for All" and to ensure that individuals are able to access services irrespective of their race, religion/faith, sexual orientation, age, disability or gender. In discharging their duties under "Fair for All – The Wider Challenge," NHS Boards should ensure that all relevant policies dovetail with and reference each other to ensure a consistent and cohesive approach.

## **SECTION 2**

### **2. BACKGROUND**

#### **2.1 Who are Carers?**

2.1.1 A carer is generally defined as a person of any age who provides unpaid help and support to a relative, friend or neighbour, who cannot manage to live independently without the carer's help, due to frailty, illness, disability or addiction. The support a carer provides may include moving and handling, help with feeding, personal hygiene and administering medication, as well as providing emotional support, acting as an advocate or guardian for the cared-for person and enabling the person with support needs to access leisure and recreation.

2.1.2 A carer is defined in legislative terms (see Annex A), but for the purposes of this Guidance the wider definition set out above has been applied.

#### **2.2 Carer Statistics**

2.2.1 It is estimated that there are around 600,000 carers in Scotland - 12% of the adult population. Most are aged between 45 and 64. 62% are women. Approximately 50% look after someone over 75, 49% combine caring and employment (either full or part-time). 26% are retired and a further 25% are economically inactive. About 20% spend at least 20 hours a week caring. In Scotland's Census 2001, 115,675 people had caring responsibilities for over 50 hours a week.

2.2.2 The National Census of 2001 identified in Scotland over 16,000 young carers under the age of 18 who are providing care at home. It is thought this figure could be higher, as it is unlikely that the Census identified young carers who care for others as a result of drug/alcohol misuse in the family or care for parents with mental health problems. A recent survey in the Highlands, for example, found that 10% of high school children provide care at home to a relative.

2.2.3 The 2001 Census recorded a minority ethnic carer population of 6,815 which is lower than might be expected if the one in ten ratio used for the majority population is applied. Local data questions the accuracy of Census information and raises the possibility of significant under-enumeration of minority ethnic carers. Carer identification in general is problematic as many people do not recognise their caring role. There are indications that the language and concepts of informal caring may not be well understood within minority communities. For minority ethnic communities, it may also be more difficult to identify carers because of the communities' relative dispersal, the under-development of community services/networks and a lack of engagement with mainstream services and service planners.

#### **2.3 Impact of Caring on Carers' Own Health**

2.3.1 Carers have a right to have their own health and social care needs met. It is well established that caring has a direct impact on both the physical and mental health of carers. Many carers cope well with their caring responsibilities and require little or no support. But carers' needs change, often suddenly and dramatically, and it is vital that carers are identified early on in their caring role and provided with targeted and appropriate information on the sources of advice and help available to them. Early identification, information and support is

critical. Too many ‘hidden carers’ are unaware that support is available until they reach crisis point, a point at which their own physical and mental health is already often damaged. Information enables carers to make early and informed choices about seeking practical and financial support.

## **2.4 Information Required by Carers**

2.4.1 Information that carers need includes:

- information on local and national support services, including short break services/respite, access to support groups, advocacy and counselling
- targeted information on the condition/treatment of the cared-for person
- information and training in moving and handling, administration of medication, feeding, etc
- the availability of financial support through the benefits system
- health improvement information, including information and training on stress management techniques
- local concessionary transport schemes and support to enable them to attend NHS appointments with the cared-for person

2.4.2 The above list is not meant to be comprehensive in any way. In developing an NHS Carer Information Strategy, NHS Boards should identify through discussion with carers and local authorities the information that carers need. It is likely that most local authorities will already have identified these needs. Some NHS Boards are already providing or developing information for carers, by working in partnership with local authorities, carers’ organisations and carers.

**2.4.3 The Executive is committed to ensuring that all carers have access to targeted information that helps to support them in their caring role, and to making this information available as early as possible in the caring role. For that reason, an NHS Carer Information Strategy must apply to all carers, including young carers. NHS Boards are expected under their NHS Carer Information Strategy to ensure that all carers who come into contact with NHS services are identified and provided with such information. This should create a more consistent and strengthened approach to informing and empowering carers.**

## **2.5 NHS Role In Supporting Carers**

2.5.1 Traditionally the lead for supporting carers has been taken by local authority social work departments, although the NHS has a responsibility to work with local authorities to plan, develop and fund local respite services and individual respite packages. As joint working across agency boundaries increases, the NHS will have a progressively more important role to play in supporting carers. Increasingly health and social care services will be provided locally by a wide range of skilled staff working together as a team with other professions and agencies. This multi-disciplinary and multi-partner approach is essential for the provision of local, integrated and improved services to support service users and their carers. The Community Planning process and the development of Community Health Partnerships are key to ensuring that public sector agencies plan services in conjunction with patients, service users, carers and the wider community. It is vital that carers are embraced

within these partnerships at a care management level, and a strategic level in terms of service planning and design.

**2.5.2 The NHS has a vital role to play in identifying carers, offering them information and referring them on to sources of advice and support. That role was recognised in the 2002 Act which provides the legal basis for the introduction of NHS Carer Information Strategies. The NHS also has an important role to play in ensuring that carers' own health needs are proactively addressed.**

2.5.3 Shortly after the introduction of the 2002 Act, the Scottish Executive's White Paper on Health, "Partnership for Care", reaffirmed the need to work in partnership with carers at all levels within the NHS. "Partnership for Care" stressed that staff and professionals throughout the NHS, many of whom are, or will be, carers themselves, must work closely with carers as key partners. It also highlighted the need for NHS staff to be aware of the vital contribution made by carers as well as the needs of some carers for practical support and for training (eg moving and handling skills, the administration of medicine). "Partnership for Care" recognises the importance of carers having appropriate and targeted information about sources of support and advice. It stresses too the need of carers for information that will help them deal with the condition/treatment of the person they care for, whilst recognising and respecting patient confidentiality. The importance of such information to carers of people with mental health problems has already been recognised in legislative terms under the Mental Health (Care and Treatment) (Scotland) Act 2003.

2.5.4 Under this Guidance, NHS staff at all levels will be required to:

- be carer aware – through staff training/induction procedures
- provide carers with targeted information to help them in their caring role
- seek patient consent at all times for the provision of personal information to carers
- provide general information to carers on medical conditions, effects of treatment, etc
- advise carers of their potential right to an assessment of their support needs as a carer
- refer carers on to sources of support and for assessment of their needs
- involve carers as key partners in the provision of care

## SECTION 3

### 3. NHS CARER INFORMATION STRATEGIES

#### Legislative Background

- Section 12 of the Community Care and Health (Scotland) Act 2002 ('the 2002 Act') gives Scottish Ministers the power to require NHS Boards to prepare and submit to them a 'Carer Information Strategy', setting out how the Board will inform carers who appear to them to be 'substantial and regular' of their potential right to an assessment of their support needs as a carer.
- The definition of a carer for the purposes of an NHS Carer Information Strategy and the current legislative position of carers in terms of their right to an assessment are set out fully in Annex A to this Guidance.
- The 2002 Act provides Ministers with the power to specify the date for submitting Strategies, the format and content that a Strategy will take, and the consultation that NHS Boards must undertake in preparing their Strategy.
- This Section of the Guidance sets down the minimum requirements of an NHS Carer Information Strategy, as prescribed by Scottish Executive Ministers. It also gives the timescale for submitting Strategies to the Scottish Executive.

#### 3.1 Purpose of an NHS Carer Information Strategy

3.1.1 The purpose of an NHS Carer Information Strategy is to ensure that NHS Boards create a strategic framework within which the objectives set out below will be delivered. Scottish Executive Ministers expect a Strategy to demonstrate clearly how these objectives will be met and monitored. How this is achieved is a matter for the local discretion of each NHS Board working in partnership with carers, patients, NHS staff, local authorities and the voluntary sector. In partnership with these key stakeholders, NHS Boards must determine which other relevant groups they need to work with to develop and implement their Strategy. Examples of current good practice in local partnership-working to identify, inform and support carers within NHS settings will be set out in Section 4 of this Guidance, which is missing at present and will be produced using the good practice examples provided as part of this consultation exercise. The objective of an NHS Carer Information Strategy is to ensure that:

- NHS Boards work in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups to ensure the identification of carers by staff and professionals at all levels within the NHS.
- NHS Boards work in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups to ensure the effective provision of targeted information to carers at every point of their journey through the NHS. This

information should assist carers in their caring role and be provided by staff and professionals at all levels within the NHS. Effective partnership working should help to minimise duplication of activity across agencies. A Strategy must take into account how and when information is most effectively provided.

- All carers, and not just regular and substantial carers, are identified and provided with targeted information at first point of contact with the NHS.
- Patient consent is sought at all times to enable the provision of personal information to carers. Where tension arises between the needs of carers and patients, the use of independent advocacy should be promoted.
- Where consent for the provision of personal information is not given, carers must be provided with general information on medical conditions, medication, treatment and practical issues relating to care at home and long-term care.
- For patients who are unable to consent through incapacity, practitioners must work with nearest relatives and consider what actions may need to be taken under the Adults With Incapacity (Scotland) Act 2000.
- The Strategy must reflect the requirements set out in the Mental Health (Care and Treatment) (Scotland) Act 2003 around the provision of information to carers. Standard 7 in the NHS QiS Clinical Standards for Schizophrenia requires that carers are informed about the illness, acknowledging the particular needs of mental health carers for information.
- All carers are informed of the potential legislative right to an independent assessment of their support needs as a carer.
- Systems are in place to ensure that carers are formally referred to appropriate sources of support and advice such as local carer organisations or carer centres.
- Young carers are recognised as a distinct group with specific needs, but, over and above that, they are recognised first and foremost as children.
- Carer awareness is mainstreamed as part of the day-to-day activities of NHS staff at all levels, whether employed by or contracted to the NHS.
- Clear, measurable outcomes are delivered for carers in terms of carers being better informed in relation to accessing appropriate support as a result of targeted NHS information.

### **3.2 Content of an NHS Carer Information Strategy**

3.2.1 NHS Boards, working in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups, will be expected to demonstrate within their Carer Information Strategy how the Strategy will deliver the objectives listed in paragraph 3.1.1.

3.2.2 A Strategy must also, as a minimum requirement, set out how the specific requirements in the rest of Section 3 will be addressed locally. The following paragraphs make explicit the need for NHS action in certain areas of service delivery. They also set out requirements for action in key areas such as training, accountability and community involvement.

3.2.3 This Guidance describes the minimum requirements of an NHS Carer Information Strategy. However, local areas are expected to evolve strategies, structures and services to meet local needs. The aim will be to encourage local innovation and commitment to develop approaches that may be applied to other areas, if successful. In developing local approaches and an NHS Carers Information Strategy, it should be remembered that any actions/measures must help to deliver the clear, measurable outcomes for carers set out in Annex C to this Guidance as well as the cultural change described in paragraph 3.8.1.

### 3.3 General Principles

3.3.1 Section 2.5 of this Guidance explores more fully the vital role of carers as major care providers and the need for carers to be recognised and treated as key partners by staff, professionals and consultants at all levels of the NHS. An NHS Carer Information Strategy gives practical effect to some of the elements of partnership-working with carers and has a major role to play in ensuring that carers are better supported. An NHS Carer Information Strategy must clearly set out the following fundamental principles upon which it must be based:

**Action: An NHS Carer Information Strategy must contain:**

- statements of principle about recognising and treating carers as key partners in the provision of care. This statement must reflect the different position of young carers who must be engaged, consulted with and supported but not viewed as key care providers
- a statement of commitment that all levels of the NHS will work in partnership with carers in line with “Partnership for Care”
- a statement which recognises the statutory duty placed on NHS Boards by the 2002 Act in relation to informing carers of their potential right to an assessment and the requirement contained in Patient Focus and Public Involvement Action Plans to have a Strategy that meets the information needs of patients, relatives and carers
- a principle of accessibility, ensuring that information will be provided to carers in a wide range of formats or languages, enabling all carers to access information irrespective of their age, disability, ethnicity or other specific needs
- a statement of intent making it clear that information and support are available and accessible to carers from black and minority ethnic groups, as per the statutory duty placed on NHS Boards under the Race Relations (Amendment) Act 2000 and to meet NHS responsibilities under “Fair for All”
- a statement of commitment to the principles of equality and diversity

### 3.4 NHS Delivery

3.4.1 Carers must receive the same level of recognition and information, irrespective of the area of the NHS they come into contact with. Identification, information provision and referral must happen at the first point of contact with the NHS. This will mean that carers will be offered information at other points in the system but it is essential that the key areas of NHS activity specified in paragraphs 3.4.1 to 3.7.2 deliver the objectives set out in this Guidance.

3.4.2 An NHS Carer Information Strategy must demonstrate clearly to Ministers the mechanisms and processes that will ensure carer identification and the provision of targeted information to carers. It will ensure too that carers are advised of their potential right to an assessment and that carers are referred on to appropriate sources of advice and support by NHS staff, professionals and consultants in all areas of the NHS.

3.4.3 The NHS is undergoing significant change through the introduction of Single System Working and Community Health Partnerships. NHS Boards will therefore be organised in different ways. There may be geographically-based operational areas, (including acute and primary care services). There may be primary care or acute care operating divisions, or other structures in place, together with emerging Community Health Partnerships. NHS Boards must ensure that a General Manager or other Senior Manager is invested with the responsibility of ensuring that all staff in that operational sphere are appropriately informed, trained and equipped to support carers as detailed in the Board's NHS Carer Information Strategy. Frontline service managers in particular have a crucial role to play in this area. The good practice examples which will be available in Section 4 of the final Guidance will highlight how some areas of the NHS have already taken this forward effectively through the creation of specific staff posts dedicated to carers.

**Action: An NHS Carer Information Strategy must:**

- describe the practical steps which will be undertaken to deliver the NHS Carer Information Strategy objectives systematically throughout local NHS provision
- describe how each NHS operating sphere/service and joint arrangements with local authorities and the voluntary sector will support the objectives of the NHS Carer Information Strategy
- identify a lead officer at General Manager or Senior Manager level to promote carer identification and information and with responsibility to ensure effective development and implementation of the NHS Carer Information Strategy. Links with the Patient Focus and Public Involvement Designated Director should be a priority (see 'Accountability').
- identify specific staff within primary care, acute staff and nursing teams to promote carer identification and to take responsibility for the provision of information to carers
- develop strategic proposals to address the identification and information needs of specific carer groups such as young carers and carers from minority ethnic communities
- set out how the Strategy will help to identify and support carers working within the statutory agencies themselves

➤ set out what Boards will do to review and improve internal carer-friendly employment practice

### 3.5 NHS Activity

3.5.1 Research shows that for 4 out of 5 carers, their first point of contact with any statutory agency is with a community-based health service. Research also shows that this first point of contact is generally within a primary care setting, either at a health centre, GP practice or at home. Identifying carers and providing them with information at first point of contact is central to the aim of an NHS Carer Information Strategy. Paragraph 2.4 of this Guidance discusses this issue in more detail.

3.5.2 A wide range of health services have a crucial role to play in ensuring that carers are identified and provided with information at first point of contact. Where professionals/staff are independently contracted, NHS Boards must take a proactive role regarding carer identification, information and referral amongst such professionals/staff and to identify within the NHS Carer Information Strategy how this is being taken forward. Key services include:

- GP Practices/Primary Care Teams
- hospital and community-based pharmacists
- community hospitals
- community assessment and rehabilitation
- psychiatrists
- dieticians
- podiatrists
- community child health services
- community health projects funded by NHS Boards
- school nursing
- community-based health/social care services as part of the Joint Future arrangements being incorporated into the Community Health Partnerships. These will include:
  - council home care/day care/housing services/leisure services
  - older people's services
  - children's services
  - community mental health services (including psychology)
  - learning disability services
  - acquired brain injury services
  - services for people with physical/sensory disabilities
  - rapid response teams
  - drug and alcohol services (addiction services)
  - community-based services provided by the voluntary sector

**Action: An NHS Carer Information Strategy must:**

- demonstrate how NHS Boards are promoting carer identification and the provision of targeted information to carers by GPs and Primary Care staff
- indicate the systems in place to ensure that carers are referred on to sources of advice and support and are advised of their potential right to an assessment. This must demonstrate the link between practice involvement and the new GMS contract Organisational Quality Indicator 9 involving carer identification and referral
- set out how NHS Boards are promoting with community-based pharmacists their role in supporting the Strategy objectives

### **3.6 Acute/Hospital Level**

3.6.1 Each hospital directorate/service must be able to fulfil the requirements set out in this Guidance. A carer's first contact with the statutory agencies could be in any of a hospital's departments/directorates. General Managers /Senior Managers and frontline managers must be identified to implement the Strategy in their area of responsibility (see 'Accountability').

3.6.2 Current guidance from the Executive on joint hospital discharge protocols in both acute and longer-term settings (CCD 9/2003) already requires the full involvement, at all times, of patient and carers in decisions about an individual's care. In the case of planned admissions, discharge planning should be initiated prior to admission. Discharge guidance already requires hospital teams to set out in their protocols the arrangements for involving patients, relatives and carers. This is reinforced by NHS Quality Improvement Scotland's generic standards on 'Safe and Effective Patient Care'. One of the generic clinical governance standards says "Discharge arrangements [should] aim to ensure that discharge planning is a continual process which involves the patient and, where appropriate, their carer, and to encourage effective transfers between different parts of the NHS".

**Action: An NHS Carer Information Strategy must:**

- demonstrate how hospital staff ensure that carers are routinely identified and given targeted information and how staff ensure that carers are referred to appropriate support services and made aware of their potential right to an assessment
- set out how carer identification, the provision of targeted information to carers, carer referral on to sources of advice and support, and advising carers of their right to an assessment is integrated into hospital discharge procedures
- set out how carers will be involved in hospital discharge protocols

### **3.7 Health Promotion/Health Education Services**

3.7.1 In December 2000 the Scottish Executive published 'Our National Health, a plan for action a plan for change'. This emphasised the Health Improvement agenda and introduced the requirement for NHS Boards and their local authority partners to produce a Joint Health Improvement Action Plan for each council area. In working to improve the health of individuals and communities and reducing the need for hospital treatments, Boards must ensure that the health needs of carers are addressed.

3.7.2 Additional health problems can occur as a result of caring. These can be physical, emotional/mental health problems. Provision of services to prevent health problems due to caring are vital. Health staff should actively engage with carers to ensure they look after themselves. They should ensure carers are aware of their right to an assessment of their needs and are aware of the information, training and services that can support them in their work as a carer and prevent their own health deteriorating.

### **3.8 Culture**

3.8.1 An NHS Carer Information Strategy must operate within a shared culture based on partnership-working, team-working, information-sharing and service integration across all levels of the NHS. It must function in partnership with carers, patients, NHS staff, local authorities, the voluntary sector and other relevant groups. Such partnership working is not new. An NHS Carer Information Strategy must be built upon the existing partnerships already created through delivery of the Joint Future Agenda, Joint Health Improvement Plans, Local Health Plans, Local Partnership Agreements, Community Planning, the introduction of Community Health Partnerships and implementation of Patient Focus and Public Involvement. The success of an effective NHS Carer Information Strategy will depend greatly on the quality of these partnerships and joint working arrangements. It will also depend on open and robust accountability.

3.8.2 The introduction of single shared assessments (SSAs) for all community care client groups and the increasing role of health practitioners in conducting SSAs is already leading to new ways of working across health and social care teams. Joint working and joint information-sharing is at the centre of SSA and requires that agreed information-sharing protocols are in place for communicating and consulting with all key stakeholders, including carers.

3.8.3 An NHS Carer Information Strategy must be perceived as an enabler of more effective carer support. The development and maintenance of an effective Strategy will require some realignment of NHS expertise and resources in order to deliver the requirements set out in this Guidance. A Strategy must exist in a shared culture in which both individuals and organisations understand the potential benefits and opportunities of supporting carers.

3.8.4 NHS Carer Information Strategies should be closely linked to local carer strategies, which have generally been jointly developed by local authorities in partnership with NHS Boards. As well as providing the development framework for services to support carers, local carer strategies generally address issues such as carer identification and the provision of targeted information to carers.

**Action: An NHS Carer Information Strategy must:**

- describe how the NHS Carer Information Strategy sits alongside other key policies such as Partnership for Care and within that delivery of Patient Focus and Public Involvement, Joint Future, Community Health Partnerships, Health Improvement
- describe how the NHS Carer Information Strategy sits alongside jointly-developed local carers strategies
- describe how the NHS Carer Information Strategy sits alongside equality legislation, including “Fair for All”, and requirements to implement Race Equality Schemes

### **3.9 Engaging Carers/Communities**

3.9.1 An NHS Carer Information Strategy must be developed using a bottom-up approach in partnership with key stakeholders. NHS Boards must also maintain an effective, formal dialogue with local carers and carer organisations to ensure that the Strategy is working effectively and providing carers with the information they need. This reflects the existing duty on NHS Boards to involve and consult the public on service delivery and the wider public involvement agenda which aims to make public services more responsive and accountable to citizens and local communities. NHS Boards must report to their local communities, through existing networks of patient/user and carer groups and community care forums, on how their views are taken into account in the development of an NHS Carer Information Strategy.

3.9.2 An NHS Carer Information Strategy must be tied in to the wider range of public involvement structures and processes already in place to ensure community engagement in care management and service planning. This will require NHS Carer Information Strategies to work with and inform the wider range of community consultation structures which are being developed to take forward the Community Planning Process. These mechanisms will vary across Scotland but might, for example, include citizen’s panels and forums, area committees, community councils and Social Inclusion Partnerships. Public partnership forums, being developed under Community Health Partnerships will also feed into these local involvement mechanisms, particularly in relation to health improvement. These provide a good opportunity for those working in the health arena to discuss with local partners, including the voluntary sector, how best to streamline and improve local involvement processes, building on good practice and joining up activity wherever possible.

**Action: An NHS Carer Information Strategy must:**

- specify the arrangements for the involvement of carers, carer organisations and other key stakeholders in developing and reviewing the Strategy
- specify the arrangements for the involvement of young carers
- specify the arrangements for the involvement of carers from minority ethnic groups and other equality groups

### 3.10 Training

3.10.1 NHS Health Boards must build on successful local partnership-working so that frontline staff and professionals are trained in carer awareness issues. This should include awareness-raising about the issues for young carers. Training should happen in a range of ways, including induction, joint training and, on-going education and communication in relation to health and social care. Joint learning opportunities must be promoted to increase the awareness of carers' issues within the NHS and also with local authorities and the voluntary sector. The role of the voluntary sector in training provision must be taken into account when developing awareness-raising programmes.

3.10.2 The Executive will support NHS bodies and local authorities to achieve this objective, by seeking to improve carer-awareness training in the graduate training curriculum for health and social care professionals.

3.10.3 In recognition of the need for professionals in the mental health field to work in partnership with carers as key partners, the Royal College of Psychiatrists has already agreed to prepare a code of conduct for professionals on issues relating to carers. From 2005, the College will require post-graduate accreditation to have a carer awareness component to the curriculum, with carer-led training. Section 4 of this guidance, which will appear in the final version, will outline additional good practice currently being undertaken by the College.

#### **Action: An NHS Carer Information Strategy must:**

- include detailed action plans for training of all staff, outlining how carer awareness, carer identification, the provision of information to carers, advising carers of their potential right to an assessment, carer referral to sources of advice and support and working with carers as key partners are being mainstreamed into NHS practice, specifically through induction programmes, pre-qualification professional training, continuous personnel development and professional training and leadership development
- identify proposals for the development and provision of joint training provision for carers, aimed directly at supporting them in their caring role. This must include generic training on moving and handling techniques, stress management training for carers, etc, and training on specific conditions such as caring for someone with dementia, physical disability, mental health problems, special needs, etc
- include specific awareness training on culturally-sensitive issues for carers from minority ethnic communities

### 3.11 Accountability

3.11.1 An effective NHS Carer Information Strategy will require significant and sustained organisational and management development with successful leadership. NHS Boards will be expected to support the development and maintenance of an effective NHS Carer Information Strategy. It will be critical to ensure that there is effective leadership at all levels, but particularly at a senior level in the Board, to ensure that staff are appropriately trained and

aware of the requirement to identify carers, to provide carers with targeted information, to advise carers of their potential right to an assessment and to refer them on to appropriate sources of advice and support.

**Action: An NHS Carer Information Strategy must:**

- identify specific staff responsibilities within primary care, acute staff, nursing teams and main stakeholder groups, including lead officers at a General Manager or Senior Manager level, to promote carer identification and information and to ensure implementation of Strategy objectives
- indicate management and leadership arrangements with front-line staff
- specify functions and services which will be contracted to various key partners, eg, local authorities, voluntary sector organisations

### **3.12 Monitoring**

3.12.1 Scottish Executive Guidance to NHS Boards, local authorities and other key stakeholders on 'Re-Invigorating the Joint Future Agenda', published in March 2004, sets out how the Executive wishes to see the focus of joint working move to improving outcomes for individuals and their carers. The Executive is working in partnership with statutory bodies to move towards an outcome-based approach to monitoring community-based social care services. Outcome measures for carers that can be monitored at a national and local level are being developed for implementation from 2004 onwards.

3.12.2 This Guidance seeks to ensure that a similar focus on outcomes for carers is built into each NHS Carer Information Strategy, particularly through the systematic development and implementation of baseline information, performance indicators and meaningful statistics against which quality improvements for carers can be measured. **The outcomes for carers of an effective NHS Carer Information Strategy are set out in Annex C.**

3.12.3 Under the Patient Focus and Public Involvement agenda, NHS Boards are required to have in place an Action Plan to meet the information needs of patients, relatives and carers. This arose from an existing requirement set out in generic clinical standards on Patient Focus. Monitoring the requirements set out in this Guidance must therefore be built into the Performance Assessment Framework of all NHS Boards.

3.12.4 Aggregate information from carer assessments, including self-assessments, should yield important data on the information and support needs of carers and the extent to which these needs are being met. This in turn will improve strategic planning of services to support carers and lead to better outcomes for carers.

3.12.5 NHS Boards will be required to report annually to Scottish Executive Ministers on how they are implementing and evaluating their NHS Carer Information Strategy, in addition to on-going monitoring under the Performance Assessment Framework.

**Action: An NHS Carer Information Strategy must:**

- provide baseline information against which quality improvements can be measured
- identify joint performance indicators and outcomes for carers
- set out arrangements to monitor and evaluate implementation of this Guidance – setting out auditing and accountability arrangements within the NHS and on a joint basis with local authorities
- set out how monitoring arrangements fit in with accountability to the Executive for other areas such as Performance Assessment Framework, Community Health Plans, Patient Focus and Public Involvement Action Plans, Local Health Plans, Hospital Discharge Guidance, Local Partnership Agreements, etc
- ensure that effective monitoring arrangements are in place to establish accessibility to information for carers from minority ethnic groups, in line with the requirements of the Race Relations (Amendment) Act 2000 and Boards' Race Equality Schemes.
- set out proposals for reviewing the NHS Carer Information Strategy in consultation with carers and other stakeholders

### **3.13 Submitting NHS Carer Information Strategies**

3.13.1 NHS Boards are required to submit an NHS Carer Information Strategy for approval to Scottish Ministers. The NHS Carer Information Strategy must cover the whole Board area and be developed in the context of single NHS systems, the development of joint health improvement plans, and local plans to extend Joint Future partnerships and evolve Community Health Partnerships.

3.13.2 Each NHS Carer Information Strategy must be jointly signed off by the Health Board Chief Executive, the relevant local authority Chief Executive, and a representative acting on behalf of carer groups/organisations operating within the Health Board area.

3.13.3 NHS Boards must formally submit their NHS Carer Information Strategy to Scottish Executive Ministers by [ ]. A Strategy must address all the areas and objectives contained within this Guidance.

3.13.4 Once a Strategy has been approved by Ministers, NHS Boards will have a statutory duty to implement their Strategy within timescales prescribed by Ministers. If a Strategy is rejected because there is insufficient detail or a Board has failed to meet the requirements set out in this Guidance, the Strategy will be returned to the Board with a requirement to resubmit it within a specified timescale.

3.13.5 Once NHS Carer Information Strategies have been set up, NHS Boards will generally be able to extend their functions without resubmitting their Strategy for approval by Ministers. However, if an NHS Board wishes to alter substantially the nature of its NHS Carer Information Strategy, a revised Strategy will require Ministerial approval.

## LEGAL DEFINITION OF A CARER

### Background

In legal terms the definition of a “carer” is tied up with the legislative right of a carer to receive an assessment of their ability to provide, or to continue to provide, care for the cared-for person. The term “ability to provide care” is not meant to infer that there is a value judgement to be made by professionals about the carer’s own ability as a carer. It is intended to ensure that professionals, as part of a carer’s assessment, consider a wide range of factors in determining whether a carer is able (due to health or other considerations) and/or willing to provide care at a particular level.

In law only ‘regular and substantial’ carers are entitled to an assessment of their support needs as a carer. These legislative positions on a carer’s right to an assessment are set out in Section 12AA of the Social Work (Scotland) Act 1968 and Section 24 of the Children (Scotland) Act 1995. These Sections are replicated below. The application of ‘regular and substantial’ is designed to ensure that only carers with substantial caring roles have the right to an assessment, as a gateway to securing practical support from the statutory agencies. ‘Regular and substantial’ has never been defined legislatively. Interpretation of ‘regular and substantial’ has been left to professionals on the ground to decide, based on the individual circumstances in each case and taking into account a wide range of factors. The factors to be taken into consideration were set out recently (March 2003) in Scottish Executive Circular CCD2/2003 which gives local authorities, NHS bodies and the voluntary sector guidance on effective implementation of all the legislative provisions affecting carers contained the 2002 Act. The guidance on defining ‘regular and substantial’ is replicated in Annex B of this guidance, for ease of reference.

The availability of early and targeted information is however important to all carers and not just ‘regular and substantial carers’. Particularly as carers early on in their caring role can benefit in terms of their mental well-being from knowing that support can be available should the caring role become considerable at some later stage. Carers who are not caring on a ‘regular and substantial’ basis may have information/training needs in terms of moving and handling and generally also require information on medical conditions, etc, to help them provide the appropriate care (See Annex B – Preventative Approach).

### Legislative Definition of Carer

**Section 12 AA of the Social Work (Scotland) Act, as amended by the 2002 Act states that:**

(1) A person (“the carer”) who provides, or intends to provide, a substantial amount of care on a regular basis for another person aged eighteen or over (“the person cared for”) may, whether or not the carer is a child,[8.I.6.39] request a local authority to make an assessment (“the carer’s assessment”) of the carer’s ability to provide or to continue to provide such care for that person.

- (2) The local authority to whom the request is made shall—
- (a) comply with the request, where it appears to them that the person cared for is a person for whom they must or may provide, or secure the provision of, community care services; and
  - (b) if they then or subsequently make an assessment under subsection (1)(a) of section 12A of this Act of the needs of the person cared for, have regard to the results of the carer’s assessment—
    - (i) in the assessment of the person cared for; and
    - (ii) in making their decision under subsection (1)(b) of that section as respects that person.
- (3) Subsection (1) above does not apply as respects a carer who provides, or will provide, the care in question—
- (a) by virtue of a contract of employment or other contract; or
  - (b) as a volunteer for a voluntary organisation.
- (4) Section 8 of the Disabled Persons (Services, Consultation and Representation) Act 1986 (c.33) (duty of local authority to take into account abilities of carer in deciding whether to provide certain services to disabled person) shall not apply in a case where a local authority make an assessment, by virtue of subsection (2)(a) above, in respect of a carer of a disabled person.
- (5) Subsections (4) to (7) of section 12A of this Act apply to a local authority making an assessment by virtue of subsection (2)(a) of this section as they apply to a local authority making an assessment under subsection (1)(a) of that section.
- (6) In this section, “community care services”, “disabled person” and “person” have the same meanings as in section 12A of this Act. [section 8(2)]

**For carers of disabled children similar legislative rights around carers assessments are set out in Section 24 of the Children (Scotland) Act 1995 which states that:**

- (1) Subject to subsection (2) below, a person (“the carer”) who provides, or intends to provide, a substantial amount of care on a regular basis for a disabled child may, whether or not the carer is a child,[9.I.7.33] request a local authority to make an assessment (“the carer’s assessment”) of the carer’s ability to provide or to continue to provide such care for the child.
- (1A) The local authority to whom the request is made shall—
- (a) comply with the request, where it appears to them that the child, or another person in the child’s family, is a person for whom they must or may provide services under section 22(1) of this Act; and
  - (b) if they then or subsequently make an assessment under section 23(3) of this Act to determine the needs of the child, have regard to the results of the carer’s assessment—
    - (i) in the assessment of the child; and

(ii) in making a decision as to the discharge by them of any duty they may have as respects the child under section 2(1) of the Chronically Sick and Disabled Persons Act 1970 (c.44) or under section 22(1) of this Act.

(2) No request may be made under subsection (1) above by a person who provides or will provide the care in question—

- (a) under or by virtue of a contract of employment or other contract; or
- (b) as a volunteer for a voluntary organisation.

(3) Where an assessment of a carer's ability to continue to provide, or as the case may be to provide, care for a child is carried out under subsection (1) above, there shall, as respects the child, be no requirement under section 8 of the [1986 c. 33.] Disabled Persons (Services, Consultation and Representation) Act 1986 (carer's ability to continue to provide care to be considered in any decision as respects provision of certain services for disabled persons) to have regard to that ability.

(4) In this section "person" means a natural person.

## INTERPRETATION OF SUBSTANTIAL AND REGULAR

An interpretation of ‘substantial and regular’ is not defined in legislation but guidance to health and social care practitioners on how to interpret it was set out most recently in Scottish Executive Circular CCD2/2003 (March 2003). The section in the Circular is replicated here for ease of reference.

Extract from CCD2/2003

“The 2002 Act builds on the existing concept in the 1968 Act and the 1995 Act, which establishes that carers who provide “a substantial amount of care on a regular basis” are entitled to an assessment. The 2002 Act does not change these terms. As the terms “regular” and “substantial” are not defined in legislation, it is for local authorities to interpret them in relation to individual cases. This approach allows local authorities, in partnership with other agencies, to reach appropriate individual decisions about whether a carer’s particular circumstances make them eligible for an assessment.

Authorities should make public their approach in interpreting ‘substantial and regular’, in consultation with local carers’ representatives. Authorities should consider the merits of developing consistent approaches to interpreting “substantial and regular” in discussion with other authorities and carer organisations.

### **In interpreting “substantial and regular” local authorities should -**

- focus on the impact of the caring role on the individual carer and their family
- address the following questions:
  - is the caring role sustainable without additional support?
  - how great is the risk of the caring role becoming unsustainable without additional support?
- take into account a range of factors, including:
  - the total time spent caring
  - type of caring tasks
  - intensity and pattern of caring
  - cultural background of caring situation
  - distances travelled to and from caring situation
  - number of people being cared for
  - nature of the cared-for person’s needs and their likely duration
  - employment status of carer
  - whether other family members including children are affected by the caring situation
  - age of the carer
  - carer’s physical and mental health

- the history of the caring relationship
- the carer's view
- always take a wide view of the extent and nature of the carer's role as a whole
- take account of situations where the caring role is sporadic and difficult to forecast
- recognise that the carer's role may fluctuate, particularly where the cared-for person has mental health difficulties that recur periodically
- recognise that carers from minority ethnic groups may have different caring patterns (and may be caring in more than one location)
- recognise that the needs of the cared-for person may be unpredictable, particularly where they have drug or alcohol problems
- recognise that carers may also need to combine caring responsibilities with other family responsibilities or activities, including parenting, employment or education
- always ensure carers are aware of how the decision on "substantial and regular" has been reached.

#### Caring at a distance

##### **In interpreting "substantial and regular" local authorities should -**

- think carefully about the interpretation of "substantial and regular" in the context of carers who -
  - travel significant distances to carry out their caring role, especially where a carer looks after more than one person,
  - are caring for someone who uses or could use services in a different local authority area from the carers' own area.
- work in partnership with the other authorities affected.
- develop local agreements for handling such cases (usually the authority where the cared-for person lives should take the lead in assessing the carer).

#### Young carers

##### **In interpreting "substantial and regular" local authorities should -**

- not adopt the same approach in interpreting "substantial and regular" for young carers that they would use for an adult carer in a similar role.
- take account of the impact of the young person's caring responsibilities on their current and future development, as well as their ability to access social, leisure and educational activities.
- take account of the age of the young person and the nature of the caring responsibilities.
- ensure that a child or young person does not have a level of caring responsibility that may undermine their ability to participate in education and leisure and social activities.

- ensure that the cared-for person is receiving sufficient other support so that the young person is not undertaking an inappropriate caring role that might amount to “substantial and regular”.

Older carers

**In interpreting "substantial and regular" local authorities should -**

- recognise that caring is likely to demand more of an older carer.
- ensure they focus on the impact of the caring role on the individual.

Preventive approach.

In many instances, ensuring a carer has early access to advice and practical help will reduce the subsequent need for increased levels of support, and may prevent a future breakdown in the caring relationship.

**In interpreting "substantial and regular" local authorities should -**

- recognise the value of early intervention to sustain carers.

## OUTCOMES FOR CARERS

The Executive is currently developing outcome measures for carers that will provide a clearer picture than has previously been available of what is happening for carers across Scotland in terms of:

- the availability of support services, including respite
- whether carers are being treated as key partners in the provision of care
- whether the legislative provisions for carers contained in the 2002 Act are being met locally
- whether carers are being meaningfully engaged at a strategic level in local service planning and delivery

Building on existing and developing qualitative and quantitative information systems the measurable outcomes for carers of an effective NHS Carer Information Strategy will be:

- carers are identified early at first point of contact with the NHS
- carers are informed of their potential right to an assessment of their support needs as carers under Section 12AA of the Social Work (Scotland) Act 1968 or in the case of young carers under Section 24 of the Children (Scotland) Act 1995
- carers are well informed of the process and procedures of hospital admission and discharge and are fully involved in the decisions taken at these key stages
- carers are provided with targeted information based on a survey of information needs involving local carers. Such information must include:
  - signposting information about sources of local and national support
  - general or specific information on medical condition/treatment in accordance with patient confidentiality
  - for mental health carers specific information on their legislative rights
  - information on the Adults With Incapacity (Scotland) Act, if appropriate
  - information on Direct Payments for parent carers of disabled children
  - information on local forums where carers can input on service planning and development.

**In monitoring the effectiveness of their NHS Carer Information Strategy all NHS Boards must monitor effectively and regularly the impact of their Strategy on local carers, in order to identify whether carers are benefiting and what, if any, gaps need to be filled (see ‘Monitoring’ in Section 3).**