

Introduction of NHS Carer Information Strategy: Draft Guidance

Response from Carers Scotland

Introduction

Carers Scotland very much welcomes the draft Guidance. The scope of the Guidance is comprehensive and the content clearly informed by the views of Carers and carer agencies.

Our comments will hopefully enhance the document. Carers Scotland appreciates the considerable efforts now being made to ensure that Carers' experience of the NHS is a more positive one.

The responses attached are informed by the results of a questionnaire to and discussions with Carers throughout Scotland. The response is framed to offer observations, comment and alternative text and is illustrated by individual comments made by Carers who responded to our questionnaire.

The results of the questionnaire are attached at Annex B.

NHS Boards and Carer Information Strategies: General Approach

Carers Scotland recognises that there is merit in NHS Boards deciding locally how best to implement the Guidance. However, it is essential to ensure that all local strategies are informed by Carers and meet minimum national standards. It is imperative that robust strategies are in place to ensure that Carer Information Strategies are actually implemented in a consistent way to ensure that Carers throughout Scotland receive an equitable level of service, no matter within which Board area they live.

We would recommend that the Executive put in place a time-framed monitoring mechanism to ensure this implementation.

This also ties in with a welcome reference at 3.9 of the Draft Guidance to promoting a “bottom-up” approach towards the involvement of Carers. This has to be tempered, of course, by the reality that NHS Boards are neither locally nor democratically appointed. We should not, therefore, over-estimate the extent to which local strategies could be said to provide a “bottom up” approach to Carer Information Strategies.

The Guidance should be framed in a manner that ensures that NHS Boards comply with it in spirit as well as in letter of the Guidance.

Section 1: Introduction

The description of the relationship between the Guidance and the provisions of the Community Care and Health Act, are very helpful. Also useful is the assurance that the final Guidance will contain a fourth section setting out good practice in identifying and working with Carers. *It is essential that Carers are involved in the identification of such examples of good practice.*

1.1 Who is the Guidance for?

No additional comments on this section

1.2 What is the Guidance for?

No additional comments on this section

1.3 How the Guidance was produced

No additional comments on this section

1.4 Format of the Guidance

No additional comments on this section

1.5 Links with other policies/legislation/guidance

1.5.1 No additional comments

1.5.2 No additional comments

1.5.3 No additional comments

1.5.4 No additional comments

1.5.5 No additional comments

1.5.6 No additional comments

1.5.7 This section identifies the benefits of promoting the use of advocacy. This is consistent with the principles of other legislation including the Mental Health (Care & Treatment) (Scotland) Act 2003. This legislation helpfully promotes the use of independent advocacy and places new duties on health boards and local authorities to ensure that such services are available and appropriate for the needs of their users. *However, it is important to recognise that independent advocacy services for Carers and those they care for are limited in large parts of Scotland (Forth Valley NHS Board area for example).*

1.6 **Minority ethnic Carers: a policy and legislative background**

No additional comments in this section

Section 2: Background

Section 2 helpfully sets out the policy context of the Draft Guidance. It is particularly significant that the Guidance here uses a much wider definition of “Carer” than the legal definition given in Annex A. Importantly, it acknowledges that the information needed by Carers on support services, training, benefits, stress management, concessionary transport, etc may involve services outwith the NHS *per se*. We believe that it is important to stress the role of other services such as housing and civic amenities in joint working arrangements.

2.1 **Who are Carers?**

2.1.1 No additional comments

2.1.2 The term used to describe a Carer within the Guidance - “relative, friend or neighbour” – is not inclusive.

We would suggest that the following definition is instead used. “Carer: a person who looks after family, partners and friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid”. This is consistent with the principles of equality and diversity and also in keeping with the definition used within the National Care Standards.

2.2 Carer statistics

2.2.1 This section describes 25% of Carers as being “economically inactive”. Whilst this may be the category used in government statistics, it is a term which demeans many Carers who are unable to work as a result of their caring responsibilities, particularly given that the work they do is actually saving the state money, rather than draining its resources. Research by Carers UK identified that Carers in Scotland saves the state over £5 billion annually – more than £7,500 per Carer, demonstrating that unemployed Carers are anything but economically inactive.

We recommend that the wording be revised.

2.2.2 No additional comments

2.2.3 No additional comments

2.3 Impact of caring on Carers own health

The acknowledgement of the impact of caring on Carers’ own health is welcomed. Recent research¹ has found that Carers who are heavily involved in caring (115,675 people care for 50 hours or more each week²) have a significantly increased likelihood of their caring responsibilities affecting their own health. For example, compared with non-carers, full-time Carers’ risk of experiencing distress is increased by 60% in women and 40% in men.

2.3.1 *We would suggest replacing “Many Carers cope well with their caring responsibilities and require little or no support” to “Many Carers require little or no support with their caring responsibilities”. This use of the term “cope well” makes a judgement on the individual as opposed to recognising that each Carer’s situation is unique and that those who require additional support may do so because of the intensity of their caring responsibilities or because of additional factors such as age, infirmity or poor health.*

2.4 Information required by Carers

As recognised in the Draft Guidance, Carers need information at key transitions in the caring process, to support them as individuals and in their caring role. The Carers responded to Carers Scotland’s questionnaire identified the most pressing areas in which they felt they needed information, and the findings confirm the priorities of both Carers Scotland and the Draft Guidance.

¹ “Hearts & Minds: the health effects of caring”, Michael Hirst, Social Policy Research Unit, University of York, 2004.

² Scotland’s Census 2001

Carers identified that they needed information at all points in their caring journey. However, they placed specific emphasis on when they first became a Carer and at times of change including hospital admission or discharge and when treatment or medication is prescribed or altered. For example:

- The majority of respondents indicated that when they first become a Carer and/or when the person they care for is discharged from hospital, they need clear information on what support is available and what financial assistance they and the person they care for may be entitled to.*
- Respondents also indicated the need for this information to be discussed when the person they care for is admitted to hospital, alongside information on diagnosis and prognosis. Respondents also noted their wish to be fully involved as key partners in care, with their knowledge of the person they care for being asked for and respected when planning for care both in hospital and after discharge.*
- When treatment or medication is prescribed, respondents indicated that they felt they needed more basic information about how to administer drugs. Over half of respondents commented that they had difficulty in getting the information they needed about the side effects and contraindications of medication.*

Carers Scotland Questionnaire

- 2.4.1 It would be useful to stress that, as well as having factual information about available services, Carers also need to know who to contact to access these services. They need to know that whoever they contact from the many agencies involved will provide them with an integrated information service, rather than pass them from pillar to post.

Additional bullet points along the following lines might therefore be considered:

- Who to contact in the first instance, and who is likely to be the best ongoing source of information and support*
- Who does what?: an outline of key agencies and routes to services and supports with key contacts are their designations.*

We would also suggest amending the final bullet on local concessionary travel schemes to read:

- *“local concessionary and other transport schemes and patient transport arrangements to enable them to attend NHS appointments with the cared-for person”.*

Whilst transport schemes and patient transport services are not within the scope of the Carers Information Strategy, it may be *useful to highlight these issues for future consideration* to ensure that all Carers have access to these services.

2.4.2 We would suggest adding the following at the end of this paragraph:

- *“Local Carer Information Strategies should build on and learn from these existing examples of good practice.”*

2.4.3 We would suggest the addition of *a recognition that young Carers may have different information needs and may need information presented in different formats. Equally there must be a recognition that this different need applies to other groups of Carers, for example, minority ethnic Carers, Carers with a visual or hearing impairment, etc.*

2.5 **NHS role in supporting Carers**

2.5.1 No additional comments

2.5.2 No additional comments

2.5.3 We would suggest *highlighting the fact that Carers are key partners in the provision of care and as such should be involved not only care planning but also in the development of policy and in local planning. Information provided should also include information on how to become involved in these processes at a local level.*

2.5.4 Overall, these requirements are welcomed. *However, further information is needed on how NHS staff at all levels will actually achieve this.*

In addition, we would suggest additional areas should be highlighted:

- *Information sharing should not be solely a one-way process i.e. from the NHS staff member to the Carer. Carers are key partners in the provision of care and it is imperative that NHS staff ask for, listen to, record, value and respect their knowledge and experience of the needs of the person for whom they care. NHS staff should utilise the Carer's knowledge to ensure that the best possible care is provided for the person for whom they care. We would suggest that Boards are encouraged to implement a system to acknowledge, identify and record the information, resources and support that each Carer is providing. Additionally initial assessments should identify with the Carer these resources and services provided to patients or service users by their Carers.*
- One of the few contentious things about the Guidance – in fact more a reflection of the legislation behind it – is the concept of a “potential right” of Carers to an independent assessment of their needs.

“Right” gives the impression of a moral right, and so is perhaps rather difficult to qualify in the way suggested. People either have a right or they don't - witness the contradiction of a phrase like “We hold all these rights to be potentially self-evident”. It is to be hoped that the use of the word “potential” does not impede carers' rights to be assessed.

The larger question regards the fact that far from all Carers have received an assessment within a reasonable time-scale. Although the Executive is only in the process of developing ways to monitor the availability of assessments, there is substantial anecdotal evidence that many Carers are waiting apparently indefinitely. This indicates a problem which neither the Guidance nor its attendant local strategies are going to solve. *The Guidance should, nonetheless, acknowledge this reality, rather than give the impression that Carers' Assessments are more readily available than they actually are.*

Section 3: NHS Carer Information Strategies

Section 3 sets out in helpful detail the required format and content of an NHS Carer Information Strategy. The main concern of Carers Scotland would be to ensure that this aspect of the guidance is phrased strongly enough to represent an enforceable obligation on NHS Boards.

Breaking Section 3 down into its component subsections, the following identifies areas of the Draft Guidance, which Carers Scotland believes would benefit from strengthening in this way.

3.1 Purpose of Strategies

3.1.1 The objectives identified here are all ones that Carers Scotland would strongly endorse. We make comment on each bullet point in order below:

- No comments made in addition to those in section 2
- No comments made in addition to those in section 2
- *We welcome that all Carers are included.*
- *We would again note the limited availability of independent advocacy.*
- This is a very short point for what is a complicated subject. In addition, the term “nearest relatives” may exclude some Carers. *The Act itself refers to “nearest relative and primary Carer” and “relevant parties” and we would recommend using this more inclusive term. Additionally, it may be helpful to identify utilising the experience and knowledge of the Carer in enabling the cared-for person to exercise residual capacity to participate in any decision about their medical treatment.*
- *We welcome this joined up approach to ensuring that all Carers receive information and support.*
- No comments made in addition to those in section 2
- *This is welcomed but an additional mention could be made to acknowledge the need to monitor the outcomes of these referrals.*
- *We would welcome that the needs of young Carers are mentioned specifically.*
- *We would welcome this commitment to mainstreaming Carer awareness.*

We would suggest an additional bullet point to reiterate our point made in 2.5.4, namely recognising that information sharing is a two way process: providing information to Carers and utilising the knowledge and experience of Carers.

Finally, we would recommend insertion of a paragraph encouraging NHS staff carrying out Carers’ Assessments as part of joint working to utilise the “partnership” approach when working with Carers. Carers are key partners in the provision of care not service users. NHS staff should consider the sharing of information to be viewed in the same way in which they would view this sharing with any other partner in the process. NHS staff should also consider this approach when promoting assessments to Carers.

3.2 Content of Strategies

3.2.1 No additional comments

3.2.2 We welcome that minimum requirements must be addressed by each NHS board.

3.2.3 We would recommend that NHS Boards are encouraged to involve all key agencies – not solely health and social services – but including housing and the voluntary sector. In addition, NHS Boards should be instructed, as part of these minimum requirements, to ensure that Carers are involved in the development of their local strategies, structures and services.

3.3 **General Principles**

The principles here again are ones Carers Scotland would endorse, particularly the recognition of Carers as Key Partners and the intent to make services accessible to ethnic minority groups. However, the test of these principles is in their delivery.

3.4 **NHS delivery**

3.4.1 Respondents to Carers Scotland's survey indicated that attitudes to the provision of information varied considerably depending on which service they came into contact with.

However, Carers indicated that many services needed to demonstrate improvement in their attitudes towards providing information. 38% of respondents listed GP services. 32% hospital doctors, 25% community nursing and a significant 64% listed social services.

Carers Scotland Questionnaire

We therefore welcome the commitment to ensuring that Carers must receive the same level of recognition and information, regardless of which area of NHS they come into contact with. *However, we would again emphasise the need that each Board's strategy, whilst responding to local needs, also meets nationally agreed objectives to ensure that Carers in all parts of Scotland receive an equitable service.*

3.4.2 Whilst welcoming the aims detailed in 3.4.1, it is less clear how progress in achieving these aims will be monitored.

A Written Answer provided by former Depute Health Minister Tom McCabe to Christine Grahame MSP on 10 March 2004 indicated the following intentions regarding monitoring:

“The Executive is committed to monitoring the impact of its Carers Strategy, including the new legislative measures to support Carers. From 2004-05 the Executive will be collecting data from local authorities on the numbers of Carers’ assessments being carried out. Other performance indicators and outcome measures will be developed in due course. These are expected to look at the time intervals between an assessment being requested, the assessment being carried out and the provision of services.”

It is essential that explicit benchmarks are provided that state how this monitoring will work in more detail, and how it fits with this Guidance. It would be particularly helpful to see an emphasis on qualitative and not merely quantitative monitoring. There has to be a measurement of the overall experience of the Carer, from their request for an assessment onwards.

3.4.3 We welcome the fact that NHS boards must ensure that senior managers in all structures of the NHS – primary, acute, community health partnership and others – are invested with the responsibility to ensure that all staff are appropriately informed, trained and equipped to support Carers.

Action: We welcome these action points, particularly the identification of specific staff to take responsibility for Carer information. *However, it is less clear whether these members of staff will be publicly identified to Carers, or made available to Carers as a point of contact regarding complaints, etc. Therefore, we would suggest the insertion of the following text:*

- *“Staff given such specific responsibilities should be publicly identifiable to Carers as a point of contact for information and complaints.”*

3.5 **NHS activity**

3.5.1 We welcome the acknowledgement of the vital role that NHS services have in providing information to Carers.

3.5.2 Again, we welcome the recognition that the full range of health services have a crucial role to play.

Action: We welcome these action points but would make specific mention of action point 2 and the key role that general practitioners have in providing information to Carers.

Recent research on Carers' health³ found that over 80% of women and more than 70% of men consult a GP within six months before or after starting to provide care; heavily involved Carers contact GPs more often". *Boards should, therefore, include systems to promote and encourage not only Carer identification and referral by GPs but also the provision of information to Carers.*

Furthermore, research⁴ also recommends that that the take-up of the incentive payment in the GMS contract to introduce a protocol for identifying Carers should be monitored and the level of incentive reviewed periodically. *We would, therefore, suggest that outcome measures also include monitoring and review of the uptake of this critical protocol.*

3.6 **Acute/hospital level**

3.6.1 Again, we welcome the acknowledgement of the vital role that all NHS services have in providing information to Carers.

3.6.2 Whilst we welcome the reinforcement of the requirement that Carers should be fully involved, there is consistent evidence that discharge protocols do not work effectively. *We would recommend, that as part of the systems of providing and implementing their Carer Information Strategies, Boards review their discharge protocols to reiterate that discharge arrangements must involve the patient's Carer.*

3.7 **Health promotion**

These sections make important provisions for Carer identification and the provision of information. We have made suggestions below that may strengthen these provisions.

3.7.1 We welcome that Boards must ensure that the health needs of Carers are addressed. *However, this is a fairly general statement, which should be strengthened.* Recent research⁵ indicates that "the adverse effects of caring on health are, in principle, avoidable and amenable to policy and good practice". It further notes that "early identification of Carers is... important for increasing the effectiveness of health promotion and prevention initiatives." *The research presents a number of key recommendations for policy and practice, which we recommend for inclusion at both Board and national level strategies.* These include:

³ "Hearts & Minds: the health effects of caring", Michael Hirst, Social Policy Research Unit, University of York, 2004.

⁴ *ibid*

⁵ "Hearts & Minds: the health effects of caring", Michael Hirst, Social Policy Research Unit, University of York, 2004.

- Make available low-level health measures - examples include community groups and activities, free flu vaccinations, and alternative therapies to reduce stress. Investing small amounts of resources in Carer support could prevent serious deteriorations and crises in health and wellbeing that might otherwise have costly implications for health and social services.
- Carers' health should be checked at least once a year.
- Carers in the high-risk groups should be counted in local health needs assessment to inform policy development, resource allocation and commissioning of Carer support.
- Explicit recognition of Carers in health improvement programmes could increase their effectiveness and acceptability.
- Health inequalities associated with caring should be monitored at a national level to track the impact of changes in the Carer population, identify emerging needs and inform policy.

Furthermore, we would also suggest the following additions to facilitate addressing Carers' health needs:

- *Boards should establish a framework to provide detail on how this will be achieved.*
- *Boards should develop to ensure that Carers' health needs are routinely recorded.*
- *Boards should attempt to minimise delays in Carers' Assessments by ensuring that joint working is effective.*

3.7.2 The mention here of training Carers is extremely important. *There must be more emphasis on the NHS providing training and confidence-building measures directly to Carers themselves, as well as Carers being given the opportunity to talk about their own health needs. Furthermore, as noted in 3.7.1 measures should not solely address poor health in Carers' but also encourage and support Carers in maintaining their own health and in promoting positive health. Finally, NHS boards should provide detail in their strategy on the development of training for Carers, its content and delivery.*

We have provided comprehensive comment about training implications of both NHS staff and Carers within Section 3.10.

3.8 **Culture**

The need for cultural change in NHS attitudes to Carers is certainly recognised by Carers themselves. *The existing text on this subject could be more specific in places.* In particular, it is difficult to see how culture can change without significant changes in the content and delivery of training to all NHS staff (see Section 3.10).

3.8.1 We welcome the emphasis placed on partnership working. *However, we would reiterate the need to ensure that Carers, as key partners, are involved at all levels, from policy and service planning to service delivery as well as being viewed as full partners in planning and providing appropriate support to the person for whom they care.*

3.8.2 We welcome the recognition that information-sharing protocols should be available for all key stakeholders, including Carers. *However, we would recommend that the principle of Carers as key partners is again reinforced in all strategies to ensure that Carers are seen as integral to, and an equal partner in, effective care planning.*

Furthermore, the assertion in this section is that single shared assessments are in operation “for all community care client groups” needs to be qualified by the reality that large numbers of Carers presently find it impossible to obtain such an assessment. We, therefore, suggest the following insertion:

- *After “community care client groups”, add “(in as far as Single Shared Assessments are being provided).”*

3.8.3 No additional comments

3.8.4 No additional comments

3.9 **Engaging Carers and Communities**

We welcome the actions to involve Carers and would reiterate our comments throughout on ensuring that Carers are involved as key and equal partners in all levels of policy, planning and development. We welcome the recognition of the need to separately specify arrangements to support young Carers, minority ethnic Carers and Carers from other equality groups to be fully involved in the development and review of strategies.

3.9.1 No comments in addition to those above.

3.9.2 No comments in addition to those above.

3.10 **Training**

We welcome the recognition of the importance of staff training in changing the culture in the NHS regarding Carers. *We believe that further work is required to identify how to achieve this at every level of the NHS. We believe that more detailed guidance and resources should be devoted to ensuring that professional training for all staff within the NHS facilitates the required culture change to embrace Carers as an important resource in service provision.*

3.10.1 We particularly welcome the recognition of the need for all frontline staff and professionals to receive specific training. *We would suggest that minimum standards of training be identified to ensure effective outcomes.*

To support the effectiveness of the training, the content should include key elements of effective communication and information delivery, including consideration of the best means of communicating important information.

For example, Carers have indicated preferred options:

Carers indicated in the questionnaire that they needed a mix of face-to-face and written information to feel properly informed. 67% of respondents ranked “face to face” as their first preference – only 3% gave first preference to “by telephone”. However, it is important to recognise that other methods are also needed to ensure that all Carers have equal access to information – for example, one visually impaired Carer suggested providing information on tape or video.

Carers Scotland Questionnaire

3.10.2 We welcome the Executive’s intention to “support these efforts by seeking to improve Carer awareness training in the graduate training curriculum.” However, the phrase “seek to support” is equivocal. It certainly does not amount to a commitment to action, and imposes no new obligations on those who train staff in the NHS. *It is important that this intention is strengthened by specific requirements on those who train staff in the NHS.*

- *We would suggest replacing “seeking to improve” with “improving”.*

We strongly recommend that the final Guidance requires Health Boards to include non-medical staff in their strategies, and stress the practical reasons behind this, for example, receptionists and other ancillary staff.

One of the biggest complaints Carers have is that appointments are scheduled at very short notice or at times they can't make. This is clearly an example of the importance of reception staff understanding better the needs of Carers. As one respondent to the survey commented:

"We have two sons. One is autistic. I have severe pain in my right foot. In May 2003 my doctor referred me to hospital. I am still [October 2004] waiting for an operation. Reason: the hospital has rung twice to ask if I can go in the NEXT DAY for prelims and stay there all weekend for an operation on Monday. I have to explain that we have to give my son 1 week's notice for him to accept I won't be there! There is no system in the NHS for coping with the Carers of autistic kids."

Carers Scotland Questionnaire

Patient transport is another example; whilst the "agenda for change" is ensuring this is becoming more responsive to patients' needs, the needs of Carers must also be recognised.

- *We would suggest adding, at end of 3.10.2, "and in the ongoing training of non-medical staff including reception staff and other ancillary staff."*

We would further recommend that Health Boards ensure that the needs of Carers are taken into account and that they are consulted before important planning meetings are arranged.

3.10.3 We welcome the recognition of the needs for professionals in the mental health field to work in partnership with Carers. We particularly welcome the fact that the Royal College of Psychiatrists will be requiring post-graduate accreditation to have a Carer awareness component. *However, it is important to ensure that all professionals in the field are not only "Carer aware" but are actively encouraged to work with Carers as key partners.*

3.11 **Accountability**

3.11.1 We welcome the recognition that effective leadership and significant commitment will be required to ensure the effective Carers Information Strategies are actively promoted and implemented.

3.12 **Monitoring**

We particularly welcome the focus on outcomes for Carers. Carers Scotland believes that these are critical to the success of NHS Carer Information Strategies. We also welcome the commitment to monitor and review outcomes and would recommend that a framework to achieve this be developed.

Carers highlighted the importance of effective monitoring in the response to the Carers Scotland survey. As one respondent noted:

“Ongoing monitoring and evaluation needs to be conveyed to all partners. Needs careful planning to ensure that Carers’ voices (not just a few) are reflected at all times. Scottish Executive must build in adequate funding if good consultation/feedback/monitoring /evaluation are to be meaningful and effective.”

3.12.1 No comments in addition to those already made

3.12.2 No comments in addition to those already made

3.12.3 No comments in addition to those already made

3.12.4 We welcome the recognition that data from Carers’ Assessments will be recorded and analysed to inform the nature of information made available locally.

We would recommend that this information is publicly and widely available to ensure that Carers in each locality can see clearly how services in their area are responding to their needs.

3.12.5 This recommendation is welcomed. However, we would *reiterate the need to have data publicly available.*

Complaints Monitoring

The Guidance would be enhanced by clarity about the way or ways in which Carers lodge complaints.

We would recommend that current local authority complaints procedures with clear timescales and responsibilities be adopted in conjunction with local NHS boards.

It would also be helpful to have a framework which allows Carers to comment on the extent or otherwise to which local Carers Information Strategies are being effectively implemented.

3.13 Submitting strategies

3.13.1 No additional comments

3.13.2 No additional comments

3.13.3 No additional comments

3.13.4 *Time-scales for submission should be included within this Guidance not only for initial submission but also for any resubmission.*

3.13.5 No additional comments

Annexes to the Guidance

Annex A: Legal definition of a Carer

No additional comments

Annex B: Interpretation of substantial and regular

No additional comments

Annex C

Carers Scotland welcomes the outcome measures for Carers. *However, we would recommend that the outcomes are strengthened and reinforced by our comments at 3.8.1 and 3.8.2 to ensure that Carers are fully treated as key partners in the provision of care.*

Secondly, this annex notes the provision of “information for direct payments to parent Carers of disabled children”. *It would be helpful also to mention that direct payments also apply to other categories of Carer in this context, such as Carers with a Power of Attorney or guardianship under*

the Adults with Incapacity Act. This is important to ensure flexibility and choice for both the Carer and the cared-for person.

Conclusions

In conclusion, Carers will welcome the publication of this Guidance, particularly because it is clearly informed by the views of Carers and carers' agencies, and provides a sound basis to ensure that Carers play a full and effective part in shaping and informing local strategies and service delivery.

The test will be the extent to which Health Boards embrace the Guidance as an opportunity to reshape services in an inclusive and holistic way; and, as the vehicle to ensure that Carers have access to the networks of information and support to make them effective and equal partners in the delivery of care.

Notwithstanding the generally positive aspirations of the NHS Carers Information Strategies, many carers have clearly yet to be convinced that they have access to the information to enable them to be key partners in providing care.

A straw poll of the mixed audience of Carers, service providers and voluntary bodies when asked if there was evidence that Carers were being treated as key partners in the provision of care, made the following response: 27% said yes, 59% said no and 14% didn't know.

Carers Scotland conference on Carers Health, October 2004

The challenge now is for Carers and service agencies to work together to make the Guidance the driver for positive change and better outcomes for Carers and the people for whom they care.