

# **External Review of the National Carer Organisations (NCOs) in Scotland**



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## Executive Summary

This report presents the findings of a review of the National Carer Organisations (NCOs) in Scotland, carried out by Reid Howie Associates for the Scottish Government between November 2013 and June 2014. There are seven NCOs:

- Carers Scotland.
- Carers Trust Scotland (formerly known as the Princess Royal Trust for Carers).
- Coalition of Carers in Scotland (the “Coalition”).
- Crossroads Caring Scotland.
- Minority Ethnic Carers of Older People Project (MECOPP).
- Shared Care Scotland.
- The Scottish Young Carers Services Alliance (“The Alliance”).

The aims of the review included: examining options for the reform of NCOs and the NCO Network; considering a shared vision and workplan; and making recommendations about the interface between the Network and other relevant organisations, as well as potential criteria for inclusion as an NCO. The associated objectives were to help achieve: the optimum outcomes for carers; the most efficient and effective use of resources; and the optimum outcomes to ensure that the Scottish Government Carers Policy Branch and the NCOs best serve each other.

## Findings

The review identified that the NCOs represent a diverse group in terms of structure, size and areas of work. The NCOs come together as a “Network” (which was established in 2006, with the adoption of Terms of Reference). The broad purposes of the Network are set out in terms of: collective leadership for planning, development, monitoring and evaluation of policy and legislation; the promotion of effective working with the Scottish Executive (now Scottish Government); and the creation of collective responses to consultations and policy developments. Later, the Network agreed a shared vision, drawing from the 2010 National Strategy “Caring Together”:

“it is our shared vision that all Scotland’s unpaid carers will feel valued, included and supported as equal partners in the provision of care.”

The Network, as well as individual NCOs, adopted both the national carer and young carer strategies, and in particular the five key carer outcomes.

In 2013, Network members agreed that its work should be focused on four main areas: research; policy; engagement; and services. These have been described as the “four pillars” of the NCO Network. Criteria for membership were also agreed, including that organisations should be: national, and with at least a base in Scotland; have a primary focus on carers; third sector; and have a commitment to work with others to further the vision of the Network.

The NCO Network has no formal status, and cannot apply for funding in its own right, although, in a number of cases, an individual NCO has acted as host organisation for

a “Network” project (including, for example, the Alliance and the NCO Carer Training Consortium, which are hosted by Carers Trust Scotland). It has no office bearers. Staff time to work on Network business is, in effect, donated by individual NCOs. The allocation of time is generally not fixed, but varies depending on the work required.

The Network meets approximately monthly, although it is clear that there is a significant volume of correspondence between members between meetings. Meetings are chaired by rotation, or by the host NCO. Administrative support is largely provided by Carers Scotland on a voluntary basis. In 2013, two sub-groups, Policy and Research, were formed.

The Network has no formal strategy or action plan, and its work is agreed and allocated by mutual consent, either at meetings or via email. As part of its Terms of Reference, the Network agreed a mode of operation which allows any NCO to act on behalf of, or represent the Network with agreement of members.

The work undertaken by the Network is extensive, and covers each of the four areas (or pillars) mentioned earlier. It is described in detail in the main body of the report.

The review found little evidence of duplication in terms of “national” work carried out by individual NCOs. The only exception to this was in relation to information provision, where there appeared to be a lack of a coherent overall approach. In addition, there was found to be no obvious single source of information on carer issues at a national level, nor comprehensive means of signposting carers to local forms of support.

Contact between carers and the NCO Network was found to be largely through local carer organisations. In turn, contact with local carer organisations was found to be largely through individual NCOs, with onward reporting to the Network.

The research identified that a wide variety of other organisations work with, or interact with carers and carer organisations, including statutory services (particularly local authorities and the NHS) and a variety of voluntary organisations, some of which have a focus on specific conditions or groups. A range of examples were identified of ways in which the NCO Network has worked with other types of organisations, including the development of strategies, the identification of needs, the specification of services and the development of good practice. Contact with non-carer organisations was found to be largely through individual NCOs.

The review found that the prevalent view of the work of the NCO Network was largely positive. A range of benefits of the Network were identified, including providing a national voice for carers and carer organisations, and promoting a joined-up approach and good practice, as well as many benefits relating to the nature and value of the specific work undertaken.

Some concerns were also identified, however, and these related both to aspects of the work and aspects of the structure of the Network, as well as to the interface between national and local organisations. For example, the Network was found to lack an overall strategy and action plan to guide its work in relation to achieving the national carer outcomes, as set out in the national strategy. It was also found to lack

a strategic approach to particular aspects of its work (e.g. representation of carers; links to carers and other organisations). This, in turn, makes the work less transparent and accountable, and may mean that the specific issues facing some groups of carers are not identified or addressed. There is also a relatively weak “brand” and a lack of clarity about the extent to which campaigning can take place without impacting on funding. There are also aspects of specific types of work which the review findings suggest could be strengthened and developed.

In terms of structure, there are some concerns about the mix and number of participants; anomalies in participation; the criteria for participation; and the suitability of the structure for the current challenges. A range of concerns were identified about whether the current informal, “goodwill”-based model would be capable of supporting necessary future development. There were also some concerns about the current means of funding national work (as “piecemeal”), and about the heavy reliance of most NCOs on Scottish Government funding.

There was, however, a virtual consensus that there was a need for national work on carer issues. A range of cross-cutting issues were identified which would benefit from a co-ordinated approach, and which would be more efficiently and effectively done nationally, rather than by individual NCOs or local carer organisations. However, it was also recognised that much of the work to support carers needed to be done at a local level, by local organisations.

A number of common themes were identified in relation to the key purposes of a future NCO body. These were: to improve outcomes for carers; to promote carers’ rights; to provide a voice for carers; and to improve support for carers. Allied to this, the review findings suggest that the future work of an NCO body should focus on five areas, relating to these key purposes, and building on its current strengths. These are: policy development; research and oversight; developing capacity and practice; communication; and national level services.

It was highlighted that, in order to ensure that this work can be taken forward, there is a need for a professional, well-resourced national NCO body. The review identified a range of structural options, and made suggestions relating to these, as well as to the development of the NCO body’s work and the overall approach to future funding. These should help address the concerns identified, and ensure that the NCO body will be best-placed to meet future challenges.

## **Recommendations**

The review identified 5 recommendations. These were:

### **Recommendation 1: The NCOs should develop a clear strategy and action plan for the NCO body. This should include:**

- Its overall purpose and vision.
- Aims and objectives.
- Key principles.
- Areas of work and overall responsibilities.
- Key priorities, tasks and responsibilities.

- Links to carers and organisations.
- The planning cycle and timescales.
- Mechanisms for monitoring and reporting.

**Recommendation 2: The NCOs should give careful consideration to developing a more formal partnership in order to begin to address the issues raised in the review, increase effectiveness and provide a platform for further development in the future.**

**Recommendation 3: The NCOs should consider further development of equalities work and comprehensive representation of carers, broadening the focus of specific work from BME and young carers to include other groups of carers facing particular issues as a result of their circumstances (including those in rural areas), and taking a more strategic approach to representation overall.**

**Recommendation 4: The NCO body should consider the development of some consistent, high level national information and provision of this through a single point of access (e.g. shared website).**

**Recommendation 5: The current mechanism used by the Scottish Government to fund national level work with carers (unlimited separate bids to Section 10) should be reconsidered.**

## **SECTION 1: Introduction and background**

1.1 This report presents the findings of a review of the National Carer Organisations (NCOs) in Scotland. The work was carried out by Reid Howie Associates for the Scottish Government between November 2013 and June 2014.

1.2 The report is in 5 sections. This section describes the overall context for the review, and summarises the methodology. Section 2 presents the findings relating to the work of the NCO Network. Section 3 describes perceptions of the Network, while Section 4 summarises suggestions for the way forward. Finally, Section 5 summarises the key conclusions and recommendations which can be drawn from the findings. Annexes contain: a description of support available to carers in Scotland; a summary of the work of each individual NCO; issues relating to potential structures for the NCO Network; and an overview of the research methodology.

### **Background to the research**

1.3 The review of the seven NCOs in Scotland followed a commitment by the then Scottish Minister for Public Health, and built upon an initial scoping exercise by the Scottish Government's internal consultancy team. The main purposes were to:

- Examine options for the reform of NCOs and the NCO Network (a national grouping bringing together the seven NCOs<sup>1</sup>) from, at one end of the spectrum, remaining with the current set up to, at the other end, recommending a full merger of two or more NCOs.
- Consider a shared vision and workplan around the outcomes for carers that the NCOs want to achieve.
- Make recommendations about the interface between the NCO Network and other relevant organisations, as well as about potential assessment criteria for inclusion as an NCO.

1.4 Related to these aims, there were a number of objectives, which were that the recommendations made should help to achieve:

- The optimum outcomes for carers.
- The most efficient and effective use of resources.
- The optimum outcomes to ensure that the Scottish Government Carers Policy Branch and the NCOs best serve each other.

1.5 The seven NCOs in Scotland<sup>2</sup> are:

- Carers Scotland.
- Carers Trust Scotland (formerly known as the Princess Royal Trust for Carers).
- Coalition of Carers in Scotland (the "Coalition").
- Crossroads Caring Scotland.
- Minority Ethnic Carers of Older People Project (MECOPP).

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<sup>1</sup> The national grouping is referred to in this report as the "NCO Network", as this is consistent with the terminology used in its Terms of Reference

<sup>2</sup> These are listed alphabetically.

- Shared Care Scotland.
- The Scottish Young Carers Services Alliance (“The Alliance”).

1.6 The overall role of the NCOs can be summarised as being to aid the delivery of the Carers<sup>3</sup> and Young Carers strategy documents<sup>4</sup>, and to ensure that the organisations are operating effectively and efficiently to support policy relating to carers, and carers themselves. While the main focus of the review was on the NCO Network, it was impossible to undertake this without considering the work of the individual NCOs. This helped to provide an overall picture of national support to carers, and the detailed findings relating to the individual NCOs are presented in Annex 2. The main sections of the report focus on the Network.

### **The context for the report**

1.7 For around 15 years, there has been a clear and increasing focus on the needs and issues experienced by unpaid carers and young carers in Scotland. The key milestones are outlined briefly below, along with some of the key current developments, in order to set the review in its wider context. Firstly, however, it is important to clarify the terms used in the review. The definition of “carer” (from “Caring Together”) is as follows:

“Carers provide care to family members, other relatives, partners, friends and neighbours of any age affected by physical or mental illness (often long-term), disability, frailty or substance misuse. Sometimes the cared-for person will have more than one condition. Some carers care intensively or are life-long carers. Others care for shorter periods. The carer does not need to be living with the cared-for person to be a carer. Anybody can become a carer at any time, sometimes for more than one person. Carers are now, and will remain, fundamental to strong families and partnerships and to resilient and cohesive communities.”

1.8 The definition of a “young carer” (from Care 21) is as follows:

“A child or young person aged under 18 who has a significant role in looking after someone else who is experiencing illness or disability.”

### **Strategy and policy**

1.9 The first step in developing a clear focus on carers and young carers was the publication of a Strategy for Carers in Scotland (Scottish Executive, 1999). A subsequent key development was the publication of the Care 21 report in 2006<sup>5</sup>, which set the foundations for a considerable expansion in support for unpaid carers.

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<sup>3</sup> Scottish Government (2010) *Caring Together: The Carers Strategy for Scotland 2010 – 2015* Edinburgh: Scottish Government

<sup>4</sup> Scottish Government (2010) *Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015* Edinburgh: Scottish Government

<sup>5</sup> Care 21 / OPM (2006) *The Future of Unpaid Care in Scotland* Edinburgh: Scottish Government



1.10 Two strategies, published in 2010 ( “Caring Together” and “Getting it Right for Young Carers”)<sup>6</sup> set out a vision and actions to achieve better outcomes for adult and young carers. These are central to this review, and are that carers will:

- Have improved emotional and physical wellbeing.
- Have increased confidence in managing the caring role.
- Have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside of caring.
- Not experience disadvantage or discrimination, including financial hardship, as a result of caring.
- Be involved in planning and shaping the services required for the service user and the support for themselves.

1.11 Since 2010, the Scottish Government, through the NCOs, the NHS and local authorities, has invested significant sums in work towards achieving these outcomes. This has included investing in diverse areas such as: support to help organisations of and for carers; emotional and other support for carers; training; and the establishment of funds to support short breaks (and promote innovation in these).

1.12 There have also been developments in other policy areas which impact on carers, including, for example, Self-Directed Support and the integration of health and social care. Evidence from NCOs and carer organisations suggests that many carers have faced challenges as a result of reductions in local authority services and changes in, for example, prioritisation criteria. Carers have also experienced the impact of aspects of UK welfare reform. There have also been developments in policy and support for groups who may require care (e.g. people with dementia, people with learning disabilities and disabled children).

1.13 There is now a complex “system” of support for identified carers, with many organisations providing this, including some NCOs, Carer Centres, GP surgeries, social work services and, increasingly, condition-specific organisations. There is also information and support via helplines, the internet and social media. Annex 1 summarises this support, helping to set the review in its wider context.

## **Other developments**

1.14 At time of writing, there is considerable work taking place. The Statement of Intent, issued by the Scottish Government to coincide with the second Carers Parliament, set out a number of additional measures to support carers, including:

- Giving carers access to an assessment on the same basis as other service users.
- The potential for a duty on public bodies to support carers linked to eligibility criteria.
- Improved access to information and advice.
- A consultation on carers’ legislation.
- Improvements to the status of carers as equal partners in the shaping, planning and delivery of support and wider strategic decisions.

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<sup>6</sup> *Op cit.*

1.15 Previously, the Government identified a number of other initiatives, including:

- Advocacy for carers.
- Improving information for carers (e.g. through the implementation of Care Information Scotland and other means).
- Removing the potential for carers to have to pay for support for themselves.
- Changing the ways cared for persons can employ family members.
- The enactment of the Public Bodies (Joint Working) (Scotland) Act 2014, in relation to the functions of local authorities and Health Boards.

1.16 There have also been significant developments through the Children and Young People (Scotland) Act 2014, and in support to young carers (e.g. improved awareness among health, education and social care services of issues for this group, and the ability to recognise and support them). Some of the support has been made available directly to young carers (e.g. short breaks, social and emotional support, and events such as the Scottish Young Carers Festival). Some initiatives mentioned earlier are also either ring-fenced for, or available to young carers.

1.17 There have also been changes to local services. There is evidence of increasing pressure on unpaid carers through the rationalisation of support to cared-for persons (e.g. through tightening of eligibility criteria for some services). More widely, welfare reform is having a significant impact on carers, directly and indirectly.

1.18 The Scottish Government has recognised the need to continue to promote change, to improve outcomes for carers and to ensure a more consistent approach across Scotland. The First Minister indicated an intention to strengthen and extend the rights of carers and young carers at the Carers Parliament in October 2013. At the time of this review, the Scottish Government was undertaking a consultation on legislation to further support carers and young carers in Scotland (which closed on 16<sup>th</sup> April 2014). Responses were being analysed when this review report was being prepared, with a view to publication in early 2015.

### **The overall importance of issues for carers and the need for the review**

1.19 These developments illustrate the importance of carers' contributions to the delivery of health and social care and the need to ensure that the support provided to them is as efficient and effective as possible. The Scottish Government estimates that there are over 650,000 unpaid carers in Scotland, and 100,000 young carers (and is currently analysing all of the main Scotland-wide sources of data with a view to publishing revised information). There are also many "hidden carers".

1.20 Against this background, the work of the NCOs and the NCO Network was examined. The review gathered a range of information which, in summary, included: documentary information; interviews and group discussions with a range of stakeholders; and a written "consultation" with two strands (one involving carers and those working with them; the other involving relevant organisations). The full methodology is described in Annex 4. The remainder of the report provides the findings and implications of the review.

## **SECTION 2: The work of the NCO network**

2.1 This section deals with the operation of the NCOs as a group (the main focus of the review). The current group is referred to here as the “NCO Network”<sup>7</sup>.

### **The development of the National Carer Organisation “Network”**

2.2 It was clear from staff discussions during the review that carer organisations (at a national level, and larger local organisations), had met and worked informally together for many years. In the early period, this was ad hoc, with no regular pattern of meetings. By the mid-2000s, however, a de facto grouping had coalesced around the national carer organisations<sup>8</sup> and a decision was taken to develop Terms of Reference. These were agreed in August 2006, and remain current.

2.3 These set out the basis of what was then described as the “Network of National Carer Organisations”, stating that it would comprise “representatives from National Carer Organisations or Forums that have a direct focus on carers”. Rather than listing membership, examples of such organisations were given, with others able to attend by invitation only, subject to the agreement of all members. The Terms of Reference also set out the basis on which the Network would meet, how chairing would be shared, and how voting (if required) would be managed.

2.4 The purposes of the Network were identified as follows:

- Through joint working, [to] exercise collective leadership for planning, development, monitoring and evaluation of policy and legislation affecting carers.
- To promote effective inter-agency working with the Scottish Executive<sup>9</sup> and across all sectors.
- To agree where possible, collective responses to consultation and policy developments, while safeguarding the right of individual organisations to represent the interests of carers and their organisation.

2.5 The Terms of Reference also set out the basis upon which work would be undertaken on behalf of the Network, as being to:

- Ensure that the NCOs are aware they are working in such a capacity and that any involved third party (e.g. Scottish Executive, Ministers, and MSPs) is also aware of the member's role at that time to promote the group's collective view.
- Keep the NCOs informed of the progress and outcome of such activities.
- Wherever possible, ensure that each of the member organisations receive 'equal billing'.

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<sup>7</sup> The NCOs themselves do not have a consistent approach to terminology for the group.

<sup>8</sup> The current group, excluding MECOPP.

<sup>9</sup> Now the Scottish Government.

2.6 Although the Terms of Reference document was not “live” (in the sense of being regularly reviewed or updated) there was strong agreement among the NCOs and other stakeholders that it accurately described the current Network. Since 2006, however, the NCOs have sought to clarify the Network’s structure and work further.

### **Visions and outcome paper**

2.7 In 2012, the NCO Network agreed a vision and outcomes in the light of the implementation of the National Strategy from 2010. The vision stated:

“It is our shared vision that all Scotland’s unpaid carers will feel valued, included and supported as equal partners in the provision of care.”

2.8 Consistent with the partnership approach in the National Strategy, the Network agreed to adopt all of the outcomes set out both for adult and young carers. Two additional outcomes for adult carers were offered “to consider”. These were to:

- Be better informed about issues linked to their caring role.
- Be more confident in their ability to contribute to and shape local and national policy developments.

2.9 Of most direct relevance to the current review, however, was the articulation of how the NCO Network would work to achieve the vision and outcomes. For adult carers, the Network committed itself to:

- Raise the profile of carers as providers of care and equal partners in care.
- Identify key issues affecting carers and young carers in Scotland, bringing these to the attention of relevant decision makers in local and national government.
- Strengthen carer engagement in the development of local and national policy.
- Strengthen carer engagement in improving service provision at all levels.
- Promote good practice through research, practice exchange and development projects.
- Make and maintain connections between carers, carer-led organisations and national and local decision makers.
- Measure the impact of local and national policy relating to carers; holding those responsible to account where it fails to deliver on implementation.
- Campaign to make life better for carers and young carers.

2.10 For young carers, the Network agreed that carer-led organisations would commit themselves to<sup>10</sup>:

- Be more confident in their ability to explore issues, analyse developments and identify key issues confronting carers and young carers in Scotland.
- Be more confident in their ability to contribute to and shape local and national policy developments.
- Benefit from stronger links with key decision makers at a local and national level.
- Be better informed of examples of best practice, which can be replicated in their localities.
- Feel supported in highlighting gaps in the provision of local services, including gaps in the provision of short break services.
- Be more confident in their ability to monitor local and national policy developments and implementation.

2.11 Again, drawing on the National Strategy, the NCO Vision and Outcomes paper indicated that other key partners would:

- Recognise carers as equal partners in care, reflecting this in policy and practice at all levels.
- Have a better understanding of the key issues affecting carers and young carers.
- Have stronger links with carers and carer-led organisations
- Be better informed of examples of best practice in relation to the provision of carer support services.
- Be better informed of gaps in the provision of local services, including gaps in the provision of short break services.
- Be better informed of the impact of local and national health and social care policy for carers and young carers.

### **NCO development event**

2.12 In January 2013, the NCOs held a planning session, led by an external facilitator, to review the operation of the NCO Network and consider its structure. The notes from the meeting<sup>11</sup> were agreed subsequently and adopted as the basis of a forward plan. Those who attended suggested that the session was pivotal in the Network's development. Although the output document was left unfinished, and did not appear to have been revisited since 2013, it was referred to regularly in the review as being the basis of recent work.

2.13 The 2012 priorities were reiterated, with an overall priority of "making a difference to carers' lives". It was agreed that the work of the NCO Network should focus on "four pillars": research; policy; engagement; and services. This was viewed as a clearer framework for the work of the Network and its individual members (rather than a significant shift), and was seen to be consistent with the Terms of

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<sup>10</sup> It is worth noting here, however, that a number of members of the Young Carers Services Alliance are not themselves carer-led organisations.

<sup>11</sup> Notes of the NCO Development and Planning Event (2013).

Reference agreed in 2006, as well as the aims and objectives of individual members. The document set out examples of the work being undertaken by the Network in three of the four “pillars” (with the exception of “services”).

2.14 A further outcome of the planning session was an agreement to create two "standing" sub-groups: research; and policy. Terms of Reference for each were agreed subsequently. It was agreed (and remains the case) that those with a specific interest or expertise in an area would be nominated (rather than each organisation having a sub-group member by right). This was seen as consistent with the operating principles, whereby any individual member could act on behalf of the Network (and, by extension, organisations could delegate their interests to a sub-group). In practice, the sub-groups appear to have considerable delegated authority (e.g. being able to issue materials without the explicit agreement of all of the NCOs).

2.15 The planning event also developed a set of criteria for members. These were:

- [A]<sup>12</sup> national organisation (with at least a base in Scotland) or a national forum.
- [Having a] primary focus on carers.
- Voluntary sector.
- [Having a] commitment to work with other carer organisations to further the vision of the NCO.

2.16 A decision was taken that no new invitations should be issued to join, but that members should review NCO partnerships and alliances in the light of the event. The relationship between the Network and the Scottish Government was also reviewed, and a key action point agreed that the Network should “maintain the mutually beneficial open door relationship” existing with the Government.

### **The status and current work of the NCO Network**

2.17 The NCO Network has no current formal status, being an aggregation of organisations coming together for a common purpose. As such, it is unable to apply for funding in its own right, and could not enter into a legal agreement. There are no office bearers, and chairing of individual meetings is undertaken either by the host organisation (i.e. the provider of the venue), or by rotation. Neither sub-group has a nominated chairperson, nor convener. Administrative support is provided on a voluntary basis (largely by Carers Scotland, but also by others). The Network has adopted a visual identity (a graphic with the seven organisations’ logos) for the purposes of, for example, replying to Scottish Government consultation documents.

2.18 In a number of cases, individual NCOs have acted as a host employer for the Network. For example, the Carers Trust performs this function in relation to the Alliance, and a similar arrangement exists for channelling Scottish Government monies for the NCO Carer Training Consortium. This can also be the case for projects undertaken on behalf of the Network, with Carers Scotland, for example, organising the Carers Parliament on behalf of the Scottish Government. In this respect, Carers Scotland, as a legal entity, has been able to enter into contracts (an option which would not be available to the Network).

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<sup>12</sup> Minor additions to improve readability.

2.19 The specific work of the Network (in the four “pillars”) is described below.

## **Policy**

2.20 The development of policy (directly and indirectly) was identified in the review as being a key function of the Network, encompassing a number of strands.

### Policy development relating directly to carers

2.21 The NCOs have played a significant role in the development of the national carer and young carer strategies, participating in, for example: preparatory research, developing carer outcomes, and identifying proposals. Although the NCO Network was not itself a formal signatory to the strategies, it (as well as individual NCOs) has also been closely involved in taking them forward and has, through individual NCOs, received a range of funding to deliver some of the proposals (e.g. relating to carer training and developing short breaks). It should be noted that the NCOs also undertook strategic policy work prior to these strategies and, for example, individual NCOs were involved in the first national strategy in 1999, and the NCOs and some larger Carer Centres were involved in the Care 21 report.

2.22 The NCOs (although not the Network), are members of the Carer Implementation Group, set up to provide oversight of progress towards the achievement of the outcomes in the national strategies. Many local areas also now have carer and young carer strategies (building on the national approach) and it was noted that the NCO Network sometimes contributed to the development of these.

2.23 The NCO Network has also been directly involved in policy development in a number of other areas specific to carers. In some cases, this has been undertaken by individual NCOs supported, and / or taken forward by the Network. Examples include work on the Employers’ Kitemark (by Carers Scotland) and the development of Best Practice Standards for Carer Engagement (by the Coalition). The NCO Carer Training Consortium has developed quality standards for carer training, currently being promoted across local organisations. Shared Care Scotland has led on the development of a wide variety of policies relating to short breaks, generally supported by other NCOs. Such policy work by individual NCOs is considered relevant to the Network as a whole, and is discussed at NCO Network meetings.

2.24 The roles of the Young Carers Festival (organised by the Alliance on behalf of the Network) and the Carers Parliament (run for the past two years and organised by Carers Scotland on behalf of the Network) in national and local policy development were also identified by a range of stakeholders.

### Policy development in other relevant areas

2.25 Individual NCOs, acting on behalf of the Network, have also contributed to a wide range of other working groups, work streams and forums in other relevant policy areas. This has involved both written submissions, and individual staff members from NCOs attending meetings. A number of these policy areas have related to proposed Scottish Government legislation. The NCO Network, for example, contributed to the development of Self-Directed Support (SDS) policy (in early discussions on the potential shape of the legislation, at the drafting stage, and

in detailed consideration of specific issues such as charging). It also facilitated wide-ranging consultation on the draft Bill. Following enactment, the Carers Trust (on behalf of the Network) developed a guide for carers.

2.26 A range of other policy areas were identified where individual NCOs, acting on behalf of the Network, were seen to have made significant contributions. These included particularly the integration of health and social care and joint commissioning, but also other areas such as housing. The Network (as well as individual NCOs and local carer organisations) has been closely involved in the development, implementation and monitoring of Carer Information Strategies, led by the NHS. It has also contributed to policy relating to specific conditions (e.g. by highlighting carers' issues relating to dementia and autism). More generally, the Network has contributed to proposals for reshaping services for older people.

### Briefings

2.27 The Network, through its policy sub-group, has prepared a number of briefings on a range of policy issues including, for example: benefits issues; housing issues; welfare reform; SDS; and the potential impact of the independence referendum on carers and carer organisations. It has also developed briefings on both Scottish and UK budgetary matters as these relate to carers and carer organisations. Most of the briefings have been targeted at carer organisations and others working with carers (and individual carers), but a number have been prepared specifically for MSPs or Scottish Ministers. In this context, the Network has also made a range of contributions to the cross-party group on carer issues within the Scottish Parliament.

### Lobbying

2.28 In some cases, the NCO Network and its members have directly undertaken lobbying. In other cases, the Network has facilitated lobbying by carers (e.g. in meetings with Ministers, or through events such as carers' hustings). The Network has also supported UK level campaigning and lobbying via the Carers Trust and Carers UK (e.g. on welfare reform and other issues). A small number of participants in the review also mentioned the development of the Carers Manifesto, published at the time of the 2007 and 2011 Scottish Parliament elections, and updated for the local authority elections in 2012.

### Scottish and UK Government consultations

2.29 Where Scottish and UK Government consultations have a direct bearing on carers, the Network has generally chosen to respond through the policy sub-group. In general terms, the responses have represented a composite view of the NCOs (with, in some cases, direct involvement of carers via focus groups or through e-mailed requests for views). In the case of the recent carers legislation consultation, the Coalition (on behalf of the Network) organised a large number of carers to respond to the proposals on an individual basis. Members of the policy sub-group also met with a variety of other third sector organisations to provide briefings on the issues in the proposed legislation, to help inform their own submissions.



## **Research**

2.30 With a few exceptions, the NCO Network has not carried out primary research. It has, however, had a clear role in research in the following ways:

- Identifying the need for research on particular topics.
- Commissioning research (although this has been relatively unusual).
- Facilitating and providing a Scottish dimension to UK research.
- Facilitating access to carers for researchers.
- Interpreting and disseminating research carried out by others.

2.31 The NCO Network has also supported research by individual NCOs, including, for example, research on family members employed using SDS (MECOPP), and research on short breaks (Shared Care Scotland on behalf of the Scottish Government). The Carers Manifesto also drew on a range of primary and secondary research sources, and some of the supporting materials were adapted from research carried out by others at a Scottish and UK level.

2.32 In a small number of cases, members have carried out primary research on behalf of the Network. The most obvious example is the development of a Carers Charter (commissioned by the Scottish Government from Carers Scotland and MECOPP). The NCO Network has also made a direct contribution to research undertaken by others (e.g. research on developing carer outcomes, on the implementation of SDS, and the current review).

## **Engagement**

2.33 The NCOs have been involved in facilitating access to carers' views at a national and local level (although the latter has generally been through, for example, Carer Centres rather than directly). There has been a high level of co-operation and joint working in this area between national and local organisations (e.g. in hosting events, or supporting carers to take part in national forums).

2.34 Perhaps the most visible form of engagement for adult and young carers has been the Carers Parliament. The key role of the Young Carers Festival in engaging a "hard to reach" group of carers was also noted. This has run for four years (with a further event due in August 2015) and brings together young carers from all over Scotland for time out from caring and to contribute to policy development. As noted earlier, it is organised on behalf of the NCO Network by the Alliance, and is funded by the Scottish Government. There are also a range of other means of securing carer engagement.

2.35 As noted, the Coalition (with national and local carer organisations), developed and published standards for carer engagement. The NCOs, individually and as a Network, have also participated in Carers Week, which is organised at a UK level, but has a number of Scottish-specific activities.

## **Services**

2.36 Although identified as one of the key pillars of work of the NCO Network, the work encompassed by "services" has not been clearly defined. With limited

exceptions, the NCO Network itself is not a provider of services either to carers or local carer organisations (although most individual NCOs do this in some form).

2.37 The work of the NCO Carer Training Consortium (e.g. trainer training and its grants programme) and the management of Short Breaks funding, however, could be considered national level “services” provided on behalf of, but not directly by the Network. Some initiatives mentioned earlier (e.g. the Young Carers Festival or Carers Parliament) could also be viewed in this way, as could the guide to SDS. In reality, however, most service delivery to carers is carried out at a local level by, for example, Carer Centres, Crossroads branches and other organisations.

### **Relationships with other types of organisation**

2.38 Carers are also a key client group for a wide range of organisations other than NCOs and local carer organisations, including, for example, local authorities, the NHS, and third sector bodies. Examples were identified in the review of a range of ways in which non-carer organisations interact with carers. While not comprehensive, this included:

- Producing strategies, or in reference / advisory groups.
- Research.
- Awareness-raising campaigns or events.
- Development of specific services to carers and young carers directly funded by the non-carer organisation.
- Provision of short breaks to the carer by providing a specialist service to the cared for person.
- Joint national or local partnership projects with carer organisations.

2.39 There was evidence of distinctions in how different types of organisation viewed carers in the context of their work. Public bodies, for example, located carers as key partners, and clients in their own right. In some other organisations, there was a focus on carers and cared for persons as a “family unit”. In others, organisations stated that, where there was potential conflict of view (e.g. between a carer and cared for person) their role would be to support the cared for person, while some carer organisations stated that their focus would be on the carer.

2.40 Although most non-carer organisations involved in this review were familiar with all of the NCOs, most had only had contact with a subset. For some non-carer national organisations, their most sustained level of contact had been local.

2.41 Examples of co-operation between carer and non-carer organisations were:

- Carer organisations being members of other types of organisation (and vice versa) both at a national and local level.
- Shared Board membership, in a small number of cases at a national level, but more commonly at a local level.
- Supporting carers individually to be members of Boards, reference groups or other strategic groups (again at a national and local level).

## **SECTION 3: Perceptions of the NCO network**

3.1 This section highlights perceptions of the Network (from all strands of the review). It is important to state that there was found to be a near consensus that there was a need for an NCO Network, with a prevalent view of the benefits of the NCOs coming together nationally (particularly collaboration on themes of common interest). A number of other benefits were highlighted and are discussed below, along with some concerns and challenges under some broad common themes.

### **Provision of a voice for carers**

3.2 One of the most common perceived benefits of the NCO Network was the provision of a “voice” for carers. The “collective voice” of the NCOs was seen to strengthen the message and ensure it was heeded, and some NCOs highlighted the value of their specific focus on carers. It was also argued that the NCO group was seen to be “in touch” with carers and able to provide a coherent view, which helped ensure that strategies would be carried forward. The lobbying potential was also highlighted, and a number of participants added that “campaigning” work required a joint approach, as did tackling issues such as inequalities and poor practice.

3.3 In the context of these positive views, however, some concerns were raised about the lack of a clear national structure for identifying and representing the carer “voice”. One discussion group argued, for example, that there was a “fragmented” national voice. There was also a perception that national links to carers tended to take place via individual NCOs, rather than being co-ordinated by the Network. Participants in one group suggested a lack of coherent links in Scotland between local mechanisms for identifying carers’ views and regional and national structures. This was seen to be compounded by considerable local variation in the effectiveness of local consultation and the level of contact with carer organisations. One NCO discussion group expressed the related view that this constrained the Network’s ability to encourage carers to engage locally, and to be able to speak on their behalf.

3.4 Some stakeholders expressed concern that the NCOs themselves were not representative, and one carer and workers’ group argued that, unless a local organisation had a link to a specific NCO, there was no way to raise local issues. A perceived general lack of a “proactive” approach to representation was also raised. Some of the NCOs themselves were also concerned that, if an organisation such as the Scottish Government or local authority perceived the Network as unrepresentative, they may assume a lack of an evidence base, and take the issues raised less seriously. A further challenge highlighted by some NCOs was a lack of clarity about work that could be undertaken without impacting on funding, particularly in terms of the distinction between “campaigning” work and “representation”.

### **Contribution to policy and developments**

3.5 Closely related to providing a voice for carers, a further benefit of the Network identified frequently by stakeholders of all types was its role in raising awareness of carer issues in policy development. One organisational survey respondent, for example, suggested that the Network helped keep carer issues current at a national level. It was also argued that the NCOs were well-placed to inform future policy

direction and lead on long term planning. Many different participants indicated that the profile of carers and carer issues had been raised significantly in recent years.

3.6 A number of participants identified the benefits to other organisations of a “consultative” or “expert” function for the Network. This included responding to specific consultations and providing a “carer perspective” in policy development. As well as agreeing a joint response to consultations, the NCOs argued that the Network could carry out background work to enable other participants (e.g. carers, local organisations and individual NCOs) to formulate their own responses.

3.7 A number of respondents highlighted the valuable role of the Network as a strategic partner. Some NCOs, for example, identified its role in providing expert representatives to national policy groups, while one organisation argued that a key strength was the recognition by local authorities, health boards and government of its role in developing policy and practice. Some organisations gave examples of partnership working between the Network and both statutory and third sector organisations. One added that such contact made organisations more aware of issues for carers. A number of NCO Board members highlighted the impact on joint working between their NCO and local partners. Specific examples cited of the Network’s effective policy influence included: the development of the carers strategy; input to carers’ legislation and guidance on SDS, and the Carers Charter.

3.8 There were, however, also some concerns about the Network’s contribution to policy, particularly in terms of perceived lost opportunities for partnership working. It was suggested, for example, that links tended to be ad hoc and opportunistic, with a lack of strategic contact. It was noted in the NCO discussions that the selection of representatives to policy groups also tended to be ad hoc, with requests for input often made directly to individual organisations rather than through the Network.

3.9 One NCO discussion highlighted a variation in awareness of the Network among national and local organisations. It was also clear from conversations with NCO Board members that they were not all aware of the nature of other NCOs. One worker suggested that, if some of those in the field lacked awareness, many other organisations and individuals would also have limited knowledge, which could lead to variation in the Network’s involvement in relevant discussions.

## **Research and oversight**

3.10 A further strength of the NCO Network was seen to be its role in research, particularly in gathering and collating evidence to support other work. As with other aspects of the role, it was suggested that smaller organisations working individually would not have sufficient resources to carry out this type of work alone. The role of the Network in joint research was seen to enable the NCOs to take an oversight role (e.g. of service provision to carers, the work of the NCOs and local organisations, and Scotland-wide issues). It was argued that this could help highlight gaps in provision, or potential developments. Some respondents gave examples of using national level research to support local change.

3.11 The research function was also seen to give the NCOs an overall picture of their own work. The NCOs and other participants argued that this could help avoid conflicting agendas and duplication, and make more effective use of funding. There

were no specific concerns raised with this work (although clearly some of those relating to mechanisms for providing a coherent carer “voice” are relevant here).

### **Developing capacity**

3.12 The NCO Network was also seen to add value in developing capacity, both for the NCOs and others. Some organisations suggested that the NCOs’ diversity increased the Network’s capacity and range of skills, and a number of NCOs identified merit in pooling resources. Specific expertise was also seen to assist in raising issues for particular groups of carers (e.g. young carers and BME carers).

3.13 Many participants highlighted the importance of links between some NCOs (particularly the Carers Trust and the Coalition) and local organisations in helping build capacity. Board members in a number of NCOs were clear that local capacity building was a key element of their work (although these views related to individual NCOs rather than the Network). It was also suggested that the Network could enable access for local organisations to training and support which would help them to provide inclusive and varied services. It was further argued that the Network could provide coherent direction, and promote more consistent standards among organisations addressing relevant issues. A few survey respondents suggested that it could help attract resources for carer issues by supporting the national agenda which could, in turn, generate funding for local carer support.

3.14 Some specific concerns were raised, however, about the currently limited ability of the NCO Network to develop capacity further. A specific point was made in relation to supporting people with specific needs (e.g. substance misuse; mental health issues; learning disabilities; age-related issues; and autistic spectrum disorders). It was also suggested that there may be a lack of attention to carers in other particular circumstances (e.g. male carers). The role of specialist organisations (national and local) in providing such support was highlighted, and it was suggested that, given the largely ad hoc links between them and the NCOs, there may be limited attention to the needs of some groups of carers. It was also suggested that those providing support to them may feel isolated from other carer organisations. There were also some concerns about the ability of the Network to develop its own capacity, and limitations on availability of staff and time (discussed later).

### **Communication**

3.15 A further commonly identified benefit of the Network was its role in sharing information, experience, developments and good practice in carer issues. The knowledge base, diversity and expertise within the Network was identified, and one individual survey respondent suggested that this gave it additional credibility.

3.16 The role of the Network in information sharing was seen to have benefits for the NCOs themselves, with members able to draw on each other’s expertise. It was argued that this enabled mutual learning, and one NCO discussion group suggested that individual NCOs trusted each other to take an appropriate common approach. It was also argued that the Network could identify the NCO with the most appropriate expertise to take particular pieces of work forward on their behalf.

3.17 In terms of wider information sharing, some NCOs highlighted the value of providing material (such as policy briefings) to members. Some worker and carer discussions also highlighted the opportunity to share good practice as potentially contributing to consistency and improved standards in support to carers.

3.18 One NCO stakeholder described the Network as a “strong brand”, while another stated that it had become an established entity in its own right. This view was not, however, shared by all participants, some of whom suggested that the brand was weak, and not well-recognised. In this respect, it was acknowledged by NCOs that the “group” did not have a consistent title, and was referred to by different participants in different ways.

3.19 While a number of stakeholders argued that the NCO group was likely, as a “national entity” to have limited visibility to individual carers, there was a concern that this may also be the case with some organisations. For example, some of those in the survey, and many discussion group participants stated that they could not comment in detail on the NCO Network, as they were unaware of its remit or aims. At a general level, some NCOs recognised a lack of profile and national “branding” (or logo), which it was suggested could contribute to an overall lack of understanding of the Network.

3.20 Some participants expressed concerns about a perceived lack of dissemination of information to other organisations (about the work of the Network or carer issues more generally). One stated that this was particularly an issue for smaller organisations, and one discussion group suggested that the mechanisms through which the NCOs provided information to local areas tended to be ad hoc. It was also suggested that there was no obvious national point for access to carer information, and no obvious single resource to signpost carers to support. Some concerns were also expressed about the information available on NCO websites. (These issues are discussed further in relation to the nature of the Network overall.)

3.21 It was also argued that the NCOs did not always seek up to date and relevant information from local providers to enable them to maintain the “big picture” and carry out appropriate signposting. A few survey respondents identified a lack of collective reporting by the Network on its achievements, and one discussion group suggested “sporadic” reporting to and from the Network, with a lack of knowledge of how reporting should work. One organisation argued that there was a specific lack of information about whether the Network had, or intended to develop a strategy.

## **Service provision**

3.22 Some NCOs (staff and Board members), and other participants, identified strengths in some direct service provision by individual NCOs on behalf of the Network. Examples included: short breaks; the Carers’ Parliament; and the Young Carers’ Festival (with a number of local organisations stating that the Festival was a chance to explore their own policy and practice with young people in a relaxed setting, with access to specialist support if required). It was also suggested that national provision of training and dissemination of policy information could enable access to support, information and advice across Scotland and for particular groups of carers. One discussion group argued that some information would be difficult for small, local organisations to produce, but could be done efficiently at a national level.

3.23 A small number of concerns were raised with the Network's role in service provision. One NCO discussion, for example, identified a potential lack of clarity about this. It was also argued that the Network's role in developing opportunities (and resources) was constrained by a lack of a formal structure, and inability to bid directly to carry out pilot work to address gaps in provision. It was argued that, as result, the Network's role in service delivery tended to be responsive rather than proactive, and located largely with individual NCOs rather than the whole Network.

### **The nature of the Network overall**

3.24 There was a shared view that the NCO Network added value to the work of individual NCOs, and none of the NCOs (staff or Boards) identified problems with the nature of the Network overall. A number of concerns about this were raised, however, in the surveys and discussions with carers, workers and others.

### **The basis of participation and the informal structure**

3.25 There was a strong consensus amongst the NCOs that the Network operated as a democratic organisation of equal partners. They argued that the informal structure had functioned well to date, with positive working relationships forming a good basis for their work. A number of other stakeholders, however, expressed concerns about the lack of formal partnership arrangements and perceived constraints. Some NCOs themselves suggested that this could make it difficult to describe the Network, and for others to recognise it as an entity, which may lead to missed opportunities for joint working. It was also suggested in one NCO discussion that the current "goodwill" model may not be sustainable in the longer term, nor allow the Network to develop to meet new challenges. It was suggested that it could be a "fragile basis" for long term involvement, and vulnerable to changes in organisations.

3.26 A further challenge identified (linked to the structure) related to the limited resources and capacity of the Network. Some NCOs highlighted the demands of participation in, organisation and co-ordination of meetings (although the chairing and administrative processes were seen to work effectively). It was also suggested that other organisations may not realise the lack of resources, which may affect their expectations of the Network. Linked to this, a lack of core resources (and the inability to apply for funding as a result of the structural arrangements) was seen to constrain the work that the Network could realistically undertake. One NCO discussion group argued that the Network was operating at capacity, at a time when a lot of relevant work was developing.

3.27 The NCOs stated that the agenda and work streams for the Network were largely defined by mutual consent, with no issues with individual organisations pursuing their own agendas. There were seen to be challenges in responding to an agenda and timescales determined by others, often requiring "reactive" work quickly. A few individual survey respondents also expressed concerns that resource issues for individual NCOs could undermine the Network's collaborative work. Some participants also expressed concern that the source of funding may lead to conflict of interest, or constrain organisations' ability to "speak out" on some issues (although some NCOs argued that this related to the methods used rather than subject matter).

## Composition and membership

3.28 There was a shared view among NCOs that the Network membership and the work of the members was appropriate, with no perceived gaps or overlaps. Although the risk of this was acknowledged, it was argued that the existence of the NCO Network, the frequency of meetings, and the commitment to an agreed approach to taking work forward meant that this was not an issue in practice. In terms of external perceptions, however, it was argued in discussion groups and in the survey that there may be duplication in what the NCOs appeared to do, with not always clear differentiation between their functions. Related to this, it was noted that there were a number of similar posts (e.g. senior managers and policy staff) in different NCOs.

3.29 Additionally, although the NCOs argued that the number of Network members was appropriate, (with diversity seen as a strength), it was suggested frequently in the carer and worker discussions and survey that there were simply too many NCOs in the Network. A further concern expressed was that the number involved could lead to different approaches, and may not promote effective joint working. One group argued that the number of NCOs could dilute their impact on cross-cutting issues, particularly if several were working individually on these.

3.30 It was also stated in some discussion groups that the number of NCOs meant there was not a single source of national cross-cutting information (noted earlier). It was argued that separate NCO websites made finding relevant information difficult. A number of participants also noted that they had, at times, been misled by England-specific information on websites (including the Carers Trust, Carers Scotland and youngcarers.net, which is referenced by the Alliance). It was also noted in one discussion that, while they had assumed that the Carers Trust “find your local Carer Centre” search facility would identify all such centres, they found that only those paying affiliation fees to the Trust were listed (which, it was suggested, might lead to a carer assuming wrongly that there was no Carer Centre in their area).

3.31 In terms of links to other organisations, it was suggested that the number of NCOs made it difficult for local carer organisations to have contact with all of the NCOs (however beneficial this may be). It was further argued in one group discussion that it was sometimes difficult for those outside the NCO Network to know which organisation led on which issue (although the NCOs themselves believed there was clear delineation of responsibility). It was also suggested that small local organisations could find it difficult to know how to link to the Network.

3.32 Some organisations suggested gaps in representation and a lack of clear criteria. Variations were noted in current members’ remits, functions and service user groups, and it was argued that the Network may not be representative of all organisations working with carers (e.g. condition-specific organisations). A number of non-carer organisations suggested that carers, cared for people, and organisations working with them, shared a common purpose, and a small number criticised the distinction implicit in having separate carer and non-carer organisations. Questions were also raised about how representative the Network was of other subsets of carers (e.g. older carers, LGBT carers and carers in rural areas).

3.33 A small number of issues were raised about individual members of the NCO Network. In each case, these were not directed at the work of the organisation per



se, but their participation in the Network. For example, a number of stakeholders questioned whether MECOPP, as presently resourced, could capture and channel the voices of BME carers at a national level (with its primary service in Edinburgh and a small number of associated projects elsewhere in Scotland). Secondly, a small number of stakeholders raised issues with the inclusion of Crossroads (as a service provider to individual carers, and similar to others providing such a service). Thirdly, it was noted that Shared Care Scotland was primarily a provider of intermediary services to cared for persons, rather than directly to carers (although it was also suggested that this could be described better as a focus on the “family”).

3.34 The value of having members with specific expertise on issues for BME carers, however, was acknowledged. Additionally, it was noted that Shared Care Scotland provided a variety of national level services to carer organisations (e.g. in relation to sharing best practice and policy development) and, in this regard, operated in a similar manner to, for example, Carers Scotland.

3.35 It was recognised in one NCO group discussion that there had been some historical difficulties in determining the nature of membership and identifying clear criteria. One NCO stated that there may be frustration among other organisations about current members’ perceived “gatekeeping” role. Some participants argued that current representation was not necessarily the most effective use of resources.

## **Funding**

3.36 The review identified that funding for the NCOs and the Network’s work was complex. The NCOs were found to vary in their status, structures and work, making it difficult to identify funding relating specifically to Scotland, and to national level or strategic work. (Funding is described more fully in Annex 2, although specific details are not given because of commercial confidentiality.) The detailed examination of the funding situation raised some issues about how national work was being funded within the overall pattern of NCO funding. “National” support for carers has consisted of a mixture of core funding for individual NCOs and a large number of projects. The bulk of funding for the work of the Network has been provided to NCOs by the Scottish Government through Section 10, which has generally been given for individual projects. Individual NCOs have been given funding largely for purposes other than “Network” functions. The Network has received no direct funding.

3.37 This has meant that most pieces of national work have been the subject of individual bids to the Scottish Government (with a small number of exceptions). The practical effect of this has been that “national” activities have been funded in a piecemeal way (exacerbated by the fact that each national activity has been the responsibility of an individual NCO, rather than the Network). This could clearly constrain the opportunity for an overall strategy, underpinned by a budget matched to an action plan and outcomes.

3.38 It was also clear from information provided by the NCOs and the Scottish Government (which was again examined thoroughly, but not included for reasons of commercial confidentiality), that most individual NCOs have been highly reliant on Scottish Government funding. In the longer term, this seems unlikely to be sustainable, and may leave the NCOs (and their work individually and collectively) vulnerable to changes in policy or priority.

## SECTION 4: Suggestions for the way forward

4.1 As noted previously, although the review identified a number of concerns and challenges for the NCOs, there was a common view of the value of a national approach to carer issues, and the need for some form of national body. Many suggestions were made about how the NCO Network could become more effective, and enhance its national influence<sup>13</sup>. These focused on two areas: the overall purpose and work of the Network; and structural considerations.

### Overall purpose and work

4.2 The review identified common suggestions for the overall purpose and work of the NCO body. Common themes for the aims of the body were to:

- Improve outcomes for carers.
- Promote carers' rights.
- Provide a voice for carers.
- Improve support for carers.

4.3 Within this, many suggestions were made about specific areas of future work. These were broadly of 5 main types, all closely linked, as follows:

- Policy development.
- Research and oversight.
- Developing capacity and practice.
- Communication.
- National level services.

4.4 Suggestions made in each of these broad areas are described below.

### Policy development

4.5 Some key elements of the future role of the NCO body in policy development were identified, with many detailed suggestions. Firstly, there was seen to be a role in **strategic development**. Suggestions included developing a strategy for the NCO body itself, specifying its aims, key areas of work and how progress would be measured. Related to this, it was argued that an action plan should translate the strategy into practice, specifying clear tasks and responsibilities. A continuing role was also identified for the NCO body in the production of other strategic documents. A number of participants noted that the NCO body could make significant contributions to the new carer and young carer strategies (expected to be developed at some time from 2015 onwards).

4.6 The second broad aspect of policy development identified was **input to national policy**. It was suggested that the NCO body should be involved in stimulating interest in carer issues, promoting these interests in policy, and supporting the development of positive local initiatives into national practice. The role was seen to involve scrutiny of policy proposals, and negotiation and representation

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<sup>13</sup> For the purposes of this section, this will be referred to as the "NCO body", as there a number of structural options, and it is important not to imply a preferred option in the terminology used.

of carer issues at a national level (e.g. with Government) to influence policy and legislation (e.g. through participating in policy groups and forums and responding to consultations / legislation on behalf of carers).

4.7 Linked to the input to policy, suggestions were made about the role of the NCO body in **consultation and representation**. These included that it should work to develop a coherent national “voice” for carers, identifying and taking forward their views through a clear structure for regular contact, as well as through research and lobbying and campaigning. Suggestions were made about the need for the NCO body to act as an “intermediary” or “bridge” between carers, support organisations and policy makers. It was suggested that the body should also promote a clear understanding among carers about representation processes. A number of specific issues were suggested for promotion (e.g. carer involvement in service design; carers’ income level; welfare reform; the health impact of caring; succession planning; and issues for marginalised groups).

### **Research and oversight**

4.8 Some key elements of the future role of the NCO body in relation to research and oversight were also identified. Among these was **evidence gathering**, both through carrying out research and collating existing evidence on carer issues (e.g. “big picture” statistical information; other relevant national and local research; and disaggregated local information, where available). This would include, for example: gathering baseline information and mapping provision to carers. It could also include an annual survey of carers, and identifying ongoing means of gathering their views.

4.9 There was also seen to be a role for the body in identifying new areas for research, or influencing the Scottish Government’s research priorities (although it was noted that UK level carer organisations already carried out research, and that the NCO body or individual NCOs could apply for research funding from other sources). There were mixed views of the extent to which the NCO body should actually carry out research, although some potential research issues were highlighted (e.g. mental health and carers; the economic case for caring; issues for marginalised groups; and identifying “hidden” carers).

4.10 Closely linked to evidence-gathering, another key element of the research role identified was to use this information to **support other functions** of the NCO body (e.g. linking findings to policy making; representing carer views etc.). This could also include developing a research resource for other organisations to support their work and to learn from national research. It was suggested that this could provide one point of access for common information about carers, simplifying the research process, and minimising the demands on the time of individual carer organisations. It was seen to be important to publish transparent research information. The organisational survey also identified a role for the body in providing advice to researchers about carer issues, and facilitating their access to carers.

4.11 It was also suggested that there should be an **oversight and scrutiny role** for the research function of the NCO body, in terms of identifying good practice and innovation and identifying gaps in current national and local provision. There was also seen to be a role in collating information and reporting on the work of the NCO body itself (e.g. through Annual Reports, briefings for local carer organisations etc.).

## Developing capacity and practice

4.12 The development of capacity and practice in services to carers was a further area of future work identified for the NCO body. Within this, the **development and provision of training** was seen as an important function, including developing appropriate training and providing training for trainers which could be rolled out locally. A potential role was also identified in providing training and / or guidance to other professionals (e.g. health), and promoting the notion of embedding carer training in core training for other disciplines. The development of partnership training on specific issues (e.g. deaf awareness for carer organisations) was also suggested.

4.13 Many review participants (including a number of carers and carer organisations) saw a key role for the NCO body in the **development of standards** and good practice in support to carers, to encourage greater consistency in the quality of provision. There were more mixed views of whether the body should have a role in monitoring the standards. It was also suggested that the NCO body could consider promoting specific developments (such as accreditation for carers).

4.14 A further aspect of the NCO body's suggested role in developing capacity and practice related to **equalities work** and access to support and services for specific groups of carers (building on current work with BME carers and young carers). This would involve developing further understanding of issues for carers in these groups and in other specific circumstances (e.g. in other equalities groups; in rural areas; those experiencing poverty; those caring for people with specific conditions or in marginalised groups; and other hard to reach carers). It would include ensuring consideration of specific issues for them in work on carer issues, as well as ensuring that other work with these groups took account of issues for carers. A number of participants argued, for example, that the Alliance should have strong links with children's services and organisations working with children at a national level.<sup>14</sup>

4.15 The NCO body was also seen to have a future role in **supporting other stakeholders** to develop their work relating to carers. This was seen to include developing ways of promoting local carer involvement further, with a more strategic approach to contact with them. A range of general suggestions were made about how contact and engagement with carers could be improved, to include, for example: surveys, events and meetings (accessible to working carers and those outside the central belt); a more proactive approach and wider means of contact with carers (with less reliance on the internet, email and social media); development of co-production; and development of a national register of carers.

4.16 Providing support to local carer organisations and workers was also identified as part of the NCO body's role with other stakeholders (including, for example with: funding applications; local strategies; business development; events etc.). Linked to this, the NCO body was seen to have a more general role in working to secure funding for carer issues. Organisations, however, did not generally consider that the NCO body should have a role in providing services such as management, payroll and insurance to local organisations.

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<sup>14</sup> A number of participants suggested that the Alliance should develop an individual identity, separate from the Carers Trust, through, for example, having its own website and email address domain.

4.17 There was also seen to be a role for the NCO body in developing further work with other relevant organisations (including, for example: other carer support organisations; condition-specific and disability organisations; local authorities; health boards; and others such as employers) on areas of common interest. It was suggested that there could be a more strategic approach to securing input from such organisations, providing information to them, and enabling them to engage with carers to increase their accessibility to them. It was suggested that there may also be opportunities to work with different organisations by theme (e.g. disability issues, GIRFEC etc.), through, for example, a topic-based annual engagement event.

## Communication

4.18 The fourth broad area of work identified for the NCO body was communication, with two key strands of this. One strand related to the **dissemination of knowledge and good practice information**, including relevant research findings, publications and other aspects of the work of the NCO body to all relevant organisations. It was argued that this should be provided according to the principles of inclusive communication. The other main strand of communication was greater **awareness raising**, both with relevant organisations, and the wider public. Suggestions about how to undertake this included developing a national “brand” and identity (including a name) for the NCO body, and communicating this widely.

4.19 Suggestions for awareness raising with relevant organisations related to developing a more strategic approach to links and communication (discussed earlier). Within this, there was seen to be a need for feedback to such organisations of information about the NCO body and its work. It was also suggested that the NCO body should be proactive in asking other organisations to share information. In terms of public awareness raising, it was specifically suggested that the NCO body should undertake national campaigns and make greater use of the media to develop understanding of carer issues. It was also suggested that the NCO body could identify some key issues for awareness raising.

## National level services

4.20 Lastly, the NCO body was seen to have a future role in providing a small number of national level services and events (although there were mixed views of this, and the main appropriate focus of direct provision to carers was seen to be at a local level). One aspect of services to carers and workers which it was suggested, however, should be done at a national level was the development and **provision of national, cross-cutting information** (linked to all of the above areas of work). For example, some organisations in the survey argued that the NCO body could co-ordinate information and advice about cross-cutting carer issues (e.g. with a website with separate pages for carers and organisations / workers to get up to date information quickly, and signposting to local information and organisations).

4.21 A further potential development was the production of some national leaflets / booklets and information on common issues (with specific suggestions including, for example, carers’ rights; current national policy issues; differences between paid and unpaid carers; mental health; coping with caring; a “process map” for carers etc. The potential to encourage other positive developments to information (e.g. provision of

leaflets by GPs; promotion of accessible material) was also highlighted, as was the potential for a national information line for carers.

4.22 The few **existing services** provided through the NCO Network (currently by individual NCOs) were seen to be appropriate to continue at a national level. These were: short breaks; the Young Carers' Festival; and the Carers' Parliament. It was also suggested that the NCO body could expand this type of work to include, for example: an Adult Carers' Festival and a Young Carers' Parliament; and particular events (e.g. workshops; conferences; carer and family days). Some, although not all respondents expressed a desire for more of a focus on the family unit.

4.23 The third potential strand of national service provision for the NCO body was the development of **new pilot work** (e.g. testing innovative ideas). While there was not seen to be a role in "gap-filling" per se, this was identified as a way of exploring new developments which could subsequently be delivered locally.

### **Overall development and structure of the group**

4.24 As well as these particular areas of work, a number of structural changes and developments for the NCO body were suggested, although it should be stressed that there was no clear consensus about the best way forward. Some suggestions focused on particular aspects of the structure, others on specific models. The NCOs stated that they would await the outcome of the review before making a decision.

### **Composition of the NCO body**

4.25 A number of stakeholders suggested changes to the composition of the NCO body. It was argued, for example, that reducing the number of organisations could make more effective use of resources and provide clarity of role. Some argued that there should be only one NCO, for ease of identification and contact and greater perceived efficiency. A small number suggested re-considering the basis of involvement of specific individual NCOs (MECOPP; Crossroads Caring Scotland; and Shared Care Scotland) to ensure clear reasons for this.

4.26 A number of stakeholders suggested considering the best way of involving some additional organisations which are not, themselves, carer organisations but have a direct interest in carer issues. Among those mentioned were: the Health and Social Care Alliance; independent living organisations (e.g. Inclusion Scotland), age-specific organisations (e.g. Age Scotland); and condition-specific organisations (with Alzheimer Scotland mentioned most commonly, and a number of others identified).

4.27 One stakeholder suggested that one way to extend the reach of the NCO body would be to retain current membership and establish a wider forum alongside it (involving, for example: the NCOs; the Scottish Government; the NHS; local authorities; and a range of third sector organisations). It was acknowledged that membership would be similar to the Scottish Government's Implementation and Monitoring Group, but it was argued that, with a wider remit, it could provide a better mechanism for oversight of the National Strategy outcomes.

4.28 Alongside these suggestions, a common theme was the identification of clear membership criteria. A key issue for the NCOs has been the importance of members

having carers as part of their “core” business, as well as being national organisations. However, it was recognised that it was difficult to determine when carer issues became “core business”. In reality, there was a view among the NCOs that this should be an NCO’s “primary” or “sole” function, to ensure that members linked well with the focus of the NCO body, and to avoid becoming a “talking shop”.

4.29 As noted previously, the NCOs had produced a “holding” list of criteria, but recognised that there were anomalies in these. It was agreed that they should reflect and enable the most effective composition for the NCO body, but it was clear that there would be a reluctance to extend membership to other organisations working with carers, where this was not their sole focus. The NCOs suggested that the best option may be to co-opt expertise from other organisations as required.

### **Formalisation of the structure**

4.30 A very common suggestion was the adoption of a more formal structure, to allow the NCO body to make funding applications and potentially increase its capacity to carry out additional specific work, and develop some of the areas suggested. It was stated in one NCO discussion that there would be a need for clear management and governance arrangements with such formalisation.

4.31 A further common suggestion was to have clear aims, objectives and purposes and high level priorities for the NCO body and for the responsibilities of members (and those carrying out functions on behalf of the body) to be clarified. It was also argued that the criteria for membership, the current members and the means of becoming involved should be specified. It was stated that there would be a need for clear oversight arrangements for each area of work (and, depending on the structure, potentially of the NCO body). Linked to this, it was suggested that there should be a clearer and more coherent approach to funding national work, identifying this clearly as being provided to the Network, and distinct from the work of the individual NCOs.

### **The overall approach to work**

4.32 It was argued frequently (including by some NCOs) that there should be a more strategic approach overall by an NCO body. For a number of participants, this was seen to require the development of a strategy and action plan for the body, and a clear coherent approach to seeking funding.

4.33 It was also argued that there should be a more strategic approach to links with carers and relevant organisations. It was suggested that there should be an identifiable first point of contact for the NCO body, particularly for the co-ordination of links to others. It was stated that this would provide a better way of enabling organisations such as the Scottish Government and others to seek participants for policy groups and initiatives.

4.34 It was also noted that, at a local level, and particularly a national level, there would be benefits in greater joint working (e.g. on areas of current Scottish Government policy such as the integration of health and social care). It was also suggested that there could be campaigns on common issues such as poverty or welfare reform, and increased joint working on issues such the examination of the

local impact of policies, and the provision of consistent support across Scotland. There was a strong view from many participants that it would be essential for a high level of contact between the NCO body and other organisations with an interest in carer issues.

### **Changes to individual NCOs**

4.35 A few suggestions were made about the work of individual NCOs (although these tended to be general). It was suggested, for example, that they should provide clear information about their individual aims and work and that their names should reflect their areas of expertise, to ensure clarity. There was a prevalent view that NCOs should not have a role in providing local information, services and support, as they were not in the best position to know what was available, nor the nature of key local issues. As noted previously, however, there was seen to be a role for the NCO body in the provision of high level national information and signposting. It was also suggested in the carer survey that they should be held to account for their work.

4.36 A few suggestions were made about the work of named NCOs, or about how to amalgamate to a smaller number of organisations. Given, however, that this was not an evaluation of individual organisations, these will not be presented here.

### **Specific options**

4.37 In addition to these general structural issues, a range of suggestions were made about specific structural options that could address some issues raised and develop the NCO body. While, as might be expected, there was no consensus view of the most appropriate structural option, three broad themes emerged:

- Retention of the current model of informal partnership.
- Development of a formal partnership.
- Development of one (or a small number) of national organisation(s).

4.38 Broadly, the NCOs favoured retention of a partnership in some form, while other stakeholders tended to focus on greater formalisation of the partnership, or the development of one NCO (or a reduction in number). A range of detailed suggestions were made about the models (e.g. in terms of: general structure; staffing; potential for development; efficiency; effectiveness; and achievability). These helped develop a summary of some of the key considerations implied by each and to shape the recommendations, and are presented in full in Annex 3.

### **Changes and developments in other organisations**

4.39 A few suggestions were also made for consideration by other organisations, to assist in creating the conditions for the most effective functioning of the NCO body. For example, it was suggested that organisations such as the Scottish Government should seek the collective expertise of the NCO body as the first point of contact when inviting input. One organisation in the survey argued that carers should be part of all relevant Government groups.



4.40 It was also suggested that it would be helpful to have clear direction from funding organisations about types of work that would affect receipt of resources (particularly the distinction between campaigning work and the representational role).

4.41 A further area for development identified was the spread of understanding of carer issues (and the role of NCOs) across different organisations and parts of organisations (e.g. other policy areas in the Scottish Government). There was seen to be a need for recognition of carer issues, and clear priority for these. It was suggested that there should be mandatory training for staff in other relevant organisations about carer issues. One carer and worker discussion group suggested a HEAT (Health Improvement, Efficiency, Access to Services and Treatment) target to enable the identification and involvement of carers. Linked to this, there was seen to be a role for the NCOs and other organisations in enabling stronger links between different relevant national and local organisations.

4.42 Suggestions were also made about resources, including a general need for resources to support the work undertaken, and more specific suggestions about issues for which participants considered resources should be provided. Some comments were made about improvements to local services and support for carers, and the need for high quality, consistent provision, with appropriate resources. Specific developments to local support were also suggested, but it would be outwith the remit of this report to detail these here.

4.43 In the light of all of the issues raised, the final section draws together the implications of the findings and provides a series of conclusions and recommendations.

## **SECTION 5: Conclusions and recommendations**

5.1 It has been stated throughout this report that there is no question about the value of the NCO Network and the significant impact it appears to have had upon raising the profile of issues for carers. The review found a virtual consensus about the need for national work on carer issues to be carried out by NCOs in some configuration. The prevalent view of the Network's work to date was found to be largely positive, with a number of achievements cited, including a step-change in the profile and visibility of carer issues. A range of strengths and benefits have been highlighted (for carers, organisations working with carers and other organisations) and the Network's knowledge and expertise is well-recognised.

5.2 Although the individual NCOs represent a diverse group and vary considerably in size and structure, it is clear that there is a commonality of purpose. While specific purposes, aims and objectives vary by function, these are consistent with the national strategies and the overall aims of the NCO Network.

5.3 There are obvious benefits in providing a national voice for carers and carer organisations, and a joined-up approach. There are also a number of specific areas of work in which the Network is seen to have been effective, and it is clear that there remains virtually universal support for the national strategy for carers and young carers. The adoption by the NCO Network of the outcomes for carers and young carers in the strategy was viewed as highly positive.

5.4 A range of types of work were highlighted as being carried out best at a national level. Cross-cutting issues were seen to benefit from a coherent, co-ordinated voice, while some work was seen to be carried out more efficiently at this level (e.g. gathering and disseminating information; interfacing with the Scottish Government, NHS and CoSLA; distributing and administering grant funding etc.).

5.5 Many review participants talked of the carers' "movement" and the strength provided by national work to support and complement local resources (while recognising that much of the carer support work was best carried out a local level).

5.6 Against this positive background there are clearly some concerns, and scope for development of the NCO body, relating to aspects of its work and structure, as well as to the interface between national and local organisations.

5.7 This is a challenging time for the NCOs. Recent years have seen a significant expansion in the profile of carer issues and the funding to support carers at a national level, but it is by no means clear that this will continue. Allied to this, the local picture is one of pressurised budgets and the increasing use of competitive tendering by public sector partners. More generally, a range of non-carer organisations are increasingly providing support and services directly to carers, with strategic and pragmatic alliances being created. Individual carers themselves face a range of challenges, from welfare reform and from changing local authority priorities.

5.8 The NCOs will play a part, as a strategic partner, in the development of the next carer and young carer strategies. They will also have to respond to emerging legislation and policy developments. At the same time, the NCO members will face

the challenges of ensuring the longer term sustainability of their own organisations, and the need to meet ongoing obligations.

5.9 The “network” of Carer Centres is fragmenting and re-forming, which also has implications for the NCOs. The level of affiliation to the Carers Trust has dropped, and a number of larger Carer Centres have chosen to go forward without seeking Carers Trust affiliation. A new “Scotland Network” (formed of Carer Centre managers and trustees), was recently established, and while there is no suggestion that Carer Centres are not operating to the highest standards, the fragmentation of national support frameworks is likely to make it more difficult to promote and monitor *national* standards and good practice. The current Carer Centres themselves face significant challenges from changing local circumstances (and it is worth bearing in mind that, as freestanding organisations, some Carer Centres are significantly larger in terms of income and staffing than most NCOs).

5.10 For a variety of reasons, therefore, the NCOs face significant challenges in going forward. There is a need for a strong national grouping, with a clear direction and focus. Given the role that the Network has developed in providing a voice for carers, there is also a need for a professional, well-resourced national body and an overall national framework for taking carer issues forward, with clear roles, responsibilities and accountability. The conclusions and recommendations detailed below focus on developing the NCO body to meet these challenges.

### **The work and direction of an NCO Body**

5.11 The Network lacks an overall strategy and action plan to guide its work in relation to achieving the national carer outcomes. It also lacks a strategic approach to particular aspects of its work (e.g. representation of carers; links to carers and other organisations). This, in turn, makes the work less transparent and accountable. As the work of the Network has developed and expanded, the need to ensure an appropriate approach to these issues has become more evident. The first recommendation is:

#### **Recommendation 1: The NCOs should develop a clear strategy and action plan for the NCO body. This should include:**

- Its overall purpose and vision.
- Aims and objectives.
- Key principles.
- Areas of work and overall responsibilities.
- Key priorities, tasks and responsibilities.
- Links to carers and organisations.
- The planning cycle and timescales.
- Mechanisms for monitoring and reporting.

5.12 There is a shared view of what the key purposes and aims of the NCO body should be. Central to this is the provision of a voice for carers, identified repeatedly in all strands of the review. The stated purposes of the NCO body (from the original Terms of Reference) remain relevant, but may require some updating to reflect the views of stakeholders identified in the review. The key aims should include to:

- Provide a voice for carers.
- Improve services.
- Improve outcomes for carers.
- Promote carers' rights.

5.13 The key principles should include:

- Engagement with carers.
- Equality and rights.
- Co-production.

5.14 There are a number of broad areas of work where there is a national role, with a range of options for work within them. These are not radically different from the current four “pillars”, but the review can help define and refine them. For example, “engagement” is perhaps better conceived as a principle underpinning all areas of work, while “services” can be more defined. Some additional broad areas should also perhaps be identified among the core functions of the NCO body.

5.15 There are also aspects of specific types of work which could be developed. For example, there is a lack of single point of contact for policy work, and a relatively weak “brand” both of which impact on the level of awareness of, and involvement in its work with others. There is a need for a more strategic and proactive approach to links and communication with carers and other relevant organisations, as well as a need for a clearer local, regional and national engagement structure and framework. It is recognised that developments to NCO body’s work will depend on capacity and availability of resources which, in turn, will depend on the structure adopted, and provision by other organisations, particularly the Scottish Government.

5.16 The findings suggest that key areas of work for the NCO body should include:

- **Policy development**, to include:
  - Strategic development.
  - Input to national policy.
  - Consultation and representation.
- **Oversight, monitoring and research**, to include:
  - Evidence gathering.
  - Use of research to support other functions.
  - Oversight and scrutiny.
- **Developing capacity and practice**, to include:
  - Training.
  - Development of standards.
  - Equalities work.
  - Supporting work by other stakeholders.

- **Communication**, to include:
  - Public awareness raising
  - Publications
  - Knowledge transfer and good practice dissemination
  
- **National level services**, to include:
  - Provision of information to carers and workers.
  - Existing services.
  - New pilot work.

5.17 There is a strong view that the NCO body should have a role in campaigning and lobbying, but a lack of clarity about the extent to which this can take place without impacting on funding. In developing the strategy, the NCO body should seek clarity about the nature of work allowed or prohibited as a condition of funding. The NCOs could source specific funding for campaigning, ring-fencing this area of work.

### **The development of the NCO body**

5.18 The current structure of the NCO Network has evolved informally and has, in the past, been adequate for the work. Some weaknesses have, however, been identified, given the changing role and expansion of work.

5.19 There are some current concerns about the mix of participants and the criteria for participation. Some concerns were also expressed about the number of NCOs and potential duplication, although the review found little evidence of overlaps (with the possible exception of dissemination of information about carer issues). The number of participants was not found to be a barrier to effective working, and, arguably, the participation of seven NCOs has added value to the work undertaken. These concerns may reflect a lack of clarity of the Network's role, rather than its composition per se.

5.20 The review has, however, identified constraints relating to the suitability of the current informal structure of the Network, which is vulnerable to organisational change and lacks clear mechanisms for representation of carer views and engagement with other relevant organisations. There is also a lack of transparency; channels of reporting and communication; and accountability, as well as a lack of strategic direction and co-ordination, making the Network's agenda often reactive.

5.21 The work of the Network is currently constrained by a lack of resources (including individuals' time and funding), and there are concerns about the inability of the Network to apply for funding in its own right, as well as the current means of funding national work. There are many areas in which the work could develop further, but this would be unlikely to be possible within the current structures, with resources as presently distributed. Changes to the overall context within which the Network is operating (e.g. the volume of work; expectations of carers and organisations; and future developments) suggest a need to develop capacity and develop a firmer foundation for the work.

5.22 There now appears to be a need to revisit the structure of the Network. Key considerations in helping determine the nature of the way forward include a need to ensure:

- A focus on national level issues.
- A focus on addressing concerns and effective use of resources.
- The capacity to deal with diverse issues coherently.
- An inclusive approach to involvement.
- Transparency and accountability.
- A focus on equality.
- Appropriate resources for the work required.
- Cost effectiveness, and the identification of any opportunities for efficiency savings, alongside the identification of opportunities for redeployment of any resources freed up.

5.23 Whilst it is for the NCOs and the Scottish Government to consider the most appropriate structure to address the issues raised, the review identified a number of suggested structures, which are set out in more detail in Annex 3. These provide a starting point for further consideration and discussion of the way forward.

5.24 Although it would be inappropriate to make a definitive recommendation, it is likely that the operation of the NCO body as a partnership (whether formal or informal) would be the most feasible at this stage. Although the development of a single, or small number of national organisations would, in many respects be optimal, there may be difficulties in bringing this about in the short term (given the complexity of the organisations involved, the current funding structures and the expressed reluctance of the NCOs to move to this, at least at present).

5.25 Within the partnership options, however, consideration should be given to greater formalisation to address some of the emergent concerns. (This could include considering the employment of shared staff, and incremental development of a stronger national entity.) The main benefits of this approach would be:

- The opportunity to develop the work to meet current and new challenges, while preserving existing strengths.
- The opportunity to apply for funding to enhance capacity (particularly from sources other than the Scottish Government).
- The development of a more transparent and accountable approach.
- The potential for some efficiency savings.

5.26 The second recommendation is, therefore, as follows:

**Recommendation 2: The NCOs should give careful consideration to developing a more formal partnership in order to begin to address the issues raised in the review, increase effectiveness and provide a platform for further development in the future.**

5.27 In the medium to long term, the NCOs should keep the structure under review, and consider the potential benefits of working towards the establishment of a single body, or a smaller number of national level organisations.

## **Key considerations about the development of a more formal partnership**

5.28 Regardless of the structure adopted, there are a number of further considerations relevant to the development of a more formal partnership.

5.29 The NCO body could, for example, in the first instance, establish itself as a formal entity and apply for development funding to explore the options for a new structure and strategy in more detail. This could build on the review suggestions, taking advice from organisations with appropriate expertise in third sector development. The NCO body could consider employing a Development Officer to facilitate this (e.g. hosted by an individual NCO), or commission short-term support. This process could involve detailed consideration of the nature of the structure, the development priorities (with timescales) and the best means of funding the developments (including the implications for NCOs).

5.30 The NCO body should consider working towards the employment of some shared staff to develop its work within the new structure. In the first instance, this could involve the employment of a shared Co-ordinator to support the administration of the NCO body through the process of change, with subsequent employment of some additional shared staff to take forward key areas of work. (Given the view of the Scottish Government that it will not provide additional financial resources, funding for such developments would either have to come from other sources, or from the redeployment of current resources.)

5.31 The NCO body should also consider its current membership. Whilst this does not preclude retaining existing members, the rationale for membership should be considered, as well as any changes required to the roles of individual NCOs to reflect their role in the group (e.g. having Crossroads as “representing” direct service providers; or developing MECOPP’s “national” functions). Clear membership criteria should be agreed and specified, as should procedures for management, co-option of relevant expertise and accountability. The partners should revisit the Terms of Reference as part of considering the overall structure.

5.32 The NCO body should have a single name, logo and consistent branding and communicate this widely. The current arrangement where the NCO Body does not have a fixed name, nor a manageable logo is unsustainable, and arguably counterproductive. Partnership communications should come from a domain attached to that name, rather than individual partners.

## **Specific issues in relation to equalities work and representation**

5.33 While the particular issues faced by carers in some equality groups have been recognised, there are other equalities issues (e.g. disability; gender; other aspects of age etc.) and issues for other groups of carers (for example, those in rural areas) which are arguably not currently being adequately represented or addressed. There is also a lack of a coherent approach to effective representation of all carers. Regardless of the structure adopted by the NCO body, the third recommendation is:

**Recommendation 3: The NCOs should consider further development of equalities work and comprehensive representation of carers, broadening the focus of specific work from BME and**

**young carers to include other groups of carers facing particular issues as a result of their circumstances (including those in rural areas), and taking a more strategic approach to representation overall.**

5.34 There is a need to ensure not only that the NCOs and NCO body focus on issues for particular groups of carers, but also that other key relevant policy areas (e.g. GIRFEC; rural policy; independent living etc.) take account of issues for carers.

#### **The development of national level information for carers**

5.35 There is a lack of a coherent approach to information provision by the NCOs, with no national level entry point for carer information, and no obvious single resource to signpost carers to support. There were concerns about the information available on NCO websites (e.g. as not necessarily comprehensive, impartial or Scotland-specific, and information relevant to young carers being presented within the Carers Trust UK website). The fourth recommendation is:

**Recommendation 4: The NCO body should consider the development of consistent, high level national information and provision of this through a single point of access (e.g. shared website).**

5.36 In order to facilitate the recommendations in this report (particularly Recommendation 4), it is suggested that a detailed mapping exercise of carer support organisations in Scotland should be carried out. The range of support provided to carers should be mapped, including provision by non-carer led organisations (e.g. condition-specific and independent living organisations, as well as free-standing projects funded by local authorities, the NHS and charitable trusts).

#### **Funding issues**

5.37 There are some issues with the current means of funding national work, relating to the fact that, at present, most NCO funding is provided by the Scottish Government through Section 10 funding for individual projects. The NCO Network itself receives no direct funding, and most pieces of work are the subject of individual bids, with a few exceptions. As a result, “national” activities have been funded in a piecemeal way, making it difficult to have an overall strategy underpinned by a budget matched to actions and outcomes. The fifth recommendation (to the Scottish Government and NCOs) is:

**Recommendation 5: The current mechanism used by the Scottish Government to fund national level work with carers (unlimited separate bids to Section 10) should be reconsidered.**

5.38 Additionally, the NCOs should perhaps consider working towards decreasing their reliance on Scottish Government funding (e.g. by identifying alternative funding sources) in order to reduce their future vulnerability.



## **ANNEX 1 The system of support for carers and means of accessing support**

This annex<sup>15</sup> summarises the wider context into which the NCOs fit, both individually and as a Network. A large amount of information was gathered in the review relating to this, which helps inform the overall picture.

### **The “system of support” for carers**

It is clear that there is a complex system of support available to carers<sup>16</sup>. Some of this support is “direct”, while some of it is “indirect”.

At a direct level, forms of support include:

- Information and advice.
- Training.
- Emotional support, and a focus on health and wellbeing.
- Advocacy, or direct assistance with e.g. carer’s assessments.
- Assistance in ensuring financial inclusion.
- Short breaks/respite.
- Peer support.
- Help to access to training, work or education.

Many forms of support to the cared for person are also likely to have a significant impact on carers. Examples of these supports include:

- Aspects of the promotion of independent living, including appropriate housing, aids and adaptations.
- Practical support, including appropriate housing, adaptations, equipment and assistive technologies, including telecare etc.
- Support from a Personal Assistant, or support service provider.
- Support to access training or employment.
- Access to day care and other forms of periodic support.
- Access to respite care and short breaks.

Although less common, there are also forms of support which are accessible to family units, and which may improve outcomes for carers, including:

- Support for access to social and other settings.
- Some forms of short breaks with a focus on “family” holidays.

“Indirect” support for improving outcomes for carers can include:

- Legislation, including the granting of rights etc.
- National and local strategies.
- Ensuring that carer issues are included in other strategies and through the widespread adoption of carer “proofing”.

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<sup>15</sup> The information in this annex is current at June 2014.

<sup>16</sup> See, for example, Scottish Government (2008).

- Improving awareness of carer issues, including issues for young carers, BME carers and other groups facing additional barriers.
- Identifying a minimum standard of service provision to carers throughout Scotland, and ensuring that this is met.
- Improving the identification of both adult and young carers.
- Improving the support provided by carer and other organisations.
- Developing standards and quality assurance.
- Promoting quality assured training for carers, and for those working with carers.
- Improving joint working.
- Helping improve the sustainability of support services.
- Researching carer issues, or developing on new forms of support, training etc.

### **Organisations involved in providing support to carers**

A primary source of “support” for carers is their own resilience and research, for example through the internet, as well as support from the cared for person, other family members and friends. More widely, a significant number of organisations are involved in providing support to carers. As will be clear from the descriptions below, some of these organisations provide support only (or largely) to carers, while others have a primary focus on, for example, the cared for person. Some organisations provide support to carers as part of a much broader remit.

#### Organisations specifically or largely for carers

- Carer Centres and other similar organisations.
- Other carer organisations.
- Specific projects, specialist services and specialist advice givers for carers, or particular groups of carers.

#### “General” organisations

- Health services and social care services.
- Education services, particularly for young carers.
- Housing providers.
- Short break and respite providers.
- Money advice and benefits advice agencies, such as the CAB.
- Advocacy services, some of which may be specifically for carers.
- “Unconnected” organisations, for example churches or colleges.

#### Condition-specific organisations

In addition, there is a significant number of organisations across Scotland which provide support to individuals with specific conditions, many of which also provide support directly and indirectly to carers, or provide respite and short break services.

## **Indirect influences on the system of support**

There are also a range of organisations involved indirectly in influencing or shaping the system of support, including:

- Carers themselves.
- Lobbying organisations, including NCOs.
- Policy and research organisations, including NCOs.
- Local authorities, health organisations, partnerships and public bodies, for example, the Care Inspectorate.
- The Scottish Government.
- The UK Government.

The role of the NCOs individually and as a Network is largely, although not wholly concentrated among the indirect means of improving outcomes for carers. However, the Carers Trust; Coalition; Crossroads Caring Scotland; and the Alliance operate in two ways. Each is, either directly or through its members, responsible for local service delivery (or “direct functions”), as well as performing a national role (or “indirect functions”). Even this distinction is slightly blurred with the provision of, for example, the Carers Scotland helpline, and the information provision on most NCO websites.

## **Carers’ interaction with sources of support**

It is clear that there is a considerable amount of both direct and indirect support available to carers. A clear finding from the meetings held with carers and workers as part of this review was that, while carers may view Carer Centres as their primary source of support, they are by no means their only source. Many identified that they used Carer Centres in conjunction with other sources, primarily organisations dealing with specific conditions, as well as a variety of health services.

A total of 135 carers who responded to the survey addressed the question about whether or not they were associated with carer-specific organisations. Interestingly, 51 of these (38%) identified that they were associated with more than one carer organisation. Generally, this was either a Carer Centre and an NCO, or a Carer Centre and a smaller, local organisation.

Around 54% of those who responded to the survey identified that either they, or the person they cared for, were associated with one or more condition-specific, or generic non-carer organisation. As might be expected, there was no particular pattern to these responses, with the most common being national organisations. Among those identified (at a Scottish and UK level) were:

- Age Scotland.
- Alzheimer Scotland.
- Arthritis UK.
- Barnardo’s.
- Bipolar Scotland.
- Enable.
- Health and Social Care Alliance.

- MS Society.
- Muscular Dystrophy Campaign.
- National Autistic Society.
- PAMIS.
- Parkinson's Society.
- SAMH.
- Scottish Autism.
- Scottish Huntington's Association.
- Sense Scotland.
- Spinal Injuries Association.

Carers also identified a wide range of local organisations, including, for example, local branches of national organisations or freestanding organisations (too numerous to list here).

Many also identified that they would use the internet regularly, and, increasingly Facebook as a means of sourcing both information and peer support. However, it is worth noting that the use of Facebook appeared, at least from those who attended the carer and worker meetings as part of this review, to be focused on a number of specific conditions, rather than on carer issues per se.

A number of Carer Centre workers who participated in the discussions (reaffirmed by carers) identified that their approach to supporting carers embraced multiple sources of support. A number indicated that they routinely referred clients to condition-specific organisations, as well as other forms of support (including, for example, personal development or counselling). It was also noted that Carer Centres routinely received referrals from non-carer organisations on behalf of carers.

In a number of locations, it was noted that local Carer Centres were actively working with non-carer organisations (largely branches of condition-specific organisations) and health services, as well as youth, age and faith organisations, to create, in effect, a seamless service to carers. An example was provided of this approach being supported by extensive multi-agency training on carer issues, funded by the local authority and NHS in partnership. A number of examples were also noted of Carer Centres providing training on specific conditions, in some cases supported by non-carer organisations.

It was also noted that a good deal of joint working at a local level has been undertaken as part of initiatives to identify hidden carers. Again, these have not only involved health, social work and education services, but also condition-specific, and age-specific organisations.

It was suggested by some carers that they used different sources of support at different times, and for different purposes. This was allied to the "carer's journey"<sup>17</sup> concept where, for example, early needs related primarily to knowledge about the condition, with specific "caring" needs, as well as "family" needs (such as short breaks), coming later in the journey. (The idea of a "journey" also acknowledges the

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<sup>17</sup> The "carer's journey" is a way of conceptualising how agencies can best provide support to carers. It was initially developed in Lanarkshire, but is now used in other areas as well.

fact that carers seek support [including information, advice, social and peer support] from a wide range of sources, even where a Carer Centre is the hub).

Carers and workers identified a significant number of barriers and difficulties in gaining access to support. Although many of these were specific to local circumstances or individuals, or related, for example, to the policies of individual services (and they were not analysed quantitatively), they are worth noting here in relation to the potential actions of NCOs. These included:

- Difficulties in carers recognising themselves as carers.
- Difficulties in being recognised as a carer.
- Lack of awareness of carers among professionals and other services.
- Reluctance of some professionals to focus on carer issues (particularly in the NHS).
- Lack of joined-up working at a local and a national level, with apparent failures to signpost carers to the best forms of support from carer and non-carer sources.
- “Territorialism” between carer and non-carer organisations, and a lack of a shared approach.
- Lack of “single point of contact”.
- Difficulties in assessing the accuracy of information on the internet, or in sifting through the volume on information.
- The presence of much information on some NCO websites which is not relevant to Scotland, leading to confusion, raised hopes and frustration.
- Differences in interpretation of apparently national policies.
- The “postcode lottery” in service availability.
- The sharp divide in support available between rural and urban areas, with a clear perception of an “urban” bias among NCOs and other types of national organisations.
- Failure to recognise the costs of being a carer in a variety of ways, including funding replacement care costs or acknowledging rural transport costs.
- Difficulties in securing advice and information about carer issues for specific communities, particularly BME communities.
- Lack of services for some groups, including, for example, young adult carers (now being addressed).

### **Consultation with carers**

More than half of the carers who responded to the survey in the review recalled being asked for their views about carer issues (with one suggesting “too many times to mention”). Clearly, those responding to this survey could not be assumed to be representative of all carers on this issue. However, what is relevant is the range of forms of consultation identified by these carers. Among the carer organisations and public bodies cited as having asked carers for their views were:

- Care Inspectorate.
- Carer Centres.
- Carers Scotland / Carers UK.
- Carers Trust.
- Coalition of Carers in Scotland.

- Local authorities.
- NHS.
- Scottish Government.
- Scottish Social Services Council.
- Shared Care Scotland.
- The Scottish Young Carers Services Alliance.

A wide range of non-carer organisations were also identified who had asked for views about issues relevant to caring, including:

- Alzheimer Scotland.
- Capability Scotland.
- CHAS.
- For Scotland's Disabled Children.
- National Autistic Society.
- Scope.
- Support in Mind Scotland

A number of other local non-carer organisations were also identified as having asked carers for views relevant to caring. Again, these are too numerous and diverse to list here.

The issues about which carers identified being consulted were many and varied. The most common response, both in the survey and in the meetings with carers, was “general” carer issues, along with requests for feedback on services received (of which the most commonly mentioned was a short break).

Among the service-related issues were:

- The choice of courses available to carers.
- The issues which should be covered at carers' meetings.
- Means of reaching carers or communicating with them.
- Carer assessments.
- The contents of carer leaflets and other publications.
- How carers identify professional service providers.
- Emergency cards.

A number of examples were provided of carers being asked about wider, policy related issues, such as:

- The financial costs of caring.
- Time spent caring.
- The Carers' Charter.
- The impact of caring on health and well-being.
- The effectiveness of mental health support to carers.
- How to improve the recognition of the caring role.
- Consultations at a local and national level on specific policy developments, e.g. the Carers Card, proposals for hospitals and health services.

Some were related to specific conditions, or specific circumstances, for example:

- Experiences of caring for someone with dementia.
- Autism-linked resources.
- Disability issues.
- Mental health issues.
- Transitions for young people.
- Caring for a disabled child.

Carers also identified a range of legislation, and both local and national policy issues, such as:

- The Carers Legislation.
- SDS.
- ILF.
- Welfare reform.
- GIRFEC.
- Children and Young People's Act.
- Local care plans.
- Local carers' strategies.

From material gathered from the survey, from the meetings with carers, meetings with NCOs and from documentary analysis, it was clear that there were a wide variety of means by which carers were invited to make their views known. Among those identified were:

- Questionnaires circulated by post and by e-mail.
- Via carers assessments (with some noting that social work departments were assumed to analyse and assess these for trends and issues).
- Questionnaires for completion online.
- Carer Forums, focus groups, reference groups etc., some regular and constituted, some ad hoc (with some noting specifically a distinction between adult and young carers)
- Participation in planning groups relating to services, or through, for example, local planning structures such as CHCPs or specific carer planning groups.
- Events, both locally and nationally.
- Requests through social media.
- Individual contact by workers or managers.
- Feedback forms after service delivery.
- Participation in research, by carer organisations, the Scottish Government or independent organisations, such as universities.
- Service evaluations, or, in a small number of cases, participation in inspections.
- General requests via emails or newsletters.

Some carer organisations identified having local structures in place to seek carers' views, including forums or panels which met regularly.

However, a range of constraints were also identified to carers' voices being heard. These included:

- Lack of time.
- Lack of funding to support carer engagement, including the costs of replacement care and transport.
- A reluctance on the part of carers to express their true views because they fear they might lose services, or otherwise be discriminated against.
- A perception that “equal partner in care” is only a true reflection of the situation when carers are not raising issues.
- A concern that only junior level staff, or local staff, ask for views, with senior managers not being exposed to them.

A number of carers and workers (and some NCOs) expressed a concern that carers were “being consulted to death”, with a fear that they would say “no more.” Paradoxically, other workers and carers suggested that there was too little consultation, and that carers were not seen as important.

There were mixed views of the means of passing views from a local to a national level. Interestingly, among the formal methods, the one mentioned most commonly was via the NCO to which a local organisation was affiliated, particularly the Coalition, but also the Carers Trust and the Alliance, and to an extent Shared Care and Crossroads. Also identified were more ad hoc means, such as conferences and requests for information. In a small number of cases, local organisations also identified making views known through local CHCP and other structures, or directly to MSPs or Scottish Ministers.

However, some of the carers and workers who took part in discussions as part of this research expressed concern that, in their view, issues did not appear to be passed from a local to a national level, or there was a lack of transparency in which issues were chosen to take forward, and a lack of feedback on the results. It was also suggested that some local carer organisations appeared to find it easier to have issues raised nationally than others. This was linked to some carer organisations, for example, having Board level representation on individual NCOs.



## **ANNEX 2: The National Carer Organisations**

Detailed information was gathered about the individual NCOs, which provides additional contextual information. While it should be stressed that the review did not involve an evaluation of these organisations, this annex describes their structure and operation in the following areas:

- Legal status.
- Management, structure, staffing and membership.
- Aims, objectives and areas of work.
- Funding.

The material has been developed from documents provided to the research team by each of the NCOs. By necessity, the summaries are brief, and cover only the main strands of the work of the NCOs. The findings were current at the time of writing the report (June 2014).

The NCOs represent a diverse group. Each has its own aims and objectives. Some are, in the context of the voluntary sector, relatively large, while others are small. Some deliver services, while others do not. However, it is worth noting at the outset that all of the NCOs avowedly share a common purpose. Each has, at an individual level, adopted the outcomes in Caring Together, and set these alongside their individual aims, objectives and outcomes.

### **Legal status**

In terms of their legal status, six of the seven NCOs are Scottish charities. The exception to this is the Alliance (which is hosted by Carers Trust Scotland). The Coalition, which is an unincorporated association but also a Scottish charity, is hosted by VOCAL.

Two of the NCOs are part of larger UK organisations (although they are also Scottish charities). Carers Scotland is part of Carers UK, and the Carers Trust Scotland is part of the Carers Trust. The relationship between these Scottish charities and their UK parent organisations will be explored in more detail later.

### **Management, structure, staffing and membership**

The management, structure, staffing and membership of each of the NCOs will be examined in turn. As will become clear, there is some consistency across the NCOs in most of these areas.

The four “freestanding” Scottish-based NCOs each has a Board, while the two UK organisations have a Scotland-specific Committee with representation at national Board level. The Alliance is slightly different in having a Management Committee.

With the exception of Crossroads, which has a number of local branches, each of the NCOs has a simple structure, with a single national base. Both Crossroads and MECOPP have staff dedicated to direct service delivery to carers, although in both cases, the NCO Network function is limited to part of the time of the Chief Executive.

Among the remaining NCOs, the largest has 11.7 full-time equivalent staff, the smallest (the Coalition) has only one.

The Carers Trust and Crossroads both operate affiliation programmes, where services are provided to partners on payment of an agreed fee. The others operate membership schemes of various kinds, both for individuals and organisations.

### **Carers Scotland**

The Carers UK Board has overall responsibility for operations in Scotland. It comprises 18 trustees, the majority of whom are carers or former carers. The Scotland Committee is nominally a sub-group of the UK Board. It is comprised of a maximum of 18 members, and all of the current members are either current or former carers. Up to a third of the Scotland Committee members can be co-opted in order to provide specific expertise. The Scotland Committee nominates a member to sit on the UK Board. Carers UK is a company limited by guarantee, and Carers Scotland is a Scottish charity.

Although the overall direction of Carers Scotland rests with Carers UK, in practice it has a significant amount of autonomy in terms of its overall direction. As will be noted later in relation to its work, Carers Scotland has chosen to focus on a number of areas which are led at a UK level by Carers UK, but this appears to have been by choice, rather than by direction.

At the time of the review, Carers Scotland had seven staff based in Scotland<sup>18</sup>. Six of these were based in Govan in Glasgow. The final worker was based within an Advocacy project covering parts of the south side of Glasgow.

Carers Scotland operates differing membership schemes for individuals and for organisations. There is a two-tier system in place for individual members. "Full" members pay a minimum donation and have access to all services of Carers Scotland. "Standard" members do not pay anything, and receive information by e-mail. As at January 1, 2014, Carers Scotland had 264 full members and 691 standard members.

Carers Scotland also operates an affiliate membership scheme for organisations. This entitles members to receive policy updates, but does not provide any voting rights. At January 1, 2014, Carers Scotland had 33 affiliate members (including other NCOs).

### **Carers Trust Scotland**

Carers Trust Scotland is part of the Carers Trust, which is a private company limited by guarantee (while Carers Trust Scotland is a Scottish charity). The Carers Trust was created at a UK level in 2012, bringing together the former Princess Royal Trust for Carers and Crossroads. In Scotland, the respective organisations chose not to merge.

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<sup>18</sup> At a UK level, the organisation had, at January 1, 2014, a total of 76 staff including those in Scotland.

The Carers Trust Board at a UK level has up to eleven Trustees, one of whom is a network representative from Scotland. There is also a UK Partnership forum, with two Scottish representatives. At a local level in Scotland, direction is provided by the Scotland Committee, which is comprised of representatives of the Managers Network (3); the Trustees Network (3); a member of the UK Board; Carers Trust staff and up to 3 co-opted places.

The Carers Trust in Scotland has 11.7 full-time equivalent staff, including 3.5 full-time equivalent staff funded by the Scottish Government to work on Alliance projects.

The Carers Trust provides a variety of support to affiliated member Carer Centres (referred to as "Network Partners") on the basis of a flat fee. Currently, 21 Carer Centres have affiliated for 2014-15, a reduction of 4 on the previous year. The Managers' Network meets quarterly and comprises all affiliated Carer Centre managers.

### **Coalition of Carers in Scotland**

The Coalition of Carers in Scotland is an unincorporated association. It was established in 1998, and became registered as a Scottish charity in 2008.

The work of the Coalition is directed by an Executive Committee, comprised of carers, former carers, staff and former staff of carer organisations around Scotland. The members of the Executive Committee are elected at the AGM.

The Coalition has one full-time member of staff. Since the establishment of that post, one Carer Centre (currently VOCAL) has acted as employer and responsible organisation for the staff member, in terms of both receiving and disbursing funding. The work of the Coalition is supported both by Executive Committee members and staff from member organisations who donate time to take forward projects under the banner of the Coalition.

As at January 1, 2014, the Coalition had 107 organisational members, including Carer Centres, Crossroads branches and young carer projects. Carers Scotland, the Carers Trust, Shared Care Scotland and MECOPP are also members of the Coalition. The Coalition also has a small number of individual members (around 30). Payment of an affiliation fee is optional.

### **Crossroads Caring Scotland**

Crossroads was established in the late 1970s to provide domiciliary care. Until 2012, it was part of a wider UK organisation. In 2012, Crossroads in England and Wales merged with the Princess Royal Trust for Carers to form the Carers Trust. In Scotland, however, Crossroads and the Carers Trust Scotland chose not to merge, and Crossroads now operates as an entirely independent Scottish charity. It is a company limited by guarantee.

In common with other NCOs, the Board consists of elected members (12) and co-opted members (up to 6). There is no eligibility requirement in relation to status as a carer.

Crossroads has three elements. It is:

- A direct provider of support to carers and their families through 24 directly managed services.
- An umbrella organisation for a further 17 affiliated services.
- A “representative” organisation (its “NCO” function).

The national office consists of 10 posts including the Chief Executive, and, in total, the organisation employs more than 800 people. This figure includes only directly managed Crossroads services. As noted earlier, Crossroads now directly manages 24 schemes. A further 17 schemes are affiliated. Each of the affiliates is an independent charity. Crossroads Caring Scotland (the national body) provides a range of shared services in return for an affiliation fee. The “NCO” element of the work of Crossroads (the representative function) consists of part of the time of the Chief Executive’s post.

## **MECOPP**

MECOPP was established as an independent charity in 2000. It is a company limited by guarantee, providing services directly to a number of ethnic minority communities within Edinburgh. Over time, as will be set out below, that remit has expanded significantly.

MECOPP has a Board of Directors, which, at the end of the 2012-13 financial year, consisted of nine members, seven of whom were carers. The Board is elected at an Annual General Meeting, and, in common with other NCO boards, can co-opt additional members.

In total, MECOPP has around 20 staff providing services in Edinburgh and in Gypsy Traveller projects. Although there are a number of BME-focused workers employed by organisations around Scotland, none of these is employed by, nor directly affiliated to MECOPP. The “NCO” element of MECOPP consists of part of the time of the Chief Executive’s post.

MECOPP has 77 individual and 4 organisational members (although this does not relate to the NCO element of their activity).

## **Shared Care Scotland**

Shared Care Scotland (SCS) is a company limited by guarantee, and is a Scottish charity. The work of SCS is directed by a Board, elected at an AGM. The Board currently consists of seven members, together with three co-opted advisors. Although there is no eligibility requirement specified, carers can be co-opted onto the Board. SCS has six full-time staff, based in Dunfermline and is not a membership organisation.

## **The Alliance**

As noted earlier, the Alliance is not a legally constituted body. It was created in 2001 as a means of bringing about informal networking, at which time it was agreed that there would be no benefit in formalising the structure.

The staff of the Alliance (3.5 full time equivalents) are employed by the Carers Trust, which also acts as the responsible body in relation to funding. The staff are line managed by the director of the Carers Trust.

The Alliance has a small management committee, drawn from its members. At present, the post of Chairperson is shared between two members. Unusually, the management committee has no responsibility either for the contract with the Scottish Government, nor for the day-to-day work of staff members. In both cases, this rests with Carers Trust Scotland.

The Alliance operates an open approach to membership, which is free. It has members not only from Carer Centre-based projects, but also from other voluntary organisations and, in a small number of cases, from social work-led services. The Alliance currently has a total of 48 members, of which 20 are associated with organisations affiliated with the Carers Trust.

### **Aims and areas of work**

NCOs' aims and areas of work were explored in discussions with them. Additionally, some of the individual NCOs have formal strategic plans which provided further information.

In all cases, the aims of the individual NCOs appear to have been defined in the light of the work they do, and to be entirely consistent with, for example, the national strategy (see Section 1) and the purposes of the NCO Network (see Section 2).

The NCOs carry out a diverse range of work. Crossroads and MECOPP both have extensive local service delivery to individual carers, combined with a national management, policy and research function. The Carers Trust and Crossroads also provide a variety of support services to those organisations which choose to affiliate. The Coalition and Alliance both provide a range of services to their members. The main work of Shared Care Scotland is the distribution of Scottish Government funds for short breaks, as well as the overall development of policy and capacity.

Most of the NCOs undertake some form of policy work related to carer issues, as well as research to support this. A number undertake campaigning and advocacy work for carers (as well as carer organisations) at their own hand, as well as part of the NCO Network.

### **Carers Scotland**

Carers Scotland works within the overall Strategic Plan for Carers UK, and does not have either a specific Strategic Plan or Business Plan for Scotland although, at the time of the review, the latter was being produced for 2014-15. The Carers UK plan, at the time of this review, covered the period from 2011-14, with a new version in preparation.

Carers UK describes its vision as:

“We want society to respect, value and support carers.”

The Strategic Plan sets out five objectives for 2011-14 (and it is understood that they are unlikely to be changed in the new plan in summer 2014). These are:

- Providing carers with the support they need where and when they need it.
- Bring about lasting change through influence, education, and training.
- Giving carers a stronger voice.
- Partnerships in collaboration.
- Well-managed and governed organisation.

With the exception of a small project providing advocacy in one part of Glasgow (funded by the Scottish Government), Carers Scotland generally does not provide services directly to carers. This was a conscious choice by Carers Scotland. Carers UK provides some services in England.

The work of Carers Scotland has three main strands: advice; information; and campaigning. Carers UK operates a national helpline for carers five days per week, and this is accessible from Scotland. Carers from Scotland are directed to basic relevant information, and signposted to resources in Scotland. A monthly newsletter is circulated to all members, and includes both UK and Scottish policy and service issues. Carers Scotland is also able to circulate a wide range of briefings prepared by Carers UK on UK policy and financial matters (for example, the Budget and Autumn Statement, benefit changes and other legislation).

Carers UK has an extensive programme of research to which Carers Scotland generally contributes a Scottish dimension. A number of research reports and enquiries which have provided material for NCO Network publications.

Carers Scotland has chosen to focus on a number of areas of work which are quite separate to any of the other NCOs, taking forward work in relation to employers, telecare and telehealth. These areas of work have generated a number of UK level research reports which are also relevant to Scotland.

Carers Scotland also has a training programme, focused largely on service providers. This is separate from the training programme for carers funded by S10, and hosted by the Carers Trust (although Carers Scotland participates in this).

Carers Scotland (through Carers UK) has good links to national UK level issues. It also provides much of the administrative support for the NCO Network, and has organised the Carers Parliament (with funding and support from the Scottish Government).

## **Carers Trust**

The objects of the Carers Trust are:

- The relief of those in need by reason of age, ill-health, disability, financial hardship or other disadvantage through the provision of comprehensive support services for carers throughout the United Kingdom, the Channel Islands and the Isle of Man.

- The assistance of carers in need including by raising awareness of issues affecting carers.
- The promotion of the efficiency and effectiveness of charities which operate for the care and support of carers.

The Trust has four key themes:

- Reaching out to more carers.
- Working with carers with complex needs (with a current focus on mental health and dementia).
- Improving the quality of services.
- Focusing on young carers and adult carers.

The work of Carers Trust Scotland splits into two main areas: work to support “Network Partners” (affiliated Carer Centres); and policy and development work on wider carer issues. The Trust also hosts the Alliance, as noted, and acts as lead partner for a National Training Consortium on behalf of the NCO Network.

In terms of support for Network Partners, the Trust provides a variety of services, including quality assurance and information. It also supports its Network Partners with employment, legal and other technical matters. Development work has been focused both on national issues and on supporting Carer Centres. As noted earlier, there is a current focus on mental health issues, and other areas of development work undertaken have included, for example: procurement; SDS; the use of social media; and the interface between community pharmacies and young carers. As noted earlier, the Trust is also working in the area of young adult carers.

A Fundraising Officer and a Partnership Development Officer are among staff employed at a national level, and both work at a national and local level on behalf of the Carers Trust and their Network Partners. The focus of the latter post is on developing links with non-carer organisations with an interest in carer issues, such as condition or age-specific organisations. A member of staff from the Trust undertakes a significant proportion of the policy-related work of the NCO Network.

### **Coalition of Carers in Scotland**

The Coalition has a shared vision (consistent with the Shared Vision in “Caring Together”) that:

“All Scotland’s unpaid carers will feel valued, included and supported as equal partners in the provision of care, and will be able to enjoy a life outside of caring.”

The Coalition agreed six aims in its current development plan:

- To strengthen the provision of information and mutual support to carers and carer-led organisations in Scotland, and strengthen communication between local carer-led organisations and national partners.
- To monitor and evaluate the impact, implementation and outcomes of national policy and legislation for carers locally.

- Develop and disseminate examples of best practice throughout Scotland and highlight areas where improvements are desirable.
- Develop a collective response to key issues enabling members of the Coalition to bring their concerns to the attention of interested parties at local, regional and national level.
- Promote the active participation of carers in local and national strategic planning meetings.
- Contribute effectively to the implementation of the Carers and Young Carers Strategy 2010 to 2015 'Caring Together'.

The work of the Coalition includes:

- Providing information and advice to member organisations and individuals.
- Providing an opportunity for networking and information exchange through quarterly network meetings.
- Carrying out local consultation, and supporting local engagement.
- Developing briefing and other material for circulation to members, as well as for the use of other organisations including the NCO Network.
- Promoting carer training.
- Campaigning directly as the Coalition, as well as supporting campaigning by members on local issues.

In 2012-13, the Coalition carried out a joint project with Volunteer Action Shetland to develop a virtual Carer Centre. It has been proactive in supporting a network of rural Carer Centres, though, for example, a regular teleconference. It has also acted as a channel for the views of Carer Centres in rural areas.

The Coalition has developed Best Practice Standards for Carer Engagement. It has also identified the Health and Social Care Alliance and Age Scotland as partners, with a focus on channelling information about specific conditions, and age-related carer issues to members.

### **Crossroads Caring Scotland**

The overall aim of Crossroads is to:

“Improve the quality of life, health and well-being of carers across Scotland through the provision of short breaks and other practical support.

The organisation has four broad objectives:

- To develop sustainable local services throughout Scotland which provide practical support, including short breaks, for carers and their families.
- To ensure that such services are of the highest quality and exceed the expectations of carers, service users and regulatory bodies.
- To support the involvement of local carers and their families in the planning and development of local services.



- To inform the public debate on the need for greater access to and expansion of carer respite services.

Crossroads provides short breaks to carers and their families in their own homes. In 2013, Crossroads provided more than 820,000 hours of short breaks. Crossroads Caring Scotland is the national body which provides a variety of central services to directly managed schemes, and to affiliated Crossroads schemes.

## **MECOPP**

MECOPP's vision is of:

“... a Scotland where minority ethnic carers have full and equal access to services and supports which promote and protect their quality of life and sustain them in their caring role.”

In 2013, MECOPP secured external funding for an organisational review, facilitated by external mentors. This focused on the overall strategic direction of the organisation, and on the management of its diverse strands.

MECOPP's work is focused firstly, on improving outcomes for individual BME carers, and secondly, on a set of outcomes designed to ensure that organisations are better able to “recognise, understand and respond to the specific needs of BME carers.” It was originally established as an organisation to provide support to BME communities in Edinburgh under contract to the local authority and NHS. However, in recent years, it has expanded its reach, and the largest strand of its work by value is in managing a variety of Gypsy Traveller projects in seven local authority areas around Scotland, with funding provided by the Scottish Government.

Although none of these activities can be regarded as central to MECOPP's status as an NCO, the organisation had provided specialist input and training in relation to working with BME carers to a number of organisations in Scotland prior to being invited to join the NCO Network in 2011–12.

In the last three years, MECOPP has been successful in securing non-recurring grant funding from a number of Scottish Government divisions to take forward work to extend elements of relevant Scottish government policy to BME communities.

MECOPP has developed an audit tool for use by public sector partners in relation to support for BME carers. The publication “On the Margins” was created with support from the Scottish government Carer Policy Branch and contains a diagnostic questionnaire and action plan. MECOPP also developed a training pack on cultural competences in single shared assessments.

MECOPP is presently undertaking a project, funded by the Carers Policy Branch, to enable BME employers to support carers. This is allied to the Kitemark project being taken forward by Carers Scotland (described elsewhere). MECOPP has also done work on the implementation of self-directed support (SDS) in south Asian communities.

MECOPP has provided responses to a number of Scottish Government consultations, focusing on issues specific to BME communities, as well as being a signatory to NCO Network responses. Additionally, MECOPP and Carers Scotland were commissioned by the Scottish Government to develop a Carers Charter.

## **Shared Care Scotland**

Shared Care Scotland's current purposes are:

- To improve short breaks policy and practice at all levels through collaborative effort.
- To advance good practice through research, learning exchange and development projects.
- To provide accessible, up-to-date information and advice about short breaks to those who use, provide or plan services.
- To connect people together to share experiences and ideas.

The bulk of SCS's work is related to the promotion of short breaks, the development of innovation in short breaks and the management and distribution of Scottish Government funds. In addition, SCS provides an online and telephone enquiry service to help carers and service users (as well as support providers) to find short break and respite services to match their needs. Information is also provided to national and local organisations about short break services.

SCS promotes events, networks, publications and learning resources to share knowledge, experience and successful practice. This work, although primarily in the area of short breaks, also extends to other areas of carer policy.

SCS has commissioned research on behalf of the NCO Network, both in its own right and using funding from the Scottish Government.

## **The Alliance**

Although, as noted, the Alliance has no legal status, and is located within the Carers Trust, members agreed a specific statement of purpose, as follows:

“The Scottish Young Carers Alliance exists to service all young carers initiatives in Scotland with information and support to develop their practice and provide quality services to young carers. The Alliance also provides information and advice at strategic level, seeking to influence those developing national policy, guidance and legislation to ensure that the needs of young carers are acknowledged and met.”

The primary direction for the work of the Alliance is taken from “Getting it Right for Young Carers”, the National Strategy. The Alliance, as well as (it is understood) the vast majority of young carer projects, have adopted the outcomes set out within the National Strategy.

The work of the Alliance has two main parts: networking; and national services. There is substantial variation across Scotland in the work of individual young carer projects, and the perceived role of the Alliance is to facilitate the exchange of

information between them. It hosts four meetings a year, which are promoted at no cost to attendees. The Alliance also acts as a channel for the views of young carers both to other carer organisations, and to the Scottish Government.

The Development Worker supports these activities, and also provides direct support to individual young carer projects and workers. Support has also been provided for the development of local young carer strategies. Although the post is based with the Carers Trust Scotland, support is available to any young carer organisation, regardless of affiliation. The Alliance also has access to policies, templates etc. from the Carers Trust, which can be made available to non-affiliated organisations.

The most visible element of national service provision by the Alliance is to promote and organise an annual Young Carers Festival. This is done nominally on behalf of the NCO Network as a whole. As a result of consultation with young carers at the Festival, the Carers Trust, on behalf of the Alliance, obtained funding to employ a Mental Health Development Worker. This post has now been extended to cover adult carers as well.

The Carers Trust at a UK level obtained a significant corporate donation to support work with young adult carers, a group previously identified in Scotland as falling between existing sources of support. This work is understood to be being taken forward as a Carers Trust Scotland project, although the local delivery of services may be taken forward alongside young carer projects linked to the Alliance. (A number of workers and carers who took part in this research expressed disappointment that this work was not being implemented as an NCO project, open to all Carer organisations). The Alliance has also taken part in an EU-sponsored project, "Together for Young Adult Carers".

## **Funding**

Funding was examined in detail, although full details cannot be given here because of commercial confidentiality. Overall, however, the issue of funding is complex. As has been clear throughout this annex, the NCOs vary considerably in relation to their status, structures and work. This makes it difficult to distinguish the funding which relates (a) specifically to Scotland, and (b) to national level, or strategic work.

In the case both of Carers Scotland and the Carers Trust, neither publishes specific Scottish accounts. Both, however, were able to provide summaries of the budgets allocated to work in Scotland.

The Alliance has not published any accounts as it has no legal status. The host organisation, the Carers Trust, acts as the responsible body for the receipt of grant funding and all expenditure.

As in other respects, Crossroads and MECOPP are different to other NCOs in that a significant proportion of their income is derived from local contracts for service delivery direct to carers. Additionally, MECOPP delivers a number of services to Gypsy Travellers through Scottish Government grant funding. All of the NCOs, with the exception of the Alliance, benefit from some core funding from the Scottish Government in relation to their national (although not specifically Network) activities. The scale of this core funding varies considerably, as does the proportion of overall

income it represents. Most of the NCOs also receive non-recurring grant funding. Much (although not all) of this funding is also derived from Scottish Government sources.

Both the Carers Trust (in relation to the Alliance and the NCO Training Consortium) and Shared Care Scotland (in relation to the management of government grant funding) also receive management fees.

The total amount of core funding provided by the Scottish Government to the NCOs was £613,080 in 2012-13.

The total funding overall in the last three years, excluding grants for short breaks distributed by Shared Care Scotland was:

- 2010-11 £543,545
- 2011-12 £1,196,699
- 2012-13 £1,267,808

## **Overview and perceptions of the individual NCOs**

Throughout the research, a number of comments were made about individual NCOs. As the focus of this research was on the operation of the NCOs as a group, and not an evaluation of individual NCOs per se, some of the broad themes are discussed. These provide some insights into the perceived benefits of the individual NCOs, some of the concerns and challenges faced, and some of the issues which are relevant to the interface between the individual NCOs and the NCO Network.

Many comments were made on the overall effectiveness of the work of individual NCOs, with a wide range of examples of ways in which they were seen to provide a good service, to carers, workers and organisations.

### **Areas of work and the pattern of provision**

Many comments were made on different aspects of the work of the NCOs. For example, the value of support from the NCOs to local organisations was highlighted, with some of the organisations responding to the survey suggesting that individual NCOs helped increase knowledge among support providers, as well as facilitating understanding of the “bigger picture”. In some cases, NCOs were identified as an effective first point of contact for carers and organisations, and would make onward referrals.

Some NCOs were identified as either having services or interests tailored to the needs of particular communities of interest, or specific issues. Among the examples given were: rural communities; young carers; older people; BME carers; and LGBT carers. In terms of the coverage of the NCOs, it was suggested, however, that there could be gaps in provision to carers in some specific circumstances.

Respondents to the individual survey highlighted strengths of particular NCOs in terms of, for example: providing a channel for carers' views; providing a link to decision making and policy; awareness raising and campaigning; and research. These areas of work were also identified by both boards and staff members. A

number of respondents to the surveys suggested (in various ways) that individual NCOs seemed “well-connected” to their members and affiliates.

In terms of the work of individual NCOs, however, an issue raised in some of the discussion groups was that their arms’ length function in relation to carers means that they can only provide information on national issues, making it difficult to use this information locally, given the level of local variation in practice.

A number of participants in the review noted that there appears to be a positive approach to joint working among the NCOs (including to bilateral joint working, separate to the multi-lateral joint working facilitated through the NCO Network).

One of the concerns raised, however, by respondents of all types (including both national and local staff, board members and trustees) was a general lack of knowledge of the individual NCOs and a lack of clarity about what individual NCOs offer carers. It was argued, for example, that the “reach” of the NCOs was not as great as it could or should be, and one of the organisational respondents suggested that they were not proactive in communicating with small third sector organisations. It was also suggested that the titles of some of the NCOs did not always make their role clear, nor differentiate between them.

A further concern expressed was that some NCOs appeared to be no longer representative of their “constituencies”, and had adopted much more of a “top-down” approach. It was also suggested by a few of the organisations responding to the survey that there appeared to be variations in the quality of the work of individual NCOs.

A further issue raised was that the challenging financial climate appeared to have led to NCOs taking on increasingly diverse areas of work, which, it was suggested, could result in a reduced focus on key areas of work. One of the discussion groups also expressed concern that the impact of some of the work taken on by individual NCOs would impact on the way they operate.

### **Composition of the NCOs**

A number of carers suggested that having a number of NCOs, in conjunction with local carer organisations, meant that carers could have a choice of where to obtain support, including the option to obtain multiple perspectives on an issue should they choose to do so. This was also echoed by workers who identified that having multiple NCOs allowed them to choose, for example different routes to raising issues.

A common thread among the strengths identified for the work of the individual NCOs related to their knowledge, skills and expertise specific to the needs of carers. Individual NCOs were described by carers and workers, for example, as supportive, carer-focused, friendly and welcoming, and non-stigmatising. NCO staff and Board members also viewed these factors as among their strengths.

It was noted by some carers, as well as some staff and board members, that having a diversity of NCOs appeared to allow a greater level of focus on marginalised groups, such as people in rural areas, BME carers and older carers.

The most common concern, however, from participants of different types (but particularly carers and local workers), was that seven NCOs was “too many”, and that there appeared to be areas of overlap in terms of their functions and services. A small number of organisational survey respondents also suggested that there was not always clarity about which of them were part of the NCO Network and what the criteria for inclusion were. Related to these comments, although there was little knowledge of the actual costs of the individual NCOs, some participants suggested that individual NCOs were “expensive”, or did not provide good value for money.

## **ANNEX 3: Issues relating to potential models**

As set out in Section 4 of the main report, a range of suggestions were made about structural options for the NCO body, and these could be grouped into three main types of model (although there would clearly be a range of different ways of translating these into practice). These were:

- Retention of the current model of an informal partnership.
- Development of a formal partnership.
- Development of one (or a small number) of national organisation(s).

These models, and some of their potential implications (based on the findings of the review) are set out below, as a starting point for further consideration. It is recognised, however, that there would be a need for further detailed discussion of these models, and their strengths and weaknesses.

Issues relating to each of the models have been grouped under a range of headings:

- Structure.
- Staffing and responsibilities.
- Potential for development.
- Efficiency and effectiveness.
- Achievability.

### **Informal partnership**

#### **Structure**

- This model would retain the status quo, being an informal partnership without a constitution or any formal legal status.
- Participation would be on a voluntary basis by each organisation.
- Participation would be based on informal agreement of the contribution of each NCO.
- The model would continue to rely on “goodwill” as the basis of participation, but the informal nature of the partnership may make it vulnerable to change.
- Oversight of the work of the partnership would be undertaken by members at partnership meetings.
- There would be no management structure, formal scrutiny, or clear accountability, although some of these processes could be developed further than they are at present.
- There would be no single point of contact for the partnership, although this could be developed.
- The model would not preclude the development of mechanisms for inclusion of a more diverse range of legitimate stakeholders as participants, and membership arrangements and responsibilities could be clarified.

#### **Staffing and responsibilities**

- Responsibility for the functions identified in each of the key areas would be split between the NCOs on the basis of mutual agreement as at present.

- It would be possible to develop this model further, to identify a voluntary lead officer (perhaps supported by a sub-group) to take responsibility for each of the overall areas of work (e.g. through co-ordination of the specific tasks and accountability for reporting on progress).
- The allocation of responsibilities would be on a relatively ad hoc basis, with a risk of duplication.
- There would remain no dedicated administrative support for the work of the partnership.
- The partnership would be unable to employ staff directly. The only way for the partnership to have staff support would be through an indirect route (i.e. where one NCO applies for funding and employs a member of staff dedicated to partnership activities). However, this member of staff would neither be employed, directed nor managed by the partnership. This has a range of potential risks in relation to partnership working, transparency, accountability and how the work is directed.

**Potential for development**

- The partnership could continue to develop its strategy, aims and objectives as at present.
- There would be relatively little potential for expansion of the role or development of the functions, largely due to resource constraints.
- There could be a lack of capacity (given the volume of potential work and the increasing challenges, as well as members' individual responsibilities within their own organisations) and the partnership would be unable to apply for funding in its own right to develop capacity.
- The model relies almost totally on funding from the Scottish Government to individual NCOs for those aspects of the work which they are able to bring to the partnership.
- Although the partnership, as it currently operates, can work around the issue of Scottish Government funding, this brings potential difficulties.
- The partnership would not be able to apply for non-Scottish Government funding, other than through a third party (e.g. an individual NCO).
- There may be scope for some efficiency savings through sharing office space, sharing functions etc.

**Efficiency and effectiveness**

- The model would ensure the retention of existing strengths of the NCO Network, as identified in the review.
- Some of the concerns and challenges, however, would not be addressed.
- The work could be constrained by the availability of staff time and financial resources, and many of the types of work identified could not take place, or would be limited in scope and scale.
- There is potential for competition, disagreement and conflict



to undermine the partnership working (although this has not happened to date).

- There is a risk that the programme of work would be based upon the availability of donated staff time, and that agenda would be driven by the interests and specialisation of individual NCO members, rather than by a more strategic approach.

### **Achievability**

- The implementation of this model would be achievable with no, or minimal change.
- Most of the NCOs appear to prefer retention of the status quo, making implementation straightforward.
- This model would not directly challenge the participation of any of the current organisations.
- This model would not cause any disruption to existing work.

### **Formal partnership**

#### **Structure**

- This model would build upon the existing structure, and would involve a formal partnership structure and the establishment of a formal “entity” (with or without staff members).
- Arrangements for management and governance of the partnership and any staff would be clarified in formal documents.
- There would be more formal scrutiny and transparency, although there would be a need to avoid problems with a lack of clear support, supervision and accountability for any staff.
- Oversight would be through a specified structure (either involving the members, or a “board” or “advisory group”).
- The model would not preclude the involvement of additional stakeholders, but the basis of this would be clear.

#### **Staffing and responsibilities**

- The model could be implemented with or without staff, but would allow the partnership to appoint some shared core staff if this were considered beneficial.
- Alternatively, responsibility for work could be shared between the NCOs on the basis of formal agreement.
- Any staff appointed would need an appropriate level of delegated authority to be able to carry out their work effectively.
- In the first instance, staff could be “hosted” by an individual NCO, but overseen by the partnership (although this would require a clear agreement on how the post would be line managed, and how their work would be directed). In time, any national staff could be employed and managed by the NCO partnership itself.
- At the most basic level, there could be a dedicated Co-ordinator who could provide a “postbox” resource to facilitate

and co-ordinate the work, with the rest of the work carried out by members, as in Option 1.

- A further potential role for a shared member of staff at an early stage would be to assist in developing a detailed structure and strategic plan.
- It would also be possible to have additional shared staff for some key aspects of the work of the partnership as the structure developed. These posts could be added incrementally. For example, there could be a national development officer for the following functions:
  - Policy and strategy.
  - Monitoring and research.
  - Developing capacity and practice (e.g. funding and training).
  - Communication.
- The services function (for which a specific national development officer would seem least necessary) could be taken forward as per Option 1 (i.e. via a lead officer and sub-group).
- These staff members could co-ordinate and develop work in these areas, with direction from a sub-group and assistance with the day to day work (as per Option 1) from other relevant staff in the NCOs.

### **Potential for development**

- The partnership could apply for funding in its own right, both from the Scottish Government and other sources.
- This would extend the capacity of the partnership, whether or not there were specific shared staff.
- It could provide dedicated resources for strategic development, and could potentially enhance the work of the partnership.
- However, this model could not be funded by subscriptions (as happens with some other similar networks), as there are not enough NCOs to do this.
- Using the example of the Health and Social Care Alliance, this could perhaps be an option that the Scottish Government could consider funding directly.
- If shared staff were to be appointed, these would be unlikely to be wholly additional posts. It may be that some NCOs would have to give up some element of their funding to support these as it is unlikely that additional funding would be forthcoming from the Scottish Government.
- There may be scope for some efficiency savings through sharing office space, sharing functions etc.

### **Efficiency and effectiveness**

- The model would retain and build upon the current strengths of the partnership, while addressing many of the concerns highlighted.
- There would be an opportunity to focus on the co-ordination of the group, its strategy and activities and links with relevant

stakeholders.

- There would be a single and clear point of contact for the NCO partnership, and arguably a more coherent approach to the development and implementation of the work.
- This model would reduce the likelihood of duplication. It would allow joint working on joint projects (or where there would be a risk of duplication), while retaining individual organisations' strengths and areas of expertise.
- The model could enable a clearer identity and "branding" for the partnership.
- The model would enable a more strategic approach to work undertaken, but further formalisation could impact on the "goodwill" in the current partnership, and reduce flexibility and co-operation.

### **Achievability**

- The model could be implemented incrementally and at a pace to reflect the changing needs and capacity of the partnership.
- A number (although not all) of the NCOs stated that they would consider this to be an acceptable way forward or "first step", but there were also some reservations.
- While addressing a number of the perceived concerns, an incremental approach would lead to relatively slow change, retaining some of the problems which have been identified in the meantime.
- The model would not directly challenge the participation of any of the current organisations, but would provide a clear basis for this.
- The model would be unlikely to be particularly disruptive to current work, at a time when there are high profile carer issues requiring input from the NCOs.
- There is considerable longer term potential for this model to address many of the issues highlighted in the review.

### **One national "organisation" or a small number of national organisations**

#### **Structure**

- This model would involve major structural change.
- There would be one overall NCO organisation, or a much smaller number of NCOs than is currently the case.
- Some or all of the NCOs would have to amalgamate, with functions transferred to the "new" NCO or NCOs.
- The single national organisation could have different "branches" for each of the different work streams identified, and a range of staff within those branches.
- Alternatively, a small number of re-configured or new NCOs could each focus on a key area of work (e.g. policy and research; training, awareness and capacity development; and services and support).
- The management and governance structure would be clear

- and specified, and there could be a single point of contact.
- There would be clear arrangements for oversight and supervision.
- There would be greater transparency, accountability and arguably more efficient use of resources (both time and money).

### **Staffing and responsibilities**

- Staff would be appointed to fulfil key roles in the specific areas of work required.
- In each case, the functions within the existing NCOs (identified in the key work) would be replicated in the new organisation(s), although the actual staffing composition may differ.
- While there would clearly be a need for detailed discussion and consideration of the optimum structure and staffing, the types of overall functional areas and roles might include:
  - Overall management and co-ordination (e.g. CEO; Senior Managers; Admin support / finance). With more than one organisation, there may be a need for an overall Co-ordinator for each work stream to be located within one of the NCOs.
  - Policy and research (e.g. Policy manager / officer(s); Research Manager / officer(s)).
  - Training, awareness raising and capacity development (e.g. Training and development manager / staff; Funding officer; Local services and centres development and support staff; Equality development officer(s) / specialist staff; Media and Communications manager / staff).
  - Services and support (e.g. Services and events manager / staff; Information Officer and Assistants; Shared care manager and staff; Festival Coordinator; Parliament Co-ordinator; and Project Officer(s) as required).

### **Potential for development**

- A single NCO, or small number of NCOs with specific responsibilities, could apply for funding (bringing the benefits described previously, in terms of increasing capacity and developing work further).
- There would be efficiency savings through the consolidation of office space, creation of shared functions and potentially in other areas, although these may take some time to emerge, and may need to be offset in the short term against the costs of making the necessary changes.

### **Efficiency and effectiveness**

- There would be a straightforward means of strategic planning and co-ordination, with clear roles and coherent aims and objectives.
- This model offers the option with the lowest likelihood of duplication of functions and potentially the best value for money.
- There would be a single and clear point of contact for each of

the areas of work of the NCOs and there would be an obvious route for the provision of a national “voice” for carers, as well as for robust links to other relevant local and national organisations.

- There would be clear branding and identity.
- There is, however, a danger of the loss of organisational diversity and skills and some of the strengths of the current arrangements.
- There would also be a very large amount of disruption in a move to such a structure, at a very busy time for the NCOs. This would impact on the work of the NCOs themselves, and on other organisations which value their input, however, it is likely that with prior planning, these impacts could be minimised.

### **Achievability**

- The model would require wholesale change to the NCOs individually and as a group.
- This model would not be favoured by any of the NCOs (on the basis of the contributions made to this review).
- There would be a loss of ownership, and potential damage to the positive work and relationships that have been built through existing arrangements.
- There would be considerable disruption to current work.
- To start to restructure from scratch would take no account of the historical development of the NCO Network and would not be considered constructive.
- The development of a “new” NCO would require funding support from the Scottish Government, both for development and for on-going revenue. It should be assumed that the funding available for such an option would be less than that currently provided for the current NCOs and network activities. However, it is also likely that there would be some reduction in overall costs as a result of the implementation of such an option.
- It is unclear how such a model could work with the UK-wide organisations in the Network, and current funding arrangements. It is considered highly likely that it would be difficult to secure agreement for mergers to take place.

## **ANNEX 4     Methodology**

The methodology used for the review was designed to reflect the overall aims and objectives, and specifically the need to identify options for the way forward to meet the related and complementary needs of carers, the NCOs and the Scottish Government.

It was also important to reflect the complexity and diversity of the nature and operation of the NCOs and the pattern of support to carers, and to recognise the need to explore the operation of individual NCOs alongside the operation of the Network. It would have been impossible to achieve the objectives of this review without taking an overview of the general nature of support provided to carers in Scotland (and identifying any points of overlap and distinction), as well as the nature of individual NCOs' input to relevant policy (both local and national).

In order to do this, there was a need to ensure that the views of all of the relevant stakeholders were identified. As such, a number of complementary research techniques were used, with a combination of quantitative and qualitative work. The methods included:

- Examination of documentary information.
- Development of a template and database.
- Interviews with a range of stakeholders.
- Group discussions with a range of stakeholders.
- A written "consultation".
- Analysis and reporting.

Each aspect of the methodology is described in more detail below.

### **Documentary evidence**

The first stage in the process involved examining existing key documentary information, to inform the development of the research tools. It was vital, at the earliest stage, to take account of the initial scoping study report prepared by the Scottish Government consultancy team. This provided specific information about the function and operation of the NCOs, the current Network, relationships and joint working, the scope for rationalisation, and the funding relationships. It also helped to avoid duplication in the information gathering.

A range of other documentary material was also examined in the course of the review, providing further contextual and operational information (both at a general level and in relation to particular NCOs). This included, for example:

- Policy and strategy documents.
- Minutes of meetings.
- Annual reports, evaluations, research.
- Funding applications and agreements.
- Website information.

## **Template for comparison**

As noted above, it was considered important, as part of this work, to examine the actual operation of the individual NCOs and to be able to compare the services provided (particularly in terms of identifying points of overlap and distinction). In order to do this, information was collected from a range of sources. Some was gathered from existing documentary information (e.g. the scoping study). Some was gathered in discussion with the NCOs. Other information was gathered using a template which was provided to each of the NCOs.

The information sought via the template included, for example (where such material was not already available from other sources), data about issues such as:

- Structure and governance.
- Perceived “national” and “local” roles, and perceived “representational” roles.
- Resources available (staff, practical and financial), and premises.
- Sources and amounts of funding, as well as revenue generation.
- Size and nature of their membership (individuals and organisations).
- Nature of clients, service provision and use (include revenue earning services).
- Online communication methods.
- Research capacity.

The material from the template was then analysed and compared. From this, RHA developed a matrix as a means of understanding the information. This provided a clear exposition of which NCOs were involved in each type of work, which were fulfilling particular roles etc.

It had originally been hoped also to examine and analyse the NCOs’ existing database information and map their membership. This proved impossible, however, as a result of data protection issues. Instead, membership patterns and key issues were explored through the written consultation process described later.

## **Interviews with stakeholders**

A series of face to face interviews was held to explore the overall views of the senior managers of the NCOs and other relevant stakeholders.

## **NCOs**

Face to face interviews with the overall Manager / Chief Executive (or equivalent) of each of the NCOs formed the first stage of gathering stakeholder views. These interviews explored issues relating to the overall strategic direction of support to carers, in the context of this review. The interviews covered issues such as:

- Overall purpose and expectations of the NCOs.
- Role of the NCOs in the pattern of provision of support to carers and input to policy.

- Links between NCOs, and links to other organisations.
- The current NCO Network, its role and effectiveness.
- Key requirements of Government and service providers.
- Current issues in service provision (e.g. efficiency and effectiveness) and any recent changes impacting on NCOs.
- Funding issues.
- Constraints faced, potential future developments and improvements.

## **Other stakeholders**

Interviews were also carried out with a sample of other stakeholders, to identify their views of the operation of the NCOs, particularly their interface in the context of carers' needs. Participants were chosen to reflect different types of organisation, as well as different geographical areas and different service user groups (e.g. disabled people; elderly people; children and young people; ethnic minority groups etc.) and organisations with a specific relevant focus. Interviews were also carried out with representatives of local authorities and the NHS.

These interviews covered issues such as:

- The role of the organisation in the overall pattern of provision of support to carers and input to carer policy.
- Overall purpose and expectations of the NCOs.
- The organisation's links to NCOs and cross-referral.
- Perceptions of gaps and distinctions in provision.
- Perceptions of the current NCO Network, its role and effectiveness.
- Impact of the Network on other stakeholders.
- Current issues in service provision to carers and carer policy.
- Potential future developments and improvements.

## **Group discussions**

In addition to the interviews, a number of workshops and group discussions were carried out to gather the views of a range of stakeholders, including:

- National staff, Boards and management groups of NCOs.
- Other workers and carers.
- The NCO Network.

These were facilitated by RHA, and detailed notes taken in each case.

## **National staff, Boards and management groups of NCOs**

Group discussions were held with the national staff members of NCOs, as well as the NCOs' Boards and management groups.



Separate meetings were held with the staff and Board members or equivalent (brought together with the assistance of the NCOs). These discussions covered issues such as:

- The strengths of the NCO.
- The purpose of the NCO, and the specific and distinct services they provide.
- Patterns of membership (both individual and organisational) and perceptions of strengths, weaknesses and any silent voices.
- Perceptions of gaps in provision to carers in Scotland.
- The role of the organisation in the overall pattern of provision of support to carers and input to carer policy at national, and local levels.
- Perceptions of the representational role of their own, and other NCOs.
- Relationships with other NCOs and cross-referral / signposting.
- Current issues for service providers and clients (including constraints).
- Awareness and perceptions of the current NCO Network, its role and effectiveness.
- Impact of the Network on carers and other stakeholders.
- Key aspects of future provision.
- Current issues and concerns in service provision to carers and carer policy.
- Potential future developments and improvements.

### **Other workers and carers**

Opportunities were also provided for other relevant workers and carers to input their views, through a series of local workshops and group discussions held in different parts of Scotland. These were arranged with the help of the NCO Network and individual local carer organisations. Meetings were held in the following areas:

- Dumfries.
- Dundee.
- Edinburgh.
- Galashiels.
- Glasgow.
- Kilmarnock.
- Perth.

Discussions were also held with young carers; workers with BME carers; and workers with carers in remote and rural areas.

These discussions involved a total of 94 participants. The issues examined were:

- Points and means of entry to receipt of support and the 'carer journey'.
- Overall purpose, expectations and requirements of information and support.
- The provision of a "voice" for carers.
- Constraints and limitations to provision.

- The role of NCOs in support and representation of carers.
- Suggested improvements to the means or pattern of provision by NCOs.
- Views of the way forward.

## **The NCO Network**

Three joint discussions were held with members of the NCO Network, and a specific discussion was held with the Research Sub-group to enable their input to the written consultation (described below). The Network provided comments on the draft survey materials, as well as assistance with their circulation.

The meetings focused on providing an opportunity for the NCOs to input to the research process as a group (in addition to the interviews and discussions held with the individual NCOs), but also (particularly in the case of the final meetings) on exploring their views of the way forward.

These meetings were arranged through the administrative process for bringing the Network together, and facilitated by RHA.

## **Written consultation**

It was also considered vital to ensure that all of those with a potential interest in the issues were given the opportunity to contribute to the review. For this reason, in addition to the targeted approaches set out above, a wider written survey or “consultation” was undertaken.

The written consultation was carried out through the use of an online “SurveyMonkey” questionnaire method between early April and mid-May 2014 (to ensure that this strand of the work did not coincide with the Scottish Government consultation on carer legislation held in early 2014).

Two separate questionnaires were made available: one to individuals with an interest in carer issues (both carers and workers); and one to organisations working with carers. These were designed in draft and discussed with the NCO Research Sub-group, whose comments were incorporated. Printed versions of the questionnaires were also made available on request.

The online questionnaires focused on the following issues:

- Information, support and the carer “voice”.
- Knowledge of, involvement with, and perceptions of NCOs.
- Optimum role and functions of the NCOs.
- Suggestions for the future.

Details of the surveys were circulated widely by the NCOs, and a total of 271 responses were received (231 from individual carers or workers; and 40 from organisations).

## **Analysis, identification of options and report writing**

Following the collection of all of the information, the material was analysed using a combination of quantitative and qualitative techniques. Some of the information (e.g. the audit and documentary information) involved a straightforward summary of the material, in order to provide the general context. The comparative material from the NCOs was analysed using a matrix created for this purpose. A small amount of the online survey material was analysed quantitatively.

Most of the material gathered, however, (e.g. material from the individual interviews and workshops / group discussions, as well as much of the material from the online surveys) required a qualitative approach. This involved working systematically through the material gathered from each source relating to each of the issues explored in the review. A series of themes and sub-themes was identified for each of the issues, including arguments and suggestions made in each case.

This approach enabled the range and depth of the qualitative views to be reflected accurately and comprehensively, and ensured that the analysis followed the material, rather than being fitted into pre-defined categories. A wealth of detail was identified from this qualitative analysis which informed the final report.

All of the themes raised were presented qualitatively, to reflect the nature and purpose of the review (i.e. to identify the range of views and suggestions about the NCOs). Any attempt to “count” or “weigh” the views of specific issues within the overall themes would have been inappropriate (and might have undermined the importance of views of smaller groups of respondents, including the NCOs themselves). Within this overall approach, however, the nature of respondents raising particular issues was identified wherever appropriate.

From the findings of the review, a number of options and suggestions for the future were identified and presented within the report.



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