

Macmillan Response – Scottish Government Consultation on Integration of Health & Social Care

September 2012

Introduction

Macmillan Cancer Support warmly welcomes this consultation on integration of health and social care as an important step in ensuring that Scotland is prepared for the challenges of a changing cancer landscape.

Our 2011 Manifesto calls stated our desire for the Scottish Parliament & Scottish Government “**To deliver a system of coordinated care for everyone diagnosed with cancer in Scotland**” and we strongly welcomed all the parties’ 2011 Manifesto promises to transform and greatly improve the links between health & social care services – and we also welcome the 2011/12 Scottish Programme for Government commitment on this.

The Scottish Government has stated its aim of a person-centred health service that shifts the balance of care away from acute and secondary care, to the community, supported self-management and supportive care. We believe better use of Cancer Clinical Nurse Specialists to deliver and co-ordinate care more effectively, including assessment and care planning for all cancer patients – linking to information provision and benefits advice – is the key.

Improving the coordination of cancer care through more integrated Health & Social Care service is vital not only to improve the patient experience but also to increase quality and cost effectiveness. People whose care is unplanned and uncoordinated are more likely to be high users of health and social care services, including emergency care. Research led by Macmillan and Monitor Group shows that improving supportive care such as co-ordination, communication and information can deliver improved productivity and is cost effective, having the potential to release about 10 per cent of cancer expenditure. This is achieved by addressing some of the problems that result in high costs for cancer services including:

- Reducing avoidable emergency admissions to hospital
- Reducing length of stay in hospital
- Improving follow-up
- Supporting patients to return to or stay in work
- Supporting patients to die at home rather than in hospital

In our recent submission to the Health & Sport Committee on preventative spending we argued that without integration of health & social care services the preventive spending on improving the co-ordination of care would not achieve the proposed outcomes.

Macmillan's experience suggests that the improved coordination of care that would be a result of integration of health and social care can significantly improve the quality of care received by cancer patients, including:

- Reduced stress
- Reduced confusion
- Increased involvement of carers and patients in their treatment
- Improved health outcomes for survivors
- Better palliative care support

The central aim of an integrated health and social care system should be to improve the patient experience by providing person-centred care that is based on assessment of individual needs, including emotional, financial and practical needs. People should, where possible be supported to self manage their condition in their own homes and should be provided with rehabilitation support and help to stay in or return to work. An effective health and social care system would also support end of life care at home rather than in hospital, an important issue for many older people.

Macmillan has extensive experience of working in partnership with health and social care across the UK and has led the facilitating of delivery of integrated services in multi-party agencies. Some examples include:

Macmillan benefits advice services are partnerships between Macmillan, local authorities, the NHS, DWP/The Pension Service and local advice agencies and support people throughout Scotland with income maximisation. Over the last few years they have generated almost £150 million for people affected by cancer. These services are based both in clinical settings and in local communities.

Macmillan information and support services based in community libraries provide health information and support in a local setting. We currently have services in Easterhouse, Fort William, Carmondean, Ayrshire, Renfrewshire and Westerhailes which have been developed in partnership with the NHS and local authorities.

The **Give Us A Break!** programme, the first of its kind in the UK, helps young people cope with bereavement, loss and major changes in their lives. It was developed as a result of joint working by Macmillan, South Lanarkshire Council education psychology services and NHS Lanarkshire.

Macmillan would welcome the opportunity to use our experience to contribute to the development and implementation of the integration of health and social care and we look forward to working with the Scottish Government on this vital issue.

Question 1

Is the proposal to focus initially, after legislation is enacted, on improving outcomes for older, and then to extend our focus to improving integration in all areas of adult health and social care, practical and helpful?

The Scottish Government's proposal to focus initially on improving outcomes for older people, at first sight, seems persuasive: According to new Macmillan-funded research by King's College London, nearly one in four (23 per cent) older people in the UK will have had a cancer diagnosis in 2040 – almost double the proportion in 2010 (13 per cent).

The scale of change also appears to be more manageable if older people are prioritised. The changing demographic pattern of old age means more and more older people will become affected by cancer amongst a range of co-morbidities and the increasing need for palliative care services.

However, we would prefer to see the broadest programme of reform of health and social care provision across all age groups.

1) Fragmentation: The Scottish Government's consultation paper itself points up the risk of dealing with older people in isolation. We believe the risks should be explored more fully. The selection of older people's services as the starting point, may well add to existing fragmentation and limit the ambitions of integration. There is also the problem of sustaining effective management and professional leadership across all areas of adult care. Inevitably the management and intelligence capacity of all agencies will shift towards the issue for older people and could undermine greater reform. Recent rounds of management savings have reduced capacity across senior management in both health and social care sectors and in the backroom support services such as finance, research and planning, and commissioning. The same is true of generic front-line staffing such as home care. Both the NHS and local authorities have managed to sustain performance by using existing staffing to good effect and maximising economies of scale. The integration proposals for older people could create stand-alone systems at a cost to wider service efficiencies. Many current services are already integrated in terms of management and funding.

2) Early Intervention & co-morbidities: By focusing on older people there is a risk of failing to support the movement towards prevention, early interventions, and anticipatory care for adults. Public health improvement is needed for all adults through self-management of long-

term conditions for all people.

If this work starts effectively with [younger] adults first encountering health problems or at risk of them, then all the issues around co-morbidity facing older people and their services may impact less on the quality of their lives. It is not necessarily age that is the problem: it is the combination of illnesses; poor practice; limited personal and community resilience; and depleted funding that represent the challenges.

The integration proposals as they stand could fail to understand the complexity of delivering the integrated care pathways required after detection, diagnosis, and treatment within the acute sector. Cancer, like other long-term conditions [and their combinations] that have most impact on life expectancy, need to be managed as early as possible. The move towards community based care has to involve the acute sector fully in the process.

Question 2

Is our proposed framework for integration comprehensive? Is there anything missing that you would want to see added to it, or anything you would suggest should be removed?

The objectives set out in the Scottish Government proposals are welcomed by Macmillan. We appreciate particularly the commitment given about the effective engagement of the third sector and users and carers in the strategic planning and commissioning of services, and our involvement in how this is implemented.

1) Workforce: Extensive reviews and research on health and social care partnerships have identified problems in part caused by inadequate time and priority being given to culture and joint workforce training and development. It would be good if this aspect of partnership development could be stated as an expectation of the new health and social care partnerships. In preparing for partnership all key front line staff have to be included in training but 'back room' finance/HR and legal teams have to be involved fully.

Macmillan have extensive experience of partnership working across the UK with the NHS, local authorities, housing providers, and third sector partners. Some of our most successful work has been developed working directly with the support of the Scottish Government – Macmillan nurses and Macmillan benefit advisers being the main examples. We have considerable experience in training and support of staff working in integrated teams and services and would be pleased to help with this work.

The tests for the new partnerships models include the ability of the reform to resolve the two great 'disconnects' in the current system: within the NHS and across the health and social care divide.

2)Acute Sector: Again it is not clear if the proposed mechanism can address the challenge of involving the acute sector in a balanced role engaged with local partnerships.

Part of the Scottish Government proposal describes an integration framework in which less funding as proportion will in future be 'directed towards institutional care' , and 'more resources will be directed towards community provision and capacity building'. This needs clarity on how it would work on the ground. Does institutional include acute hospital settings or only apply to long-term care options wherever they are placed. It needs to be clarified.

HEAT targets and expectations set for acute services remain challenging. It is difficult to see how resources can be shifted towards the community without re-defining expectations for both secondary and primary care.

Macmillan's recent experience of early work supporting the Scottish Government's 'Transforming Cancer Care After Treatment' [TCAT] suggests that clinical networks can be engaged in development which tries to follow the entire integrated care pathway that people affected by cancer need to have in place. This work recognises what happens after detection, diagnosis and treatment, and proposes models of follow up that recognise the role of patients/carers in self management and the full range of community services and capacity they need to enjoy a good quality of life.

The model should be applicable to all the major clinical networks covering significant Long Term Conditions. It is important that such networks contribute to the strategic commissioning process and funding of local partnerships.

3)Service Users/cares: Another issue that might be included more specifically within the Scottish Government's framework is the role of service users/carers. This needs to be given a more principled status and the development of Self Directed Support should be linked to the formal membership of the partnerships. SDS will increasingly shape the kinds of services partnerships will need to commission or provide. It is a pity that the SDS legislation is again lop-sided and applies only to Local Authorities in terms of statutory duties and resources.

4)Cancer Poverty: Macmillan has played a lead role in partnerships tackling cancer poverty. It is impossible to manage financial issues without understanding the interplay between work, employability, benefits, and illness and treatments. Macmillan would suggest that consideration must be given to the role of the DWP in health & social care partnerships particularly with regard to planning and commissioning services.

5)GPs: Later parts of the proposal mention the potential role of GPs and the barriers which inhibit their proper involvement. Funding to help engineer the re-definition of primary care and GP roles in long-term care management and partnership planning seems inescapable.

Question 3

The proposal will establish in law a requirement for statutory partners – Health Boards and Local Authorities – to deliver , and to be held jointly and equally accountable for , nationally agreed outcomes for adult health and social care. This is a significant departure from the current separate performance management mechanisms that apply to Health Boards and Local Authorities. Does this approach provide a sufficiently strong mechanism to achieve the extent of change that is required

1)Joint Implementation: The determination of the Scottish Government to provide national leadership on what is required [outcomes] is the right approach. The context laid out in the consultation justifying the plans for accountability rehearse the difficulties involved. The bifurcation between health and social care is at the very heart of the Scottish Government departments and ministerial appointments. Joining up the partners at relatively low levels of operational responsibility will not in itself insulate the reforms from potential conflict and divisions. Macmillan would suggest that the accountability for local implementation would be best tested through the Community Planning route. The CPP has all the key partners already focused on agreed outcomes, though currently the acute sector is not represented there.

2)Scrutiny Bodies: The legislative proposals should also include duties which ensure scrutiny bodies covering both health and social care act together in concert. This should include formal appraisal of joint commissioning strategies. There is a bank of good learning from past inspection and audit processes in this area.

It would also be helpful to prepare for reform through well funded joint workforce development and leadership training.

3)Workforce: The development of PSIF/quality type frameworks should be followed for the new Health and Social Care partnerships to encourage ownership of new ways of working and standards of performance. In the past structural reform has foundered on poor attention to culture and team building. Resources such as the Joint Improvement Team and other quality builders should be tasked to help.

Question 4

Do you agree that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements?

This is a welcome proposal. The work commissioned by ADSW and published by IRISS [An Evidence Base for the Delivery of Adult Services , Allison Petch 2011] rehearsed a range of positive approaches including :

Outcomes which are defined in 'personal terms'; nationally agreed data sets; joint strategic commissioning plans based on the totality of spend.

Macmillan's extensive work with people affected by cancer confirms the consistent themes that are important to people when they access services and support. These are important goals for the joint enterprise. It is important that they are not lost in historically formed acute focused targets. The new partnerships will have to support greater inclusion of people themselves in exercising choices and defining success.

Question 5

Will the joint accountability to Ministers and Local Authority Leaders provide the right balance of local democratic accountability and accountability to central government, for health and social care services?

The proposals address some of the concerns previously expressed about CHPs. It might be possible to experiment with the models explored. The use of SOA might be best tackled by a joint accountability across Cabinet Secretaries responsible for Health and also Local Government.

Reference is made to 'ministers' as is common in the language of drafting legislation [4.2] The role for the Cabinet Secretary for Health and Wellbeing and Cities is set out in 4.9 and suggest an ultimate point of accountability. This might not be suitable for a joint model as discussed in Q3.

The question of the missing acute sector will provoke concern in respect of local democratic control.

Question 6

Should there be scope to establish a Health and Social Care Partnership that covers more than one Local Authority?

Macmillan's involvement across the UK has included working with local authorities that share key posts such as Chief Executives or Directors. This can seem attractive in terms of economies of scale and shared resources.

If however the model of accountability centres on unique SOAs and local democratic control the option of wider Health and Social Care Partnerships might be counterproductive.

Again from the experience of trying to promote integrated working across clinical networks Macmillan is attracted to the idea of generating service standards and commissioning strategies that can be shared across a network covering many local authority areas. But this can be achieved without joint structures which could weaken local accountability.

Question 7

Are the proposed Committee arrangements appropriate to ensure the governance of the Health and Social Care partnership?

The membership proposed will meet some expectations around parity and status, though more thought should be given to mechanisms to resolve conflicts and differences. Previous incarnations of partnerships have not been able to deal with disputes and perceived lack of trust and openness. These are cultural issues as well as procedural matters.

The increased emphasis on adult protection duties and wider ambitions about user/carer participation need to be explicit within the Committee arrangements.

Question 8

Are the performance management arrangements described above sufficiently robust to provide public confidence that effective action will be taken if local services are failing to deliver appropriately

If agreed national outcomes are based on the experience of people and their needs, are understandable, and are given wide support; then this will help public confidence. The

diverse bodies offering scrutiny, inspection, and audit need to be co-ordinated. The best approach will be self-assessment by partners and users and carers and this should follow tested self-evaluation models. The legislative proposals should examine this issue and make expectations about appraisal clear. Public events and transparent meetings about accountability are welcome but should not replace local visibility and enabling people to make proper comparisons about services across Scotland.

The performance management system cannot be allowed to overwhelm the actual work that needs to be done. Front line services need to focus on people rather than serving audit processes which do not reflect real experiences and outcomes.

Question 9

Should Health Boards and Local Authorities be free to choose whether to include budgets for other CHP functions – apart from adult health and social care – within the scope of the Health and Social Care Partnership?

Yes, local partnerships should be encouraged to be as inclusive as they can be.

From earlier comments Macmillan would re-iterate the need to involve the acute sector and other aspects of community based services such as parts of leisure and exercise, libraries, and transport which can impact on positive outcomes for people affected by health and social problems. Consideration should be given to how other bodies such as the DWP can be brought into partnership working. The proposals mention housing but do not identify how their vital role and resources will be captured in the new partnerships.

Question 10

Do you think that the proposals described above can successfully deliver our objective to use money to best effect for the patient or service user , whether they need ‘health’ or ‘social care’ support?

There are helpful guidelines and principles in the proposals. There is still an underlying question about rising demands and expectations and the overall funding levels available to partners.

Implicit in the proposals is the acceptance that new partnership arrangements can achieve more effective use of existing resources. It will be important for this set of reforms to make sure they can identify baselines of expenditure and performance for each of the partnership areas and provide the ability to benchmark and compare savings and use of resources across all of Scotland. It would make sense to allow this change to take place over several years with transitional resource made available to make it all work.

We would draw attention to the fact that little attention is paid to the different 'accounting' cultures between the NHS and local authorities and the key question of managing deficits. Cost shunting or displacement is not helpful and the proposals try to establish ground rules to avoid these chronic problems.

This will be a challenging area of work but should be a task that all Health Boards, Local Authorities, the Accounts Commission, Cosla, and scrutiny bodies can deliver.

It is suggested that all new partnerships, as part of their preparation and a condition of their inauguration, should produce such transparent 'accounting' and this would create the baseline needed to demonstrate future progress.

The difficulties in managing joint funding are considerable. There has been a history of inflexibility for NHS funding. Within the arena of primary care and independent contractors such as GPs, Pharmacy, and Dentists there are major tranches of 'untouchable' spend. Similarly, the spend in the acute sector can be difficult to influence/change.

The movement of much needed investment into other community based services has always been at the margins of overall spend or confined to special funds such as; resource transfer, hospital closure and discharge funding, and 'change funds'. Macmillan's experience suggests that long-term conditions groups such as people affected by cancer are not included in such schemes.

More traditional groups of adult care service users, such as people with learning disability or older people, usually attract more attention in terms of historical budgetary pressures. We need to ensure SDS funding reaches groups of people living with long-term conditions as these long-term condition groups are the people who account for most of the unplanned hospital admissions.

It is unclear from the proposals what levels of funding can be diverted, delegated, or devolved into Health and Social Care Partnerships. What is clear however is that current practice and increased demands for acute services due to demographic pressures cannot be sustained without investment in alternative models of care and treatment, and follow up in the community.

Question 11

Do you have experience of the ease or difficulty of making flexible use of resources across the health and social care system that you would like to share?

Macmillan has been involved within increasingly complex partnership arrangements across the UK. Over the past decade we've used our own investment plans to encourage the integration of services across NHS and local authority boundaries. In the last decade our attention has turned more and more towards working with local Councils; especially in Scotland.

Recently Cosla, and the UK Iga national chronicle gave awards to the Glasgow City Council LTC financial benefits services. These emerging models of partnership commit NHS and Local Authority spend in partnership with Macmillan investment and contributions from a range of other statutory and third sector partners. The shared approach to investment achieves three goals: sustainable services; integrated ways of working from acute to community based services; responsive services that start off with what works for service users and carers.

Macmillan and our partners would be pleased to share learning from these developments.

Question 12

If Ministers provide direction on the minimum categories of spend that must be included in the integrated budget, will that provide sufficient impetus and sufficient local discretion to achieve the objectives we have set out?

On the whole the Scottish Government's approach is a good balance between national leadership and local discretion.

Previously research and scrutiny evidence [SWIA national reports] has revealed that the quality of service outcomes for people is not determined purely by financial spend. Poor services can sometimes be expensive. What is more evident is that quality of strategic direction and leadership affects outcomes more directly.

On the other hand ambitious commissioning models that have pursued low costs can threaten the viability of community based options. Similarly allowing naked market forces to determine levels and types of long term care can be disastrous.

The Scottish Government needs to use benchmarking to inform spending profiles and track investment relative to outcomes to guide local partnerships about performance and spend. Our view is that the new Health and Social Care Partnerships should be as wide as possible

and include as much as possible. This leaves discretion with local partnerships to decide on the scale of integration. If the Scottish Government can help inform commissioning processes by encouraging negotiation between local partnerships and expert networks [including service users/carers] then the shape and forms of local services can be costed. There should be financial incentives for local partnerships embracing change and demonstrating achievements. Macmillan would be welcome the chance to be involved in supporting such approaches or trying out solutions.

Question 13

Do you think that the proposals described here for the financial authority of the Jointly Accountable Officer will be sufficient to enable the shift in investment that is required to achieve the shift in the balance of care?

The suggestion from ADSW that the views of chief finance officers and legal officers from both health & social care should be sought is a good suggestion. In itself a good definition of the role of the JAO cannot insulate the partnership from the inherent differences in form, accountability, accountancy practice, and priorities that the consultation proposals describe so clearly.

The 'more' that goes into new health and social care partnerships funding pool the better the chance of integrated services. But the 'more' that goes in the more difficult the role of the JAO will be; and the more complex will be the relationship between the JAO and other accountable posts such as CSWO or COO, and other executive positions in both systems.

The absence of the acute sector in a meaningful way could jeopardise the enterprise.

Question 14

Have we described an appropriate level of seniority for the Jointly Accountable officer?

This is a difficult matter to address since it will depend on the scale and range of local partnerships. It might be useful for the Scottish Government to give some thought to the kind of preparation and mentoring that such post holders will require for their role.

It is unlikely that the management authority of a key figure will be used to impose decisions within a partnership. This is the challenge of partnership working. If executive decisions have to be taken in a context of forceful objections or key strategic decisions are taken after bitter political debates and divisions on votes then partnership working is not 'working'.

Question 15

Should the Scottish Government direct how locality planning is taken forward or leave this to local determination?

This is one of the least clear parts of the consultation. The Scottish Governments naturally

wants to give local people, local professionals, providers, and partners a stake in influencing planning and decision making. It is hard, however, to produce proposals which deliver involvement and participation without cumbersome models of representation and lengthy timescales of engagement.

Macmillan thinks that the local dimension can be secured by a number of changes. Firstly the strategic commissioning and evaluation of services has to include effective service user/carer evaluation and the views of frontline staff and joint teams working in local areas. Guidance on consultation, commissioning and self assessment should help. The Scottish Government should pull together best practice and develop good standards for new partnerships to follow. Secondly joint training and team building should involve local staff in addressing how local teams can best support the new partnerships.

Question 16

It is proposed that a duty should be placed upon Health and Social care partnerships to consult local professionals, including GPs , on how best to put in place local arrangements for planning service provision , and then implement , review and maintain such arrangements. Is this duty strong enough

Although each professional group or type of front-line staff have a unique contribution to make to service planning it is probably more significant that their efforts to plan and work together are secured. This is best achieved through self assessment / improvement models that bind different groups into integrated models of treatment and care.

A duty, on health and social care partnerships, to make GPs or other independent contractors engage in planning will naturally create a reciprocal demand for compensation and different payment in their contracts.

Question 17

What practical steps/changes would help to enable clinicians and social care professionals to get involved with and drive planning at local level?

This is difficult. Time allowance, workload management support, and money will help in some parts.

Probably the best approach will come from joint approaches to developing outcomes which make sense to professionals and people using services.

Being committed to joint needs assessments and information gathering as part of day to day working is important. When casework needs assessment and recording are felt to be tasks to comply with remote management requirements for targets then the professional role can be devalued. Front line staff across all settings need to see the relevance and importance of their professional work. And service users/carers should see that their views and interests are

valued. Front-line staff and joint teams should make sure there are feedback mechanisms in place to allow users/carers to influence standards of care and future services.

Macmillan invests a great deal in these kinds of contribution to joint team development and integrated working.

Question 18

Should locality planning be organised around clusters of GP practices? If not how do you think this could be better organised ?

Local areas will know their patch best. If all services but particularly acute services begin to understand how to integrate across services in their area there may be obvious ways forward. Through our work with cancer networks and local authorities we're seeing different ideas about how to address long term condition management with more responsibility shifting from the hospital setting towards community based services and patient centred self management. When this kind of development is accepted as a shared goal other types of organisation change make sense, such as proposed joint primary care health and social work teams covering defined localities. This model is apparent in places like Dumfries and Galloway and North Lanarkshire where there are strong geographical links defining townships and community identity.

GP practices are less coherent in terms of boundaries. If the local authority is the basis of the health and social care partnership then the sum of localities should fit with Council areas. Whatever model is used it should try to avoid wasting time on boundary debates.

Question 19

How much responsibility and decision-making should be devolved from Health and Social Care Partnerships to locality

Health and Social Care partnerships should have the key role in deciding how much to 'localise' power and decision-making.

Strategic needs assessments, planning, commissioning , and evaluation has to be based around larger scale resources including the acute sector and other planning partners such as the DWP/Pensions Service.

At the same time every worker and every service user/carer should understand why decisions are made and how they can contribute to better outcomes for people using services. This is the best way to involve localities – being part of a shared set of goals and standards.

Question 20

Should localities be organised around a given size of population – eg., between 15,000 to 20,000 people , or some other range? If so what size would you suggest

This is a matter for Health and Care Partnerships. Areas with remote communities will already have organised their structures to suit local needs. The most difficult challenge will probably be in large city partnerships with less clarity about boundaries and identity.

Again this area of development should be monitored through scrutiny and inspection as part of the normal implementation and testing out of models. The Scottish Government should be alive to tensions within partnerships where local communities/service systems feel under represented or neglected.

The diversity of arrangements across Scotland will probably throw up interesting approaches that can be studied for lessons to be learned.