

Annex G Consultation Questionnaire

The case for change

Question 1: Is the proposal to focus initially, after legislation is enacted, on improving outcomes for older people, and then to extend our focus to improving integration of all areas of adult health and social care, practical and helpful?

Yes No

The MS Society welcomes the government's intention to integrate health and social care and its acknowledgement that services are, in places, disjointed and not meeting expectations. The MS Society welcomes greater coordination between health and social care services and believes such coordination could significantly improve the lives of people affected by MS.

Whilst we recognise the impact of demographic changes in Scotland, the MS Society is disappointed that the government's plans will initially focus only on older peoples' services. MS is a progressive and incurable long-term condition, most commonly diagnosed between the ages of 20 and 40. Along with medical implications, MS has a social impact. A person experiencing a relapse, for example, may require medical treatment from an MS nurse but their relapse may have caused mobility problems meaning they also require support to get dressed or need adaptations to their home. It is a condition then does not adhere to department boundaries.

MS can also be a fluctuating and unpredictable condition. People living with MS may need to access their health and social care services throughout the course of their condition sporadically but perhaps quite suddenly. Coordinated action and a shared knowledge of an individual's condition is crucial if people with MS are to receive timely and responsive services. The right support at the right time can help people with MS remain in work for longer or live independently for as long as possible.

If the government's plans were to extend to those living with a long-term condition rather than just older peoples' services, joined up working practices could have a significant impact on the lives of people with MS. If, however, the government chooses to focus on older peoples services initially the MS Society would welcome details of the timescales for rolling out integration for other groups.

Outline of proposed reforms

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?

Yes No

New legislation demonstrates the government's commitment to integrating services and this is to be welcomed. Delivering coordinated and effective care will, however, require more than structural and legislative change. Strong leadership and a change in culture will be key to improving services. Our experience shows that where health and social care work best together there is a tangible desire to coordinate action and an understanding that coordinated services provide the best outcome for individuals. Greater professional respect is also needed across departments, along with an understanding of the different professional and legal boundaries of each professional. In addition, practical barriers like different IT systems, different terms and conditions for staff and training will all need to be considered for services to improve on the ground.

We welcome the government's intention to provide a consistent service across Scotland. People with MS have often told us of their frustration at an apparent 'postcode lottery' of care. Many feel that this inconsistency stems from the different charging policies and eligibility criteria across local authorities. This local variation is a real concern for people with MS. At present, for instance, transferring a care package across local authority areas can be very difficult, which can affect where a person decides to live and work. We of course, understand the importance of local democracy but when does acceptable variation become inequality? One caller to our helpline last year asked, "*Where is the best place to live in Scotland if you have MS*"?

The MS Society would welcome greater clarity about how the integration agenda fits with plans for Self Directed Support. As services become more integrated will service users be able to use their SDS options for housing or health needs?

National outcomes for adult health and social care

Question 3: This 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?

Yes No

We believe that change is most likely to arise from performance indicators that are specific and measurable. Something similar to HEAT targets, which would apply across health and social care would be most effective.

Question 4: Do you agree that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements?

Yes No

We believe that change is most likely to arise from performance indicators that are specific and measurable. Something similar to HEAT targets, which would apply across health and social care would be most effective.

Governance and joint accountability

Question 5: Will 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?

Yes No

The MS Society is not in a position to determine appropriate levels of democratic accountability to local and central government. We are interested, however, to know how disagreement between local partnerships and central government would be resolved.

The MS Society would also welcome clarity about plans for public participation in a new system of integrated care. At present, Public Participation Forums (PPFs) are committees of CHPs. What are the plans for PPFs once CHPs have been abolished? Service user participation is essential to improving care services.

Question 6: Should there be scope to establish a Health and Social Care Partnership that covers more than one Local Authority?

Yes No

One HSCP per health board area would presumably require the local authorities covered by that HSCP to assume similar processes and procedures and ultimately integrate their budgets for social care. This possibility should not be ruled out but we would question if this is politically feasible at present.

Question 7: Are the proposed Committee arrangements appropriate to ensure governance of the Health and Social Care Partnership?

Yes No

We support third sector representation on HSCP Committees. The third sector makes a valuable partner for a number of reasons; the sector offers expertise on the needs of its service users; it acts as an advocate for service users and it plays a role in preventing crises and therefore reducing demand on statutory services. It is important then the third sector is able to participate meaningfully at a strategic level. We would not call for voting rights for the third sector on HSCPs. However, we believe that consultation with the third sector should be mandatory and enshrined in law.

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?

Yes No

The MS Society would welcome transparent performance reporting and a recognition that the public is entitled to see how public resources are being spent. Our previous experience of attempting to gauge the performance of health boards (against the *Clinical Standards for Neurological Services*) has not been encouraging. In particular we would like clarification about who would decide when a HSCP had reached a 'critical' point and required intervention. We strongly believe feedback from service users and their carers should play a role in assessing a HSCP's performance. To this end we would like more detail about how service user feedback fits in to the performance management process

Question 9: Should Health Boards and Local Authorities be free to choose whether to include the budgets for other CHP functions – apart from adult health and social care – within the scope of the Health and Social Care Partnership?

Yes No

The impact of MS is far-reaching. It can affect an individual's physical and mental health, housing requirements, educational needs, employment prospects and financial security, family responsibilities, mobility and social inclusion. It is important then that other budgets are considered when thinking about an individual's health and social care needs. Health boards and local authorities should be free to choose if other budgets should be included within the scope of the HSCP. The MS Society would encourage HSCPs to view 'health' in a holistic manner.

Integrated budgets and resourcing

Question 10: Do you think the models 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?

Yes No

Many people living with MS will require a coordinated and responsive health and social care service at some point during the course of their condition. It seems sensible therefore to think of health and well-being holistically and integrate budgets and planning processes across relevant departments.

We believe that the best outcomes for individuals are achieved when the individual is able to choose the support they believe to be most appropriate. We would welcome more clarity, therefore, on plans for Self Directed Support and whether this will be extended to health monies in light of integration.

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?

Yes No

People with MS have shared their experiences of integrated care with us and have told us what they want from health and social care services. Many individuals would like their health and social care professionals to have a holistic understanding of their MS; appreciating not just the health implications but the social and financial barriers as well. Many wanted to

know what they can expect from their care services and for professionals to be able to signpost or refer them to relevant services. People also expressed a desire for clear pathways and information about their condition. Members also expressed enthusiasm for a central point of contact – a professional in either health or social care who could refer them to the services they need.

The quality of integrated services appears to vary across the country. Some of our members expressed their concern at the lack of joined-up, coordinated services. For instance, people affected by MS in the Borders told us that health professionals often focused only on medical issues and seemed to assume that social work professionals will pick up any other issues. One member told us that after they left the consulting room they felt they were “on their own”. Another person with MS told us that they had reached crisis point before professionals in health and social care contacted each other. In Aberdeenshire, many people with MS felt their services were not coordinated and found it particularly difficult to get referrals to the MS nurse.

In various parts of the country, ‘getting into the system’ was highlighted as a particular concern, with many not knowing who to turn to for help or advice. Some people with MS have told us that they rely on the internet to find the services they need. Many told us that they did not have the energy to “fight for services” and had “given up” trying to access the services they need.

As well as lacking coordination many members found their social care services impersonal and focused on the needs of the service rather than their needs as an individual. For example, one person with MS from Glasgow told us “I would rather be on my own than talk to my social worker again”.

Where services work well together people with MS often pointed to the enthusiasm and commitment of the individual professionals involved. Many felt “lucky” to have a professional who spoke to colleagues in different departments. One individual in Paisley, for example, expressed gratitude for the commitment of their occupational therapist but worried that the quality of the service would change if that professional moved onto a new role. Many felt that working with colleagues across departments should be a requirement of a professional’s role and should not depend on the personality of the individual.

Positive experiences were shared in other parts of the country. For instance, one individual from Tayside said his MS nurse “opens all the doors I need”. In Highland, a Neurology Network operates as a strong strategic group with input from health, social care and the voluntary sector.

The group is currently in the process of developing 'formal' care pathways for those living with a neurological condition. In Dundee City, the MS social worker has fostered excellent joint-working. An Operational Group of MS staff meets every 4-6 weeks and is in regular contact by email and telephone. The group was described in an independent review as having been very effective in improving collaboration between health and social care services.

Across the country, people with MS suggested that the voluntary sector offers a more holistic understanding of their condition. Many used the voluntary sector to access information about their healthcare, social care and welfare services. One member told us that their GP "did not have a clue" about MS and others told us that their GP often referred them to them to the local MS Society branch for assistance.

To avoid this disruption to services it is important that contingency plans are put in place before any major changes and that plans for change are communicated to staff clearly so as to avoid anxiety to professionals. The experience of integration in Highland, for example, perhaps offers some lessons around change management. People with MS in Highland have told us that the quality of their care has declined since the changes took place.

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?

Yes No

The MS Society is not in a position to respond to this question.

Jointly Accountable Officer

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?

Yes No

The MS Society is not in a position to respond to this question.

Question 14: Have we described an appropriate level of seniority for the Jointly Accountable Officer?

Yes No

The MS Society is not in a position to respond to this question.

Professionally led locality planning and commissioning of services

Question 15: Should the Scottish Government direct how locality planning is taken forward or leave this to local determination?

Yes No

The MS Society is not in a position to offer advice on the best options for locality planning.

We agree, however, that professionals must be involved in planning local services. This is true of all professionals, and not just GPs. AHPs, for instance, work on the boundary of health and social care and their experiences and expertise will be crucial to planning coordinated services. It is equally important that service users are represented on locality planning groups and this may prove difficult at this level (as opposed to health board level planning). Similarly, the third sector may lack the capacity to sit on groups at this very local level. We would also recommend careful consideration before locality planning groups are organised around clusters of GPs practices. Is the intention for GPs to lead this work? If so, it is important to consider whether GPs have the capacity, desire or planning expertise to undertake this kind of work.

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?

Yes No

PLEASE SEE RESPONSE TO QUESTION 15

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?

PLEASE SEE RESPONSE TO QUESTION 15

Question 18: Should locality planning be organised around clusters of GP practices? If not, how do you think this could be better organised?

Yes No

PLEASE SEE RESPONSE TO QUESTION 15

Question 19: How much responsibility and decision making should be devolved from Health and Social Care Partnerships to locality planning groups?

PLEASE SEE RESPONSE TO QUESTION 15

Question 20: Should localities be organised around a given size of local population – e.g., of between 15,000 – 25,000 people, or some other range? If so, what size would you suggest?

Yes No

PLEASE SEE RESPONSE TO QUESTION 15

Do you have any further comments regarding the consultation proposals?

Comments

Do you have any comments regarding the partial EQIA? (see Annex D)

Comments

Do you have any comments regarding the partial BRIA? (see Annex E)

Comments