Health Services in Cumbria
Working for Rural Communities?

"You can only be ill on a Wednesday!"

a study by

ACTion with Communities in Cumbria

for

NHS Cumbria

April 2010

Contents

1. Introduction

1.1 In an English context, the depth of rurality that residents in some parts of Cumbria experience is exceptional. It is dramatically different from the geo-social context within which service delivery is conventionally planned and presents NHS Cumbria, the County's Primary Care Trust, with some serious challenges in seeking to meet the needs of residents.

1.2 Not only is Cumbria very large (6810 sq. km.) but it also has a small population at only 496,900. With over half of this population resident in rural communities, and about 21% living in areas defined by Defra as "sparse rural", Cumbria is one of the most rural parts of England. However, large scale and scattered population are not the only challenges, in many areas the physical geography of Cumbria can make travelling from one community to another tortuous.

1.3 Further, while many parts of Cumbria are attractive to visitors and retiring people, the apparent prosperity of its rural communities masks the fact that, as with other rural areas, a substantial proportion of rural households, possibly 18%, live in poverty. For these people rural life can be difficult and the added cost of accessing services and funding utilities can present a particular challenge. This is reflected in the fact that some of Cumbria's rural wards have the highest percentage of households affected by fuel poverty in England.

1.4 The national Index of Deprivation highlights a particular challenge for Cumbria's rural residents. Eden is the most deprived district in mainland England in terms of the "geographical barriers" domain which measures accessibility to services. On the same domain, Crummock ward in Allerdale is the second most deprived ward and Lyne ward (Carlisle) the third most deprived ward in England.

1.5 Reports on the "Rural Share of Deprivation" recently published by ACT in partnership with Oxford Consultants for Social Inclusion as a part of a national project add a rural perspective to our understanding of deprivation. In relation to health, this evidence for Cumbria shows that some 45% of people with a limiting long term illness live in rural communities. This proportion rises to 58% in South Lakeland, 59% in Copeland, 66% in Allerdale and 70% in Eden – all statistics that reflect the exceptionally rural character of the County.

1.6 NHS Cumbria is the County's Primary Care Trust. Established in 2006, its role is to commission health services that best meet the needs of local people. It also directly provides community health services.

1.7 In 2009, NHS Cumbria published its Strategic Plan, based upon a Joint Strategic Needs Assessment. Subsequently, NHS Cumbria has engaged with local people in a debate about the most effective way to provide services in the future. The "Closer to Home" model that lies behind its approach seeks to strengthen local services and treat as many people as possible in, or close to, their own homes.

1.8 The purpose of this study, undertaken on behalf of NHS Cumbria, has been to collate a specifically rural perspective on the health related problems and needs of rural communities and to test their views of emerging plans to move some services “closer to home”. It is in nature a qualitative study, collating opinion, not a quantitative one.

2. Methodology

2.1 To facilitate the study ACT used its established networks comprising the Cumbria Rural Forum and working relationships with community planning groups across Cumbria to sample experience and opinion. It organised, facilitated and recorded four focus group events.

2.2 One session comprised participants of the Cumbria Rural Forum, primarily people who are professionally involved in working with rural residents and on this occasion with an interest in the health needs of those residents.

2.3 The other three focus groups comprised community members from three broad localities where ACT has existing engagement, the South Copeland area comprising rural communities that use Millom as their service centre; the Upper Eden communities based around Kirkby Stephen and a similar grouping in the Sedbergh area of South Lakeland.

2.4 In advance of the workshop sessions ACT staff collaborated with colleagues in NHS Cumbria to distil key evidence from the Cumbria Joint Needs Assessment, NHS Cumbria Strategy 2008 – 2011 and the Closer to Home strategy into a short briefing paper (see Appendix 1). This briefing was provided to all participants, prior to their focus group meeting, so that they were clear about the purpose of the study, had access to some background information and explanation and were aware of the questions being posed as a part of the study to help draw out a rural perspective on the issues under discussion.

2.5 The structure of the briefing paper encouraged participants to break their discussions into four principle elements:

- The Joint Strategic Needs Assessment
- NHS Cumbria's Strategic Plan
- Established Arrangements for Service Delivery
- Future Services (Closer to Home)

2.6 In all, the workshops involved 44 participants. The remainder of this report is based upon the observations made by those individuals during the focus group sessions.

2.7 In the following narrative, Section 3 reviews the key conclusions of this study. Section 4 sets out a summary of the proceedings drawn from the comprehensive notes taken by facilitators during the focus group sessions.

3. Conclusions

Delivering services but not meeting needs?

3.1 The workshop transactions detailed in Section 4 of this report form the basis for a series of conclusions. These relate both to the challenges and the opportunities identified by workshop participants. In this section we group the challenges that have been discussed under a series of headings, reflecting the fact that some arise from the context within which services have to be delivered, others concern the experience of service users and a third set relate to the "Closer to Home" service delivery model.

3.2 Contextual Challenges

3.2.1 Geography – NHS Cumbria plans and delivers its services in an exceptionally difficult setting that reflects the physical geography of the County. A combination of sheer physical scale and small population means that potential service users are very scattered, distant from centres of provision and often living in locations that are very isolated and difficult to access. The diversity typical of rural communities, with a complex mix of relatively rich and poor, young and old, living in close proximity but small numbers is reflected in the demands made upon services. The small numbers in any one location requiring a particular service inevitably impacts upon the unit cost of service delivery. So too does the added time and cost involved in taking those services to users or in transporting them to locations where services are available. The sum of these additional costs is the so called "rural premium" that impacts on the cost of delivering a wide range of services to rural areas and which does not appear to be factored in to public sector resource allocation.

3.2.2 Demography – While the rural populations of Cumbria are diverse in their make up, it is generally the case that their age profile is older than that of urban communities, with people in the 60+ age groups forming a larger than average, and growing, component of the population. The significance of this factor to health service delivery is two-fold. Firstly it means that a larger proportion of patients will have limiting, long-term and age-related illnesses. Secondly, individuals are likely to present more often for treatment. The cost of meeting the health service needs of such populations will be higher than average.

3.2.3 Social heritage – A further factor that also reflects the diversity of Cumbria's rural populations relates to the employment traditions of particular localities. For most rural communities employment has traditionally, and in many cases continues to be in agriculture. The impact of this focus can be seen in terms of mental health issues which are the consequence of the need for individuals to cope in isolation with periodic industry-wide issues such as BSE and foot and mouth. However, some rural communities have a different heritage with the rural hinterland of Millom and other west Cumbrian towns reflecting employment in mining, steel working and manufacturing. The heritage of the latter is older people affected by industrial diseases.

3.3 Experiential Challenges

3.3.1 Isolation – A significant proportion of rural populations are people living in

single person households, often both living and working in a very isolated context. This isolation and a deeply ingrained tradition of self-reliance means that such individuals are less likely to be well-informed about the services available to them and less likely to seek advice and support when they need it. These factors will impact on the life expectancy and life experience of the people concerned.

Isolation is also a key factor in mental health and there is statistical evidence to suggest that rates of mental health problems including suicide are higher than average in populations where isolation is more prevalent.

At least one organisation represented in this project's workshops, Signposts, was able to report their contact at agricultural marts with numbers of, usually male, farmers living and working alone who had no engagement at all with health services.

3.3.2 Distance – We have previously discussed the impact that remoteness has on the cost of delivering services by NHS Cumbria. Individual patients are similarly disadvantaged. The necessity to travel some distance to access health services results in costs to patients both in terms of the cost of private or public transport and in terms of the time involved. Many workshop participants identified these costs as an unwelcome feature of their service experience. They commented too that such costs can be particularly problematic for people living on low or fixed incomes, reminding the research team that a very significant proportion of rural populations comprise households that in technical terms are living in poverty and are ill-equipped to meet the high costs that can be involved.

There is general awareness among patients that a variety of transport arrangements are in place that could help them to access services including the NHS's own Patient Transport Service and a variety of social car schemes. However, there is great confusion about what is available, the help to which an individual may be entitled and the way in which such services are accessed. This confusion is compounded by the fact that arrangements vary from place to place.

3.3.3 Timeliness – Each one of the community groups engaged in this programme identified concerns about the time taken for emergency services to reach their locality. They cited examples where the health outcomes of friends, neighbours or family members had, in their view, been compromised by the poor response times of ambulance and other services. They were concerned too about the perceived inadequacy of out of hours GP service provision, describing the inadequacies of those services and regretting the loss of weekend surgery sessions which had been a highly valued aspect of past provision.

3.3.4 Communications – Participants recognise in many ways the complexity of the services managed by NHS Cumbria. However, they believed that too often the patient's experience is compromised by failures in communication. This arises in many contexts, between GP and patient, consultant and GP, different parts of the NHS service structure, private health service providers and NHS.

3.3.5 Understanding – There appears to be a sense in which the NHS is "rural blind". Often, services are provided at times and in places that take no account of the time and cost for rural residents that is involved in accessing the services that they need. In making appointments and delivering services, the primary consideration was felt by workshop participants to be the needs of the service provider, rather than the individual circumstances of the patient with the consequence that individuals may be faced with unnecessary barriers to accessing the services that they need. These may include seemingly impossible journeys, lack of a suitable companion, excessive costs and so on.

3.4 Closer to Home

The idea that services might be provided closer to home and that the need for patients to travel to access services be reduced was, unsurprisingly, warmly welcomed. However, this does not mean that participants were unable to identify key issues that they felt must be taken into account in applying the Closer to Home principles.

3.4.1 Community capacity – The successful implementation of Closer to Home relies to some degree on harnessing the voluntary capacity of communities, making use of social networks to provide support for patients in their own homes. Good in principle, this approach would fail if that capacity does not, in practice exist. Rural communities are ageing and their volunteering capacity is declining as a result. At the same time the number of single person households is rising, some of these having little or no engagement with family or social networks to provide the necessary support. For example, an increasing proportion of Cumbria's older rural residents have moved from elsewhere to retire in the County. These people are less likely to have access to strong family or community networks to provide support during ill health, especially when they reach the stage in life where their partner has died. This means that it is essential that the individual circumstances of patients are well understood and taken into account when planning their support. There is concern that, in practice, Closer to Home will not be managed with the necessary degree of sensitivity and perception.

3.4.2 Resourcing – Caring for an increased number of people in their own homes will, especially in rural areas, involve a significant cost in terms of the time taken to travel between patients. Workshop participants have concerns that the "virtual ward" approach may prove to be too costly because of this factor, resulting in a fall in the standard of care and support that can be provided.

3.4.3 Bed reductions – A fundamental aspect of the Closer to Home approach is the restructuring of investment and resources in order to move provision closer to patients and out into the community. Participants in this study were deeply concerned about one particular aspect of this process, the dis-investment in community hospital beds. Even though the pilot implementation of Closer to Home in the area served by Penrith hospital is very recent, participants in the Upper Eden workshop were aware of one case where a shortage of beds at Penrith had adversely affected outcomes for an individual. Similar concerns were expressed elsewhere.

3.5 Opportunities

3.5.1 Evidence – The rural share of disadvantage and care need must be better understood. There are opportunities to strengthen the evidence base by:

- accessing data at a finer grain or more local level;
- drawing upon evidence gathered by other organisations, including that being collated by Signposts during their contacts with farming communities; and
- accessing detailed community knowledge and experience through community planning and other local groups.

3.5.2 Service delivery – there are several measures identified during this process that could potentially transform patient experience. These include:

- Delivering services at the most local level possible, for example through health centres, GP practices and Community Exchanges would be widely welcomed, promote service take-up and provide key routes for the delivery of preventative messages.
- The wider use of mobile services, taking services to patients rather than the other way around, would similarly improve patient experience.
- Telecare arrangements taking advantage of new technologies to improve access to both information and services has great potential for overcoming some of the challenging barriers that result from the scale of Cumbria and its scattered population. However, there are several difficulties that mean this cannot be viewed as a universal solution. In practical terms, the quality of infrastructure available to rural communities, especially the speed of broadband access available, varies greatly and is in many localities not up to the standard necessary for the delivery of e:services. It is also important to take into consideration the characteristics of the population being served. A greater than average proportion are elderly people, many of whom will be unfamiliar with modern technologies and lack either the skill or the equipment necessary to access e:based provision.

3.5.3 Communication – Improvements in communication, both within NHS Cumbria and its associated providers and between the NHS and patients would make a substantial contribution to improving the experience of service users. A specific issue which participants referenced during workshops was the confusion that surrounds transport provision for patients. This is a topic where thought should be given to improving the information made available to patients and the ways in which such information is communicated.

3.5.4 Partnership – In line with developing practice, consideration should be given to the opportunities that partnership working including with third sector providers, might create to provide services more effectively and efficiently to the benefit of patient experience.

4. Workshop Narrative

4.1 In gathering evidence concerning rural perspectives on health service strategy and delivery arrangements, ACT facilitated four workshop sessions as detailed in section 2 of this report. The following paragraphs summarise the views expressed in responding to the 13 briefing paper questions. There was a great deal of common ground in the views expressed in the four workshops, however, where differing or locally distinctive points are reported the locality concerned is indicated.

Joint Strategic Needs Assessment
Qu 1 – What are the main characteristics of your community that you think will affect the health needs of local people?

4.2 Responses to this question very strongly respond to the geophysical context within which the participants live and in relation to which there are some common aspects that impact on service planning and delivery for NHS Cumbria and numerous other organisations.

4.3 Respondents talked particularly of the following issues:

4.4 Isolation and Sparsity – communities in rural Cumbria include some that are among the smallest and most scattered in England. In consequence, some residents lead very isolated lives and have relatively little contact with the wider community. Group participants believed that this reflected in:

- Significant numbers of individuals who simply fall outside the system, who may not be registered with a GP, do not seek advice and support. These people are likely to have significantly poorer health and for any problems to have progressed further or become more extreme before presenting for treatment. The scale of this as an issue can be gauged from outreach activity delivered by third sector partners such as Signposts, an organisation that attends auction marts and regularly has contact with farmers who live isolated lives outside Health Service systems.
- Groups identified other consequences of isolation, suggesting that this is a significant driver in the development of mental health issues, a driver in the “circle of depression” and a factor in cases of alcohol addiction.

4.5 Geography – as well as impacting on individuals, the geography of rural Cumbria is seen to impact on the design and delivery of services. Patients have to incur costs in terms of time and travel to access services and response times in an emergency are a matter of particular concern. Many parts of rural Cumbria have poor public transport provision and if you don’t drive and are less well off it can be extremely difficult to access services.

4.6 Employment characteristics – across the localities participating in this study there are some distinctive aspects of employment that are believed to impact on health experience. The industrial history of Millom means that there is an incidence of classic industrial diseases that perhaps to not occur elsewhere. By the same token, the importance of

farming in rural areas and the isolation and stress (over e.g. BSE, Foot and Mouth) associated with the industry impacts upon mental health.

4.7 Cultural factors – several groups highlighted old fashioned attitudes, a tradition of self-reliance and not complaining, as being a significant feature of smaller and more isolated communities resulting in a reduced likelihood of engaging with advice, support and other services especially at the early stages in the development of health conditions.

4.8 Population structure – A large majority of the participants in the locality focus groups were relatively older, reflecting the increasingly aged structure of rural community populations. This was commented upon by the groups as a factor in designing and delivering health services. A key concern was the ability to access the support needed if older people were to continue to live independently and, looking further ahead, to wonder who would be around to provide support in the future.

4.9 Two groups (Dent and Upper Eden) talked about the local challenges that arise from people with particular needs e.g. mental health, being "imposed" from outside the community. It was observed that people in small communities are often reluctant to engage with services because of the prejudice that they fear they will experience in an environment where everyone knows everyone else's business. This challenge is greatly increased in respect of individuals who are moved into a community with a known pre-existing condition.

4.10 In the context of the workshop briefing with which they had been provided, groups did discuss particular health challenges for their communities with broad agreement that rural health issues encompass mental health, alcohol abuse including underage drinking and childhood obesity.

4.11 Participants also talked about solutions:

- The importance of outreach to engage the more isolated.
- Collaborative working between the NHS, social care and housing providers to provide older people with support for independent living.
- The need for more local care home provision to enable older people to remain within their community and support networks.
- The potential to access alternative sources of information and evidence e.g. Signposts
- "Village Agents[1]" and "Community Exchange[2]" initiatives as a route to engaging isolated groups and individuals, provided that they have good links with GP practices.

"Isolated people with mental health issues need additional support to engage with services and to overcome community prejudice"

1 Village Agents are part time information workers operating at community level to provide a first point of contact for individuals in need of advice, information and support. Coverage in Cumbria is currently only partial.

2 Community Exchanges are voluntary community initiatives that operate from village halls and seek to address locally defined social and service needs. NHS Cumbria has contributed support for the development of what is a growing network.

Qu 2 – How well are these characteristics reflected in the four challenges that the Assessment describes?

4.12 Discussion in the context of this question produced a clear divergence of views between the Cumbria Rural Forum group and those in the localities.

4.13 The former took the view that the four challenges identified in the Joint Needs Assessment did, on the whole, reflect the health characteristics of rural communities.

4.14 The perspective from within those rural communities was rather different especially in the lack of clarity about how the challenges respond to rurally distinctive issues such as isolation, the needs of rural children and the perceived differing incidence of health problems such as obesity.

4.15 One group captured these concerns in the form of some "rural challenges" – these included:

"Challenge 1:

- *Younger people are leaving the area leading to.*
    - *Skills base reducing*
    - *Elderly parents left alone*

Challenge 2:

- *Farming – some evidence of mental health problems related to isolation and concerns over things like BSE and Foot and Mouth*

Challenge 3:

- *Access to services*
    - *The less articulate get a poorer service*
    - *The less well-off have more problems accessing services because of the poor public transport links."*

"There is an ageing population. They are OK in Sedbergh as it has good services but the transport from Dentdale is poor and it's more difficult for older people."

"This is a challenging place to live in poverty. It's a low wage economy and the poverty is hidden. Older people often don't like claiming benefits. Some families won't claim for free school meals."

Qu 3 – Is there something important about your community and its needs that you think the Assessment has missed and that you think must be considered in future work by NHS Cumbria?

4.16 This question provoked a great deal of discussion in all of the groups, much revisiting issues discussed in relation to Question 1. Translating this dialogue, the issues that participants believed should be reflected in the Assessment, and that appeared to them to be unrepresented included:

4.17 Diversity - Cumbria is a large county, with diverse needs that vary from place to place. In a rural context there tend to be pockets of need such as a small percentage of people suffering from a specific complaint in a specific area. Use of wide-area statistics such as the Index of Multiple Deprivation to target services and resources result in local needs not being identified and

properly addressed, “people can fall through the gaps”. Working with partners such as Signposts would help to fill some gaps in the data available, for example, identifying the health needs of people who are outside the NHS system.

4.18 Self-reliance – the resilience of rural communities and their capacity to, to some extent, rally round and support one another can be seen as a positive. However, it also has negative consequences in that matters dealt with locally remain unrecorded and, when local networks fail, people are marginalised even further. Such marginalisation is likely to become more prevalent in ageing communities as their social networks become steadily more fragmented.

4.19 Minority needs – there was a view in some of the communities involved that the NHS fails to address or engage with the needs of some minority communities, including the County’s varying population of gypsies and travellers. Members of this community are understood to have a lower than average life expectancy, as referenced in Challenge 4 and particular service delivery needs that must be met if they are to receive the necessary support.

4.20 Access to services – the physical character of rural Cumbria is one that increases isolation and reduces accessibility to services. This is a matter of particular concern to rural residents, especially those on lower incomes or reliant on others for transport. The consequences discussed were:

- People living “outside the system” whose needs are unknown and unmet by health services.
- People in poverty facing insuperable/unacceptable barriers to accessing the services they need – a particular challenge for communities reliant on low-paid employment and with a high proportion of lone pensioners.
- Older people facing barriers to accessing services and support, especially if living in more remote communities.
- Services being provided in times and places that make them inaccessible by any means other than the private car. Someone from Dent said *“There is a bus from Dent to Sedbergh one day per week. You can only be ill on Wednesday afternoons which is when you can get to the health centre!”* Some groups such as farmers find it difficult to access GP services because of the surgery opening hours.
- Access problems exacerbated for rural residents, without their own transport, having to attend Carlisle, Lancaster, Preston, Blackpool, etc. for specialist treatment.
- Widespread confusion about hospital transport and voluntary car services. Their availability, who can use them and when, etc.
- Inadequate “out of hours” services for residents in more remote locations.
- Patchy provision of some services such as dementia care and services for people with learning, mental and physical disabilities which means that some communities receive no service or face unacceptable costs in accessing the provision that is made.

"You should look at real patients real problems – they just want fast diagnosis, treatment and care"

"Currently neighbours support each other but with the ageing population in a few years there will be a glut of older people all dependent on each other."

NHS Cumbria Strategic Plan

Qu 4 – Do these aims and priorities reflect what you think are the main needs of people in your community*?*

4.21 In broad terms, the participants in the discussion groups accepted both the aims and priorities set out in the Strategic Plan as having some validity. However, there were concerns about the ordering of the priorities and the relative importance that the order used placed upon them. From a rural perspective it was suggested that the order of priorities should be reversed with numbers 5 – 8 coming at the top of the list.

4.22 Particular discussion points arising from the priorities included:

- Reservations about the standards of service provided to older people e.g. being discharged too early from hospital, lack of quality of life support (Priority 6)
- Many expressions of concern about the inadequacies of "out of hours services" (Priority 7)
- Reservations about bringing care closer to home, especially the level of support provided to patients and whether there a genuine intention to deliver it properly or is it a cost-cutting initiative (Priority 7)

"Bringing care closer to home is of interest. Will people be supported though, or will it be like care in the community?"

Qu 5 – If not, what do you think has been overlooked in setting these as priorities?

4.23 Discussion groups challenged the apparent assumption that NHS Cumbria is the best organisation to deliver some of the services described in the priorities. It was suggested that there should be a more "joined-up" approach involving the NHS, Adult Social Care, education and third sectors in setting priorities and budgets and managing delivery.

4.24 Again, issues of accessibility dominated discussions. The issue arose in a number of ways that reflect on the need for the NHS to consider, in setting its priorities:

- Delays in accessing interventions and treatments that arise from factors that limit access including transport, isolation and surgery/clinic hours.
- Delays in accessing specialist services due to time and costs constraints
- Poor performance in terms of response times by ambulances
- Lack of access in many communities to services that contribute to health e.g. exercise facilities, preventative services

4.25 There was a common view that a key route to addressing at least some of these challenges would be to adopt a more outreach-based approach to service delivery, in partnership with others, to overcome key barriers to

access. Some opportunities to build on existing partner activities were identified including the Signposts project and the growing network of Community Exchanges.

"Best isn't always cheapest!"

Qu 6 – What changes do you think need to be made to better reflect the needs of people you know*?*

4.26 Fundamentally, the groups made the point that rural communities continue to have less access to mainstream care and expressed concern that the cost to their GPs in accessing services on their behalf might also be higher, leading to budget constraints on service access.

4.27 While steps to move services closer to home were broadly welcomed, participants in some localities (e.g. Upper Eden) were keen to point out that a service moving closer might still be too far away (e.g. a service moving from Carlisle to Penrith, while being closer still demands a 50+ mile round trip).

4.28 Instead, participants talked about moving services still closer, into health centres, GP surgeries or other forms of outreach including mobile or peripatetic services perhaps coordinated with Community Exchanges.

4.29 Participants talked of past arrangements that had served their communities well including, for example, exercise on prescription, while recognising yet again the practical challenges associated with accessing services and facilities. Given this context, opportunities were identified for the NHS to work more closely with communities to make better use of local community assets including facilities such as sports provision, informal resources such as walking opportunities and the skills vested in sports clubs, etc.

4.30 One group (Upper Eden) suggested that a local committee might help to identify and build some of these key connections, engage with isolated individuals outside formal systems and plan preventative programmes while ensuring that the NHS is better informed about local priorities and needs. Such structures could also help to improve GP engagement with the wider community, rather than their patient lists.

4.31 Preventative programmes were identified as a development priority, especially those that might engage older people and contribute to Priority 6 in the Strategy. It was suggested that these preventative programmes should be better resourced.

4.32 In view of the differing patterns of service provision, it can be quite difficult for people to understand who provides what service and where and when to access provision. All groups commented on the importance of effective communication with the public using both traditional mechanisms and new routes including the internet, video links and Village Agents.

"The aim should be to improve life for ill people, not reduce costs for hospitals"

"Local people need to know what's on offer and what's available. Good communication is important."

"There are some isolated people who are very private and very hard to reach. You need local knowledge to find those people."

Arrangements for Service Delivery
Qu 7 – How well do you think these arrangements have met the needs of local people?

4.33 One participant asked the telling question:

"Have services met our needs, or have we just coped and managed with what's been on offer?"

4.34 This observation is reflected in the comments recorded in other groups which were to the effect that current service delivery methods have not met needs of rural communities well. They have been too focused on addressing acute needs and as a result have failed to address a large section of community-based need. It is also considered that investment, through its focus on acute provision, has starved more local provision of investment.

Qu 8 – Have there been aspects of health service provision in your area that you have particularly liked or welcomed?

4.35 All of the discussion groups reflected the way in which people value their local facilities whether it be the GP surgery, local health centre or community hospital. This does not necessarily mean that participants had always used or even knew what services were provided, rather these views seemed to reflect a sense of local ownership of the provision being made and a perception that this provision offered easy access to services as a security or insurance factor.

4.36 The Upper Eden group were strong supporters of their local GP and Health Centre services (e.g. nurse practitioners and physio) but also expressed a strong desire to see more services provided e.g. x-ray, ultrasound, breast screening – perhaps through a greater use of mobile services. They considered that easier access to increased local provision would encourage greater take-up of services by isolated people.

4.37 Two groups (Upper Eden and South Lakeland) commented favourably on the past availability of Saturday morning clinics/drop in sessions, regretted that these were no longer available and suggested that they be reinstated.

4.38 The Millom group particularly valued the opportunity to recuperate locally after acute treatment and to access some clinics without having to travel further afield. This group also praised the quality of "end of life" care which draws upon both NHS and third sector provision.

4.39 While valuing these local resources, groups recognised and commented upon some of the inevitable constraints, for example getting appointments with a particular doctor, poor out of hours provision and limited outreach. For example, one participant commented that "there is a clinic in Dent once per week but it isn't used much, not because it's not needed but because the building is inadequate, there is no privacy and you can't get tests done there.

4.40 Participants also understood the inevitability of having to travel much further afield for specialist treatment.

"People value their local facilities – the security/insurance factor of it's there if I need it."

Qu 9 – What has worked less well and how could services be improved?

4.41 This question generated a great deal of discussion. Key areas in which participants sought improvements included:

4.42 Communication – communication between different providers, both within the NHS and between the NHS and external providers, was regarded as a considerable problem. Many participants cited instances of delayed or disrupted treatment and/or lack of information that had arisen as particular patients were passed from one NHS service to another e.g. GPs not following through with patients, lack of coordination with social services, patients returning from NHS funded treatment by a private provider affected by failures in communication, failure to coordinate transport and discharge arrangements.

4.43 Staff awareness – there is perceived to be a serious lack of awareness, on the part of NHS staff, of the practicalities of rural life; no understanding of just how far patients may need to travel to access provision or of the costs that they incur is doing so. Instances cited included: people being called for appointments and then turned away despite this involving a 100 mile round trip; people being called for appointments at times when there is no way that they can get there in time; being asked to attend Carlisle and Lancaster on the same day; etc.

4.44 Appointments – participants commented regularly on the difficulties that they experienced in securing appointments with all parts of the health service, including GPs, clinics and hospitals. They found that the options available to them were likely to be very limited and not necessarily practical given their individual circumstances. The existence of systems such as "Choose and Book" were recognised but so too was the fact that these were only offered for some services in some locations and that practicalities such as the number of appointment slots available often meant that the choice available was no choice.

4.45 Local delivery – As a corollary to the numerous comments made throughout the discussion sessions about the time and cost involved in travelling to access health services, all of the groups indicated support for the principle that there be a shift towards more services being provided with communities. In no particular order, groups indicated a desire for improvements in accessing GP services, minor emergency services (Millom group commented on their need to travel to Barrow), dementia services (not available within Upper Eden), the provision of intermediate care in community hospitals, pharmacy services, disability assessment (only available at Carlisle), special needs services

4.46 This is not to say that participants didn't also recognise some challenges in delivering services within the community. Two main concerns noted were: the lack of privacy that people in small communities experience which can be particularly difficult for people suffering, for example, with mental health issues; and the need to support local service provision with investment in staff training and capacity.

4.47 Service hours – These rural focus groups feel that health services are designed around urban needs in terms of underlying assumptions about transport, access and appointment arrangements. Particular issues that reflect on this perception included observations about the limited hours during which GP services and clinics operate. Concerns about hours of operation are strengthened by the poor response times achieved by emergency and out of hours provision, which were seen to impact directly on the outcome of emergency situations. Surprise was expressed that the out of hours provision in Cumbria is officially regarded as "good", contrary to the practical experience of rural residents. Such concerns were compounded by dissatisfaction with appointment arrangements.

4.48 Transport – participants in all groups recognised accessing services as a major problem and looked for improvements in transport arrangements. They believed that rural residents in effect had a "rural premium" imposed on them that arose from the time and cost to access services which, in many cases, falls on the patient. They also commented adversely on patient transport and voluntary car schemes, indicating that, at best, these are confused and confusing, to be designed around the needs of adult but not child patients and to be getting worse.

"The aim should be to improve life for ill people, not to reduce costs for hospitals"

"The main things that worry people are ambulance response times and out to hours provision, because of the time taken to access or receive services"

"The out of hours service is inadequate. You have to wait a long time for someone to come and visit or else you have to get to Kendal."

Future Services

Qu 10 – What do you think of the principles that have been described?

4.49 In the context of previously discussed concerns about remoteness from service provision, and a view that more services should be provided locally, groups welcomed the principles of "closer to home". The continued survival of community hospitals and investment in new services is supported as are plans to create additional community hospital beds in Whitehaven, Barrow, Carlisle and Kendal.

4.50 However, the Upper Eden group did make the observation that the provision of a new service in Penrith doesn't necessarily make things easier for residents in their community because access would still involve a 50 mile round trip. For this reason both the Upper Eden and South Lakeland groups called for more services to be delivered locally, through their respective health centres. Groups also suggested that an increased number of services (e.g. x-ray, ultra sound) might be provided on a mobile basis in order to bring services to people at GP surgeries, health centres or Community Exchanges.

4.51 In the course of their discussions, the groups also:

- Highlighted the need to ensure that the resources and infrastructure are in place to support closer to home, believing that the proposed approach would prove more costly to

deliver than existing arrangements
- The need for services to be delivered in a joined-up fashion
- The necessity of flexibility and sensitivity to accommodate the actual home circumstances, especially of older people who may not have the support available within their community that "closer to home" assumes.

4.52 Additional concerns related to the reduced number of community hospital beds that are a part of the "closer to home" approach with at least one case being cited where the reduced number of beds at Penrith had caused problems and people from the Millom area fearing similar difficulties.

"People can be very isolated and for those in Garsdale and Dentdale if transport is provided going to Sedbergh would be an improvement on going to Kendal. It should be noted that some people in the area go to GPs in Hawes." (which is in Yorkshire)

"Could a better range of services be offered at the Health Centre instead?"

Qu 11 – How do you think this approach might improve health services for people in your community?

4.53 Participants believed that "closer to home" would reduce the need for patients to travel and provide patients with greater support from family and other networks. The latter is viewed as particularly important, based on a belief that contact with family and friends can speed recovery. There is, however, a caveat which is that the proposed community hospital provision in e.g. Penrith, Kendal is still a very long way from the home communities of some patients.

4.54 Again, participants commented on the need for arrangements to be "joined up", especially with social care. This is particularly an issue because of comments from the focus groups described elsewhere at the numerous communication problems between different elements of the health services.

Qu 12 – What things do you think may have been overlooked in developing and piloting the "Closer to Home" approach?

4.55 While emphasising that "closer to home" should involve the whole community and engender greater personal and local ownership of health issues, participants identified a number of concerns:

- Is the "virtual ward" concept rural proof, can it be delivered in practice to dispersed patients without increasing costs and is there a risk to patients due to early discharge from hospital?
- The time taken to travel between patients would use staff time inefficiently and make the service costly.
- Not all patients have the home/community support that is assumed (e.g. older couples, young singles).
- The necessity of recognising and accommodating the specific needs of individuals.
- Cumbria's varying geography meaning that arrangements

would have to be tailored to local circumstances.
- Investment is needed in some areas in advance of the new arrangements being rolled out (e.g. a suitable base in Dent).
- Bad weather, as recently experienced, would make service delivery difficult or impossible (for example, the road from Kendal to Sedbergh is not a priority for gritting).
- The necessity for services to be supported by sufficient, appropriately qualified staff.
- The potential need to home adaptations to meet special needs and the difficulty of coordinating this provision with health services.

4.56 Some groups also spoke of the impending problems that arise from Cumbria's ageing population, especially in rural areas, asking the question *"who will care for us as the number of working age people falls?"* It was also recognised that the difficulty in accessing affordable housing in rural Cumbria exacerbates this problem, making it very difficult for young people on low wages to remain in their home communities.

"Closer to home should involve the whole community."

Qu 13 – Are there particular problems that you can think of?

4.57 Closer to home will become effective if delivered in cooperation with local communities and their established groups and organisations, to ensure that services are tailored and responsive to local needs. There is the potential to harness local resourcefulness but both trust and excellent communication are needed.

4.58 Local capacity – People living alone do not necessarily have access to friends and family to collect them from hospital and provide the day to day care that they may need. The obligation to provide support of this type within the family or community may also place an unacceptable strain on those individuals concerned, especially where these people are old and ageing. This suggests that it may be necessary to harness local volunteers.

4.59 Technology – Elements of caring for people in their own homes assume access to a certain level of technology and infrastructure, e.g. telehealth systems. However, there are many parts of rural Cumbria where the infrastructure is simply inadequate for this purpose, for example, many areas where broadband services are either much slower than supposed or not available at all.

4.60 Staffing – Some participants felt that there may be difficulties in moving NHS staff to a community-based working model and also highlighted the importance of ensuring that there is sufficient back up for community staff when they are on holiday or off sick so that there is no gap in service delivery.

"We need a buddying system for people to accompany older people to appointments who may not have a relative or friend that they can ask"

Footnote

4.61 Members of one study group were asked, at the conclusion of their session, to identify *"one thing that would make a big difference"*. Their brief suggestions reflect key issues that have emerged from this study:

- Good relations between GPs and the community are essential
- Access to services and facilities needs dramatic improvement
- Access to your own GP's Out-of-Hours service
- Access to local information about what's happening
- Appointments on-line
- A one stop shop for health services
- Improve receptionists' appreciation of patient needs and constraints
- A joined-up approach to health and social care
- Accountability of service providers

Appendix 1 – Workshop Briefing

The following briefing paper was provided, with minor contextual changes, to each of the workshop participants in advance of the session to which they contributed.

Health Services in Cumbria – Working for Rural Communities

This briefing has been prepared to provide you with background information that will be useful in the Health Services in Cumbria – Working for Rural Communities Focus Group session that you have agreed to participate in. It aims to describe, in simple terms, the way in which health services have traditionally been provided and changes that are now being made.

The purpose of the Focus Group will be to explore these changes and to better understand how they may impact on residents in different areas of rural Cumbria. To help you, this paper provides summary information about four things, all of which you will find explained later:

- The Joint Strategic Needs Assessment
- The NHS Cumbria Strategic Plan
- Existing arrangements for delivering services to local people
- Changes across Cumbria in the way that services are delivered, in line with the plans described in the "Closer to Home" strategy.

You will be invited to comment on each of these from your perspective as a resident in one of Cumbria's rural communities. Your comments will be fed back to NHS Cumbria and will help to shape its strategy for the future provision of health services.

Role of NHS Cumbria

ACT has been asked to undertake these sessions by NHS Cumbria. NHS Cumbria is the County's **primary care trust**. It has two roles to play in providing health services to local people. It buys – or "commissions" – a full range of NHS hospital and community health services. The community services it provides are based on local need across the County and work closely with GP (family doctor) practices which are know as "primary care" and are the services that you would normally access when you first have a health problem. NHS Cumbria is therefore the main organisation in the County responsible for shaping the health services that are provided and the way in which these are delivered.

Focus Group session Part 1 – Setting Priorities

NHS Cumbria plans the way in which health services are provided using evidence from the **Joint Strategic Needs Assessment** to understand what the most pressing problems are and the **NHS Cumbria Strategic Plan** to describe the work that it will undertake as a priority.

This first part of the session summarises these two key documents and will invite your reaction to their findings as a local resident.

Joint Needs Strategic Assessment
The Joint Strategic Needs Assessment describes the health and wellbeing of the people of Cumbria and the way in which it is proposed to meet those needs. It is a regularly updated piece of joint working by NHS Cumbria and Cumbria County Council which is intended to inform their decisions about the provision of both health and social care services.

The Assessment uses four types of information to understand local needs. These are:
- Patterns of health and the things that affect health
- Information on current services, strategies and policies
- Evidence about what works well
- The knowledge, experience and wishes of the public

The Assessment reviews all of these types of information on a regular basis, most recently in 2009, when four key findings were identified. It is these key findings that will influence service delivery for the immediate future. They are:

Challenge 1 – The ageing population and the declining number of young people
Services and housing will need to be planned to take into account the growing number of older people in Cumbria. Services will need to be expanded for the increasing numbers of older people with long term chronic health conditions, dementia, mental illness and learning disabilities. Prevention and providing the right care early on when someone becomes ill will be essential if health and social care services are going to cope with this increased demand. Opportunities will also need to be created to retain and attract younger people to Cumbria.

Statistic – 19% of people in Cumbria in 2004 were aged 65 or over. By 2029 this will have risen to over 28% with a corresponding increase in the numbers affected by dementia.

Challenge 2 – Mental health and alcohol misuse
There are some trends in Cumbria, related to alcohol misuse and mental health, which are of concern. Alcohol related admissions to hospital are higher than the national average and increasing. Recent surveys also indicate that alcohol consumption amongst school children is higher in Cumbria than England as a whole.

It is recognised that in parts of the County large numbers of people are out of work because of poor mental health. Each year between 50 and 60 people commit suicide, a level that is higher than the national average and closely associated with unemployment. The current economic downturn may exacerbate these trends.

Statistic – 20% of the adult population of Cumbria exceed the recommended number of alcohol units. 19% of boys and 10% of girls in year 10 drink more than 14 units of alcohol in a week.

Challenge 3 – The health of children

Recent information shows that in Cumbria one in five 10 year olds are so overweight that it is bad for their health. This is an increasing trend and higher than the national rate. The frequency with which children in the County are breast fed is also low and there are high numbers of women who continue to smoke during pregnancy. These factors all have consequences for the health of children, particularly in the most disadvantaged areas. They will need to be addressed if children in Cumbria are going to have the best start in life.

Statistic – 10% of 5 year olds and 20% of 10 year olds are so overweight that it is bad for their health. 64% of new mothers in Cumbria begin breastfeeding.

Challenge 4 – Health inequalities

The place in which we live, and the community of which we are a part, has a significant impact on our health and wellbeing. Our neighbourhood and the attitudes of those around us can shape the choices we make and affect our life chances. These differences in living conditions mean that people in the most affluent areas of Cumbria are living up to 20 years longer than those in more disadvantaged circumstances. These unfair and avoidable differences in health between social groups are what is meant by health inequalities. Tackling these inequalities in Cumbria will require action to improve support for parents and children, narrow the gap in educational attainment, improve housing conditions and break the link between poor health and unemployment.

Statistic – People living in Moss Bay, Workington have a life expectancy which is 19.5 years shorter than people living in Greystoke, near Penrith.

Qu 1 – What are the main characteristics of your community that you think will affect the health needs of local people?

Qu 2 – How well are these characteristics reflected in the four challenges that the Assessment describes?

Qu 3 – Is there something important about your community and its needs that your think the Assessment has missed and that you think must be considered in future work by NHS Cumbria?

NHS Cumbria Strategic Plan

Based upon the Joint Strategic Needs Assessment, NHS Cumbria has developed and adopted a Strategic Plan to guide its investment and service delivery.

This document describes the Vision of NHS Cumbria:

Our vision is to improve the health and wellbeing of all people in Cumbria and help them to stay active, independent and in control for as long as possible

This vision is underpinned by three key aims:

- Better Health – improve health and reduce health inequalities
- Better Life – improve independent living and self management
- Better Care – improve the way we deliver care and increase opportunities for people to influence decisions about local services.

The Strategic Plan describes the eight priorities that NHS Cumbria will use to direct its resources in order to achieve its key aims. These are

1. Reduce early deaths from cancer, especially lung cancer, where life expectancy in Cumbria is significantly lower than the national average.
2. Reduce early deaths from circulatory diseases, especially coronary heart disease, where life expectancy is significantly lower than the national average.
3. Reduce health inequalities, especially the gap in life expectancy between the most deprived communities in Cumbria and the most affluent in the priority diseases of coronary heart disease and lung cancer.
4. Support people to lead healthy lifestyles and reduce smoking, obesity and alcohol misuse, which give rise to poor health (particularly coronary heart disease and cancer) and wider problems within our community.
5. Improve mental health and wellbeing.
6. Improve quality of life and independent living by supporting people, especially older people and those with ongoing conditions, such as arthritis and diabetes, to manage their own care and by increasing choice and end of life care.
7. Bring care closer to people's home, improve access to services in communities, minimising hospital admissions and stays, and improve out of hours, emergency and crisis services.
8. Provide improved and fairer access to specialised, out of County services, such as specialist cancer services.

Qu 4 – Do these aims and priorities reflect what you think are the main needs of people in your community?

Qu 5 – If not, what do you think has been overlooked in setting these as priorities?

Qu 6 – What changes do you think need to be made to better reflect the needs of people you know?

Focus Group session Part 2 - Arrangements for Service Delivery

Over many years we have become used to a particular approach to the delivery of health services. This has tended to see a focus of investment in specialist care and equipment in a small number of centres, the acute hospitals. This has been accompanied by a trend for patients in need of assessment, monitoring and treatment to

be accommodated within those acute hospitals (e.g. Barrow, Carlisle, Kendal, Lancaster, West Cumbria or further afield), often a long distance from home.

In North Cumbria (Allerdale, Carlisle, Copeland and Eden), where there is a network of community hospitals, these arrangements have been supplemented, with patients in need of rehabilitation and observation accommodated rather more locally in e.g. Alston, Brampton, Cockermouth, Keswick, Millom, Penrith, Workington.

Everywhere, General Practitioners have been the first port of call for health advice and treatment.

Qu 7 – How well do you think these arrangements have met the needs of local people?

Qu 8 – Have there been aspects of health service provision in your area that you have particularly liked or welcomed?

Qu 9 – What has worked less well and how could services be improved?

Future Services

NHS Cumbria has been reviewing the way in which services are delivered in the context of the Joint Strategic Needs Assessment and its Strategic Plan. It has concluded that a different approach to future investment in services will better meet local needs and help to achieve its aspiration to help people to live independently for longer and to have greater ownership and management of their health needs.

In North Cumbria this approach has been described as “Closer to Home” while in South Cumbria similar issues are being explored through proposals for an “Integrated Care Organisation” for the area.

In both localities the principles being explored, and in some cases implemented on a pilot basis, are focused upon developing health services around the needs of individuals and their communities, supporting people to live healthy lives and, whenever possible, bringing health care services to them at home or in their community. This will be achieved by diverting investment from the acute hospitals to improved service provision in community hospitals, GP surgeries and health service staff working in communities.

This approach is intended to reduce the need to travel to an acute hospital for tests or to be admitted for treatment and to improve the level of support that people will be able to call upon either in their own home or locally.

What will this look like in practice? An example of the way in which “Closer to Home” is being implemented is in the area served by Penrith Hospital. This has involved:

- A new Primary Care Assessment Service offering more tests and treatment such as ultrasound and x-ray in the community hospital. This means that people will not need to travel so far for initial assessment.
- A Clinical Decision Unit as a part of the Assessment Service which will allow doctors and nurses to assess patients more locally and ensure that they receive the care

they need where they need it, whether this is at home, in the community or in hospital.

- A Short Term Intervention Service that will provide short-term support or assessment. This will provide a mix of support and rehabilitation so that people don't have to go to hospital or can go home from hospital earlier.
- The term "virtual ward" has been used to describe the way these services will work together, meaning the delivery of ward-type services outside the hospital environment.
- New clinics (such as a Breathlessness clinic) providing a wider range of services within the community hospital.
- Moving staff from working in the community hospital to working in the community itself, for example, ward nurses have begun to shadow district nurses.

One consequence of this new way of working will be that the number of bed spaces in each community hospital will reduce. However, this does not mean a lesser level of service, it is simply a reflection of the fact that these new ways of working mean that fewer people will need to spend time in hospital and, if they do need care in hospital this will be for a shorter time.

Qu 10 – What do you think of the principles that have been described?

Qu 11 – How do you think this approach might improve health services for people in your community?

Qu 12 – What things do you think may have been overlooked in developing and piloting the "Closer to Home" approach?

Qu 13 – Are there particular problems that you can think of?