

together for a healthier future.

**Together for a Healthier Future
Feedback from patient, public and
stakeholder engagement from 9 April to
mid-June 2014**

1 Purpose of report

To provide feedback to the North Cumbria Programme Board following engagement activity with patients, public, third sector and local councils across Allerdale, Copeland, Carlisle and Eden from 9 April to mid-June 2014 to help inform a five year strategic plan for the health economy and as part of this a strategy for North Cumbria.

2 Background

The North Cumbria Programme Board which is chaired by NHS Cumbria Clinical Commissioning Group (CCG) was established in February 2014, as part of the Cumbria Health and Care Alliance. Branded Together for a Healthier Future the aim of the board is to address long standing issues affecting health and care organisations across North Cumbria (Allerdale, Copeland, Carlisle and Eden) and to contribute to the development by the CCG of a five year strategic plan for the Cumbria health economy.

To make sure that the five year plan was informed by the views of patients, public and other key stakeholders a period of engagement activity was launched by the Board on 9 April and ran until mid-June 2014.

The launch involved the widespread sharing of a comprehensive briefing to targeted individuals including the MPs and through the media and existing third sector and local authority networks. The briefing outlined the challenges faced by the health economy across North Cumbria, the development of the five year plan which included a focus on delivering more care closer to where people live, closer working across health and care organisations and ensuring safe and sustainable hospital services. The briefing also set out an initial programme of roadshows being facilitated on behalf of the Board by Healthwatch Cumbria and included some examples of work already taking place which provided a foundation on which to build.

Letters with the briefing were sent to Cumbria County Council, to the four district councils and to Cumbria Association of Local Councils (CALC), for onward cascading to parish and town councils, offering the opportunity of meetings with councillors and officers.

There were also letters with briefing material, followed up by telephone calls to MPs' offices offering the same opportunity and indeed some discussions had already taken place with MPs in the lead up to the launch.

Cumbria CVS was commissioned to facilitate two events, one at Penrith and the other at Workington, for third sector representatives. The events were promoted through the Cumbria Action for Health Network.

Taylor Nelson Sofres (TNS), a world leader in market research, which was already providing substantial support to the Better Care Together programme across North Lancashire and South Cumbria was commissioned to carry out 20 focus groups.

Representatives of the CCG also attended existing meetings of the Cumbria Health and Well-being Board and the health overview and scrutiny committee where the development of the five year plan was an agenda item.

Alongside all of this activity there was ongoing media coverage to promote the public roadshows and the development of the five year plan. This included several newspaper articles and interviews on local radio and TV.

3 Public roadshows

Healthwatch Cumbria was commissioned to facilitate a programme of ten roadshows across North Cumbria and following requests for additional events to be held, a further three were organised. The roadshows were held mainly in busy public venues where there would be a high foot fall, such as markets and public and supermarket car parks. At Kirkby Stephen and Alston they took place in the local Links office and in the Alston Moor Partnership shop respectively. The schedule was as follows:

16 April	Market, Pow Street Workington (10am to 2pm)
17 April	Market, Criffle Street, Silloth (10am to 2pm)
26 April	Farmers' Market, Market Place, Brampton (10am to 1.30pm)
2 May	Farmers' Market, English Street, Carlisle (10am to 2pm)
15 May	Market, Moot Hall area, Keswick (10am to 2pm)
17 May	Market, near Band Stand, Whitehaven (10am to 2pm)
20 May	Farmers' Market, Clock Tower, Penrith (10am to 2pm)
21 May	Links Office, Kirkby Stephen (11am to 2pm)
23 May	Market, Town Square, Cleator Moor (10am to 2pm)
26 May	Bank Holiday Plant Market, Wilkinson's Car Park, Cockermouth (10am to 2pm)
29 May	Water Street Car Park, Wigton (10am to 2pm)
30 May	Co-op Car Park, Maryport (10am to 2pm)
2 June	Alston Moor Partnership Shop, Alston (3.30 to 6pm)

A highly visible Healthwatch stand was used at all outdoor events and there was a Together for a Healthier Future banner. Representatives from Healthwatch and from local NHS organisations were present at each of the roadshows.

The conversations with the public included a discussion about the challenges facing the health economy which need to be addressed, the development of the five year plan and its focus on more services closer to where people live, more joined up services and ensuring safe and sustainable hospital services. People were asked against that background about what improvements they would like to see to health and care services, what had been good about any care they had received and what could have been better. They were also asked if they had any thoughts about what more could be done to help people to stay healthy and about which health and care services were most important to them.

Comments were logged on individual forms and people were asked if they wished to share their name, address, date of birth, whether they were disabled and their ethnic origin. Some people indicated that they preferred to remain anonymous and this was respected.

The number of forms varied depending on the venue and ranged from 13 at Kirkby Stephen to 71 at Carlisle. Overall, a total of 525 forms were completed during the roadshows but many more

people were involved in the conversations as single forms were sometimes completed for couples and friends and family members out shopping together.

Also, Healthwatch took the opportunity to interview and complete forms for a further 12 people at a Cumbria Pride event in Carlisle for lesbian, gay, bi-sexual and transgender people and at the Carlisle Youth Zone.

There were high levels of awareness of the challenges facing the NHS with most people referring to money and recruitment problems without any prompting. People were generally very loyal about local NHS services and the majority were positive about their own experiences. However, those who were less satisfied raised a number of issues. People seemed happy to take part in the road shows and some called by because they had heard about them through the media.

A report from Healthwatch outlining the main findings is attached at Appendix A. However, some general themes are outlined below.

3.1 General themes

A number of general themes emerged:

Access to services

- There were many comments about having to ring the GP practice at 8am for an urgent appointment and the need for faster access. Online booking was very popular with some but older people don't always have internet access.
- Continuity was important for people with long term conditions who liked to see the same GP.
- There were comments about the availability of dental services and the cost of dental treatment.
- People commented on long waits for some hospital appointments and the frustration of having appointments and operations cancelled. There were also some comments about the administration systems associated with this, for example, patients attending the hospital for an appointment to be told that it had been cancelled, to be given a new date there and then and then a couple of days later a letter arriving cancelling the initial appointment.
- There were a number of comments about access to mental health services, including in crisis situations.

Travelling

- A number of people commented on the distance they had to travel for hospital appointments and about how sometimes the timing of the appointment made it impossible to use public transport.
- There were many comments about the lack of public transport
- A number of people commented on the cost of taxis.
- There were strong comments about the frustration of driving to either West Cumberland Hospital or Cumberland Infirmary and then finding it difficult to park. Some people commented that they gave themselves an extra hour when planning the journey so that they would have plenty of time to find a parking space. Comments

included how stressful this was when taking someone to hospital who used a wheelchair. There were also comments about the cost of car parking.

- It was clear from some conversations that there is a lack of clarity around the use of the patient transport service.
- There were comments about ambulance provision, with some reporting good experiences and others expressing concerns about proposed cuts to ambulance cover.

Patient experience

- There were many positive comments about the care received right across the NHS, including from those who had travelled to Newcastle or Middlesbrough for specialist services. One couple called by one of the road shows to say how much the husband's life had been transformed by innovative treatment at Newcastle for a chronic bowel problem. A patient whose wife had been treated for cancer at Carlisle over a number of years spoke highly of the consultant and nursing staff.
- Many spoke very kindly about their GPs and practice nurses (even those who didn't like the system of having to ring at 8am for a same day urgent appointment often said that they couldn't fault the care they received).
- There were some less than positive comments about cleanliness at both West Cumberland Hospital and Cumberland Infirmary.
- There were comments about the lack of staff at Whitehaven and Carlisle and the impact this had on patient care.
- A few people commented on the lack of extra pillows at Cumberland Infirmary, with comments that they felt this was due to the financial problems. One patient said when his wife was in hospital they took in extra pillows themselves and used red pillow cases so that the hospital staff would know that they were their own rather than NHS.
- There were variable comments about hospital food. In particular, this was a big issue for people attending the Keswick road show who expressed concerns about a proposal to stop providing food cooked on the premises and instead use readymade meals.

Better integration needed

- There were many comments about the need for better integration across all services, from patients and from family members who were caring for older people. There were also comments about the need for better integration across services for people with complex needs.

Services moving from Whitehaven to Carlisle

- There were comments, particularly at the West Cumbria road shows that more services are moving to the Cumberland Infirmary from West Cumberland Hospital and also that more people seem to be receiving hospital treatment at Hexham General Hospital (although there were some very positive comments from people who had been treated at Hexham).
- There were concerns expressed about what services would be left at the new hospital at Whitehaven.

Prevention

- There were mixed views about what more could be done to help people to stay well. Some were firmly of the opinion that it is an individual's own responsibility while others talked about the need for more education about a range of lifestyle issues, more drop-in sessions and more wellness checks.

Other comments

- The overall cost of NHS management was mentioned by a number of people, with some saying that there are too many managers. There were also comments about big salaries and redundancy payments.
- A number of people talked about how concerned they were about the privatisation of NHS services.
- There were positive comments about the NHS engagement exercise that was taking place to inform the five year plan.

4 Third sector events

Cumbria CVS was commissioned to hold two events for representatives of third sector organisations.

These took place on May 13 and 14 at the Cumbria Rural Enterprise Agency, Redhills, Penrith and St Michael's Church, Workington respectively. Each event started at 9.30 with coffee and registration and concluded with lunch at 1pm.

Each event was opened by a senior representative of the CCG who gave a presentation to set the scene and discussions facilitated by Cumbria CVS colleagues followed. Participants could choose whether to join a general group, or groups focusing on the needs of older people and children and young people. There was a brief feedback session and over the lunch period there were further opportunities for people to give their views by:

- writing their comments on a 'talking wall'
- ranking the relative importance of various aspects of health services using 'sticky dots'
- recording their views on video.

A total of 99 people attended the events, of whom 80 were representatives of a frontline third sector organisation. The remainder included councillors and officers from local authorities and colleagues from the local NHS.

A full report from Cumbria CVS is attached as Appendix B but some of the key points and recommendations are outlined below.

4.1 Key points raised during the events

A number of key points were raised:

Hospital services

- There is still further work to be done around preventing admission and/or keeping hospital stays short and third sector organisations need to be fully involved in this, as they have a good knowledge of community support.
- Hospitals and services should be more 'dementia friendly'. This would mean patients would be likely to cope with their hospital stay and subsequent discharge more easily.
- Medication changes (on hospital admission) often seemed unnecessary and confusing to patients and their carers. It is worth considering if the benefits of a change in brand really outweigh this confusion (and potentially poorer compliance and disease management), and if so, these changes should be better explained.
- Medication changes are just one example of care not being centred around the patient; this was also mentioned in relation to discharge planning and to the management of long term conditions.

Long term conditions

- Self management is important in long-term conditions – medical care needs to facilitate this and respect the knowledge the patients and carers have built up.
- Contact with other patients with the same condition and self management programmes can help people to develop ways to manage their condition.
- Patients who effectively self manage their long term conditions tend to make less use of health services, so supporting self management can save the NHS money.

Carers

- Carers have detailed knowledge of the people they care for and their condition(s); this could often be better used in planning NHS and social care.
- Unpaid carers need support and respite and there needs to be a plan for when the carer is ill. Over-reliance on informal, unpaid carers can lead to the carers themselves developing health problems.

Mental health

- People need support at the time they reach out for help – delays of weeks or months are a significant problem. The NHS should aim for 'parity of esteem', responding to a mental health crisis as quickly and effectively as a physical health crisis.
- Third sector organisations want to be 'taken seriously' when they refer a case to healthcare professionals – they see many patients and often know individual patients well, and so can identify when a patient needs crisis support, or when a child needs to be assessed.
- There may be benefits to working with other family members as well as the patient and third sector organisations often already do this.
- There are perceived to be increasing mental health problems in young people, although much of the prevention, education and early intervention to alleviate this would need to be undertaken in partnership.

- There is still significant stigma around many mental health conditions – for example, people do not always seek help following self harm, as they have previously experienced poor treatment in A&E. Therefore, the full extent of the problem may be hidden from the NHS, and intelligence from third sector organisations might help obtain a fuller picture.

Pregnancy and parenting

- Teenage mums feel they aren't always treated with respect by healthcare professionals.
- Teenage mums often need support to develop the skills to look after themselves as well as their baby, as their families sometimes aren't supportive or lack the skills themselves.
- Parenting is hard and third sector organisations believe some children end up medicated ie children with attention deficit hyperactivity disorder (ADHD) when it might be more appropriate to work with the family to develop parenting strategies.

Travel

- Effective emergency care in very rural areas needs close coordination between the ambulance service and third sector organisations, such as first responders and air ambulances.
- Telephone appointments and 'telehealth' can help reduce travel costs.
- Travel without a car is becoming harder ie though loss of bus services and changes to patient transport service (PTS) criteria.
- Young people may find it difficult to access 'sensitive services'.
- The cost of travel (to outpatient appointments and to visit friends and relatives in hospital) can contribute to health inequalities.

Health inequalities

- Poverty is a key factor in health inequalities, for example, people who are unable to afford healthy food or who lack the skills to prepare it, are likely to have poorer health, and those pre-occupied by lack of money and housing issues are unlikely to seek healthcare
- Travel difficulties mean some patients choose not to access treatment.
- Some of these patients may be eligible for help (ie grant for travel costs or a home visit from Cumbria Health on Call) but lack the knowledge or confidence to ask for it.
- Referral to practical help (ie benefits advice) can increase income and allow people to access health services and improve wellbeing.

Equality

- Access to the appropriate translators needs to be improved – it is often not appropriate to use family members to translate. During one of the CVS meetings there were comments about the need to ensure appropriate access for deaf people and following the meeting a representative from Deafvision submitted a national report entitled *A report into the Health of Deaf People in the UK* by Signhealth and the University of Bristol for the programme board to consider. The report outlined the challenges faced by deaf people and the efforts that were needed to ensure they had good access to services.
- Health promotion advice and disease specific information often isn't available in alternative formats (other languages, Easyread) – making this available would often only mean adapting it from another part of the UK, not writing it from scratch.

- Consider involving these users (or the organisations that work for them) in the planning of health services.

Joining up services that already exist

- There are many valued services in the third sector but the number and diversity of these means that it is unrealistic to expect GPs or other healthcare professionals to know the details of all of them.
- A database could go some way to addressing this but the personal approach of ‘hub coordinators’ is more likely to be effective.
- Hub coordinators should refer to non-clinical services (benefits advice, community exercise schemes) as well as medical and social care support.
- Statutory services could often be better linked, too, for example, assessing the need for home adaptations earlier could allow earlier discharge or prevent admission.

Prevention

- Prevention saves money but is often under-funded.
- Cumbria has a fantastic natural environment and we don’t always make full use of it to promote health and well-being.
- Asset Based Community Development is an important approach to continue – active communities help to reduce the demand on statutory health and care services.
- ‘Wicked problems’ take time to solve and evaluation and funding needs to take account of this.
- Is it necessary to ring-fence part of the budget for prevention?

Third sector involvement

- A clear structure through which the third sector can engage with the CCG is still needed. This should cover both input to the planning of services and access to funding.
- Third sector organisations want to be treated as professional, equal partners.
- The networks that exist within the third sector (such as Cumbria Action for Health) can help particularly smaller organisations to engage with the CCG.
- Volunteers aren’t ‘free’ and supporting volunteers requires different skills to managing staff.

4.2 Recommendations

Based on the findings presented in their report, Cumbria CVS made nine recommendations:

(a) Develop a clear process for third sector engagement with the Clinical Commissioning Group, identifying

- A clear point of contact, or “Liaison Officer”
- Mechanisms for ongoing involvement in service design, planning and review
- A process for discussing funding possibilities for specific projects
- How existing networks (such as Cumbria Action for Health) will be utilised and supported.

(b) Join up the services and support that are already there, by

- Establishing systems to refer people to support in the community, particularly expanding the use of hub coordinators
- Improving information sharing, putting in place appropriate safeguards rather than defaulting to refusing access to information
- Considering more joint training.

(c) Continue successful work to decrease hospital admissions and support people at home, but

- Include the third sector as full partners in care/discharge planning so that community support can be maximised
- Include (unpaid) carers in care/discharge planning.

(d) Support patients with long term conditions to self-manage as much as possible, by

- Supporting work such as the Expert Patient Programme, or similar disease specific programmes
- Linking patients to existing local support groups.

(e) Make services more accessible to patients with special needs, by

- Raising awareness of needs, effective communication techniques and the support available amongst healthcare professionals
- Including these patients in the planning of services
- Improving access to translation services, including for both spoken foreign languages and British Sign Language
- Making services more “dementia friendly”.

(f) Continue to address Health Inequalities, and ensure these do not worsen, by

- Considering the travel time (and public transport timetables) when allocating appointment times
- Work with other public sector agencies to ensure that cuts to bus subsidies and welfare benefits (including crisis loans) do not prevent people from accessing healthcare
- Making early referrals to services such as benefits and debt advice so that patients are better able to concentrate on their health.

(g) Ensure that rural areas receive rapid emergency care, by

- Investigating the concerns raised at the meeting around funding difficulties for First Responder groups, and difficulties in the coordination of the different agencies
- Developing innovative solutions such as the Alston Ambulance where these are the most appropriate way to meet local needs.

(h) Ensure “parity of esteem”, tackling mental health issues with the same energy and priority as physical illnesses, by

- Supporting work that maintains mental wellbeing, and prevents people reaching a “crisis point” that requires acute intervention
- Ensuring patients have support in the (sometimes long) gap between seeking help and receiving NHS treatment, whilst seeking to ensure this gap no longer exists
- Noting the reported rise in adolescent mental health problems, and investigating ways to address this need through the commissioning process.

(i) Value preventative work, including

- Ring-fencing money for prevention and community support
- Supporting asset-based community development and community asset building
- Recognising the value of volunteers and volunteering (but also the support costs)
- Work with third sector organisations to improve the evidence base for prevention work.

5 Meetings with local councils

A number of a number of local councils asked the CCG if representatives could either attend existing meetings of councillors and officers or existing council meetings.

As a result the following meetings took place:

2 May	Officers and members – Carlisle City Council
7 May	Officers and members – Allerdale Borough Council
19 May	Bolton Parish Council meeting
2 June	Alston Parish Council meeting
4 June	Carlisle Local Committee (Cumbria County Council)
4 June	Allhallows Parish Council meeting
9 June	Officers and members – Copeland Borough Council
11 June	Eden Local Committee (Cumbria County Council)

These were in addition to attendance at meetings of the County Council’s health overview and scrutiny committee meeting on 14 April and 17 May and two meetings with the chair and lead members of the committee on 8 May and 13 June, when progress on the development of the five year plan was discussed.

5.1 Discussions at council meetings

Overview and scrutiny committee

At the meeting of the full overview and scrutiny committee on 14 April a number of comments were made about the pressures on the ambulance service, about the length of time it was sometimes taking for ambulances to respond and about the potential impact this could have on a patient as a result of the length of time it takes to get to hospital.

There were also comments about the increasing number of people who are travelling to hospital in Carlisle from West Cumbria and about how difficult travelling was for some people.

In the context of travelling difficulties there was a question about how people would be able to participate in the focus groups and road shows that were taking place as part of the engagement activity to inform the five year plan.

There was a comment from a councillor about the honesty by the CCG in presenting the problems currently facing the local NHS.

At the first meeting with the chair and lead members of the OSC, the CCG representatives provided an update on the development of the plan and the engagement activity and there was a further discussion about ambulance response times and the desire of members to understand response times within Cumbria rather than for the whole area served by North West Ambulance Service NHS Trust.

At the second meeting with the chair and lead members information was shared on thinking to date in terms of direction of travel of the five year plan.

At that meeting, the importance of highlighting any actions to be taken (ie as a result of the plan) was stressed so that the committee was aware. Members said they would welcome some information as soon as possible about milestones and timescales. They said they would welcome being involved in the next stage of the process when they could look at specific issues and risks. All of the meetings were welcoming and members and officers were interested to hear about the development of the five year plan.

Carlisle City Council

At Carlisle City Council there were comments about closer working between the council and NHS organisations. There was considerable interest in working with the NHS on the preventative agenda to address health inequalities and a recognition that the individual organisations should be more joined up as they are often dealing with the same vulnerable people.

The council said it would map out all of its health-related services to share with the CCG and other NHS organisation so that opportunities could be identified for close working.

Allerdale Borough Council

Councillors and officers at Allerdale Borough Council were very interested to hear about the development of the primary care communities pilot which was being planned following a successful application for funding to the Prime Minister's Challenge Fund.

Some councillors commented on the need to improve access to GP appointments, particularly for people who are working and who sometimes find it difficult to ring in or call into the surgeries at specific times to make urgent appointments. One councillor commented positively on the availability of an online facility to book appointments and order repeat prescriptions at his practice. Another said he used the service provided by Cumbria Health on Call (CHoC) which he said was fine for him because he has a car.

There were comments about all organisations needing to work together to address health inequalities and the opportunities that could be available to do this through primary care communities were welcomed.

Some councillors commented on their frustration over the perceived increasing number of hospital services being transferred from Whitehaven to Carlisle and about the impact of travelling on people. The impact on the ambulance service was also mentioned.

Finally there were also comments about the perceived need for improvements in mental health services and on the high incidence of young people with mental health problems in West Cumbria.

Copeland Borough Council

Councillors felt that 'back office' problems in hospitals needed to be sorted out and quoted instances of patients attending hospitals for appointments when their notes were not available or had not been updated.

One councillor felt strongly that the NHS was not involving the district councils as well as it could. She felt that the NHS talked about holistic care but that this wouldn't be possible without the involvement of the districts. She also commented that the districts had a part of play in terms of recruitment because of their role in ensuring quality of life for local residents.

It was also her perception that the GPs in Copeland were not as proactive as in other areas. She said it was sometimes difficult for the council to engage the GPs.

Another councillor commented on how there had been difficulties for patients getting appointments at the new health centre at Cleator Moor and that the town council wished to engage with the GPs about this. However, so far, they had not been able to do this.

The issue of travelling to hospital was raised and one councillor commented on how the NHS needed to be clear on which services it would do its utmost to retain at Whitehaven.

There were comments about patients requiring ECT (electroconvulsive therapy) to have to travel to mental health hospitals at Morpeth because of the lack of anaesthetists locally.

One councillor commented on the health problems facing some residents in Copeland due to obesity and drinking too much alcohol and said that GPs should be referring such patients for exercise or lifestyle advice.

A councillor who said he was a retired doctor commented that he had seen many five year plans and that none ever came to fruition. He commented on the role of management consultants and said that they do not listen to doctors. He said some doctors were retiring early because they were fed up.

Carlisle Local Committee

Many of the comments were about access to GPs with a few of the councillors present referring to the difficulties in getting appointments at different practices and to the inconvenience of having to ring at a 8am to get an appointment. One commented that to see a GP he has to say that he needs an appointment urgently. However, one councillor said he had no difficulty in accessing appointments and tended to book online.

There was a discussion about how some GP practices are now using a triaging system where a GP has an initial conversation with patients to decide how quickly they need to be seen. There were differing views about how helpful this type of arrangement is.

Another councillor commented that given the financial challenges facing the NHS he could not understand why his practice had moved from its premises in a terraced house, which he felt was a reasonable building, to a new building which must have been costly.

The cabinet member for health and social care commented that she was involved with the Cumbria Health and Care Alliance and that members needed to pay attention to the work of this body. She commented that some members would remember the previous discussions around the Care Closer to Home consultation but she suggested that this time changes needed to happen given the challenges facing the system.

Some members talked about their own varying experiences of hospital care. These included one member who said after he was admitted following a collapse in January his family took his clothes home but he was then told he was being discharged at 2.30am so he had to ring his family so they could bring clothes in for him. Another said he waited seven hours in a cubicle for a bed and there were comments from one that he had had some issues locally with hospital care but that and he and his family have chosen to go to Newcastle and Hexham for treatment. However, one councillor said that over the past four years he and his wife had used hospital services and that these had been good.

Finally there were comments about the constant reorganisation that takes place in the NHS and the costs associated with this.

Eden Local Committee

The strongest messages at Eden Local Committee were about care of patients who were seriously ill and those who were approaching the end of their lives. One councillor commented negatively on her experiences at Cumberland Infirmary a year ago when a family member was being treated for cancer. This was in relation to cleanliness and standards of hygiene and also lack of staff. She commented very positively on services she had received at other hospitals outside Cumbria including Newcastle upon Tyne Hospitals NHS Foundation Trust.

Another councillor talked about recent experiences with a family member and felt strongly about the lack of palliative care available to support her and her family. She felt that unless you have someone 'shouting your corner' you are unlikely to get the treatment you need. She said that palliative care doesn't mean anything and that joining up is absolutely essential. She felt that GPs and district nurses were not joined up and that in her experience, blood tests can't be taken on Fridays because the laboratories don't work at weekends. She commented about money being wasted from drugs being prescribed that are no longer needed and also the inconvenience of not being able to get the right amount of drugs to last 28 days.

There were also very strong comments about the lack of parking at Cumberland Infirmary and about how stressful it is when taking a very sick person there for an appointment and not even being able to drop them off at the front entrance because it is often blocked with other vehicles. There were comments welcoming the aim for better integration but pointing out that different organisations had different governance arrangements and different ways of working, all of which

would have to be taken into account. This meant that the CCG would need to be clear about what it wanted from other organisations and also about roles and responsibilities.

Some said there was a need for more education in schools about lifestyle issues and that this needed to be done in partnership with councils.

There were comments that services in areas such as Alston needed to be different from other parts of Cumbria because of rurality. In such areas, getting an ambulance to people was often difficult and there was still a reliance on first responders.

Members also stressed the importance of community hospitals are important and that they should have 24 hour cover.

Bolton Parish Council

At Bolton Parish Council where there were 19 members of the public present, as well as members of the council, there were comments about the need for better access to GP services, including a comment that at one practice a GP was retiring and was being replaced by a GP who would be working only one day a week.

There were comments about the financial problems, particularly at North Cumbria University Hospitals NHS Trust with one member of the public querying why the situation had become so serious.

Another member of the public said that if any new initiatives were to be introduced as a result of the five year plan there should be build-in measures to evaluate success.

Alston Parish Council

At Alston Parish Council, where there were four members of the public present as well as members of the council, the importance of the community hospital was stressed with comments that better use could be made of the staff and facilities there. In particular members felt that the number of beds should be increased to 12 which had been the situation some years ago. There was a comment that more older people are having to go to hospital miles away because of the lack of beds at Alston.

There were comments that it was disappointing that patients could not be admitted to the community hospital at weekends, evenings and overnight.

Some members questioned why patients from Alston should be expected to go to Whitehaven for x-rays when Carlisle and Hexham were nearer and there was another comment that more people seem to be getting hospital appointments for Whitehaven.

They welcomed the concept of primary care communities and said that given its close knit community and geography, Alston would be a good place for such an initiative. However, one person said that it shouldn't always be assumed that someone would rather be treated at home or be supported to die at home since some, particularly those who live alone, may prefer to be in hospital.

Allhallows Parish Council

The discussion included comments from a councillor about the care in a community hospital of a family member who had cancer and the feeling that healthcare assistants didn't have the right experience or were too busy to provide the care required. She felt that care needed to be more patient focused.

There were also comments that nursing is a job for some, while for others it is a vocation and that the feeling that nursing staff are over-stretched does not just apply to Cumbria, with one councillor referring to a similar situation in Newcastle.

Some felt that there weren't the clerical staff needed in hospital which meant that nurses had to spend time on administration that someone else could do.

There were comments that while politicians will always fight for A&E services to be retained but that it won't always be possible for A&E to be a local service. One councillor commented that some patients who require specialist care will always need to travel to a bigger hospital where certain procedures are done all of the time.

There was a discussion about ambulances and proposals to reduce cover in some areas, with a comment that to have an air ambulance means reliance on a charitable organisation. One councillor said that there were often ambulances sitting outside an A&E department waiting to be able to drop off a patient.

6 Targeted focus groups

Taylor Nelson Sofres (TNS), a world leader in market research, which was already providing substantial support to the Better Care Together programme across North Lancashire and South Cumbria was commissioned to carry out 20 focus groups.

There were five service areas: maternity, children's services, unplanned care, planned care and services for older and vulnerable people. A focus group on each of the service areas took place in each of the four localities, Allerdale, Copeland, Eden and Carlisle. A total of 167 people participated in the groups and were recruited because of their experience in those service areas. The focus groups provided an opportunity to examine public perceptions, experiences and expectations of existing healthcare services and to provide initial insight and evidence to inform the development of services. They also provided an opportunity to test ideas for new services and to examine trade-offs such as travel vs perceived 'quality' of services. Each focus group lasted 2 hours and a total of 167 people participated.

A full report is available at Appendix C which sets out detailed findings from the different service areas and from each of the four localities. However, the following few pages provide some of the headline feedback.

Most people were well aware that the NHS nationally and locally is facing challenges, including a growing and ageing population, tighter finances and staffing problems.

In terms of general experience and perceptions of health services, from a positive perspective there were no concerns about the quality of healthcare with participants feeling that staff were mainly competent and professional. There were comments that video-link technology would be

beneficial for many including for mental health services and children's services. Cumbria Health on Call was seen to be providing a welcome and good quality service. Participants said pharmacies were helpful when people want advice but not about sensitive issues due to lack of privacy. There were comments that ambulances provide a reliably prompt service.

From a negative perspective there were comments about speed of access to appointments in both primary care and acute hospital settings. Communication between staff and departments and hospitals was often poor and that referrals between GPs and acute services were not always smooth. There were comments about access to healthcare outside of office hours and that it was far from a 24/7 service. There were concerns about services being transferred from West Cumberland Hospital to Cumberland Infirmary and questions about whether they would come back after the redevelopment of the site. There were comments about the impact of staff shortages and recruitment difficulties on patients ie longer waiting times, greater use of locums. Some commented that the bedside manner was not what it was with health care now being seen as a job, not a vocation. There were comments that the transport infrastructure can make travel challenging, particularly for some areas and population groups. People want continuity of relationship in primary and acute care but don't always get it and there was some experience of misdiagnosis particularly in hospitals. Cleanliness in hospitals was a concern as was quality of food and services were seen as often lacking basic incidentals for patients who are waiting to be seen ie toys for children, water coolers etc.

Other comments were that quality matters more than local access but not for everyday healthcare. Many expect to have to travel for some elements care, for example to see specialists, as this is 'part of living in a rural area. There were also comments that the growing aging population could become isolated unless services adapt to meet the changing needs of the area. Finally there was awareness of the tight financial situation and the challenges that this presents to health commissioners and providers.

6.1 Recurring big themes

There were several issues which were mentioned repeatedly across the service area discussions:

Quality over travel – while people would prefer to have every service available locally, if by travelling they are likely to get a higher quality outcome, they are prepared to do this, particularly for specialist treatments. However, travel is a bigger concern for older people.

Staffing – People were aware of and understood the staffing and recruitment challenges the area faces, and the consequences of this ie travel, longer waits and use of locums. There was some feeling that even if the local NHS wanted more staff and could attract them, it does not have the money to recruit them.

Patient experience – people often talked about the importance of 'customer service'. They felt that some NHS professionals no longer see their career as a vocation, it's just a job and the 'personal touch' is increasingly missing. However, there was recognition that in a system under strain spending additional time with patients and going the extra mile might suffer.

Communication – There were many experiences of breakdown in communication, particularly between primary and secondary care, and between different departments in the latter. The result is delays, confusion and anxiety for patients.

Signposting changes – If changes are going to be made, for example, services increasingly being provided outside of hospital then people need to be sure about where to go.

Patient journey – In a typical patient journey the medical intervention stage was praised (i.e. operation, giving birth, being seen in A&E) but the run-up to the intervention and aftercare were often criticised.

6.2 Importance of geography

There were some differences in emphasis across on the different geographical areas.

Carlisle – Cumberland Infirmary was seen as offering a fairly good range of services but many still travel for specialist care and this is broadly accepted. Quality was prioritised over local access, although there were some fears about what might happen to local services if travel becomes more widely accepted.

Eden – Travelling for specialist care in Eden was deemed part of the decision making process when opting to live in a rural area. Primary care services were viewed positively and appeared to be guiding patients through their decision-making process, including decisions to travel further i.e. to a centre of excellence for lower risk, and a better outcome.

Allerdale – Allerdale's positioning between Carlisle and Whitehaven hospitals was often recognised as having the 'luxury of choice', but people still needed to travel further afield for some specialist care. Participants discussed the potential for a minor injuries unit to prevent travel to either hospital i.e. for scans, x-rays, procedures, and a sense that this is underused.

Copeland – Copeland is the most geographically challenging of the four areas, mainly due to reduced services at Whitehaven, 'hazardous' roads linking to Carlisle and a primary care system that is struggling to deal with the demand on its services. Some patients make long journeys to Newcastle or Hexham for a better or more efficient service.

6.3 Key findings from the five services areas

People's experience of care across all five service areas was variable. In each instance there were good and bad stories, with the same person having a good experience on one occasion and a bad experience the next time.

Maternity

Positive experiences were largely dependent on the level of care and attention from the midwife and other delivery staff. Reports of being 'left alone' on the ward were common with some relying on family members for additional support. Home visits were welcome and valued alongside support groups/networking with those at similar stages of pregnancy. An area of concern related to problems with equipment at West Cumberland Hospital but most people had a positive experience of giving birth there.

Key messages are:

- Midwifery-led unit would most likely be a calmer environment than a consultant-led unit. This was very appealing.
- But what most people want when having a baby is a safe environment. They do not feel that all risks can be assessed in advance.
- There were opposing views regarding the midwife and consultant. Some trust a midwife more – they feel they know more than consultants but others see the consultants as more knowledgeable.
- In an ideal world women would like a midwife all the way through but reality and caution about risk means that many want a consultant on-hand.
- The best solution would be to locate a midwifery-led unit and a consultant-led unit on the same site.
- The unacceptability of a transfer from a midwifery-led unit to a consultant-led unit is exacerbated by the potential of long travel distance and times.
- There were suspicions that midwifery-led units might mean that there will be fewer consultants overall.
- Video link technology would not improve care, it might just mean that the important 'personal' link is further lost.

In terms of what women are looking for from a maternity service, there is a focus generally on the personal touch so that staff can build a relationship, provide reassurance and be on hand so that patients aren't left alone.

For antenatal care women want good advice and the opportunity to visit hospital before choosing where to have the baby. When they do go into hospital to have the baby, they would like a room to themselves with partners allowed to stay 24/7. They would also like a room to rest in following delivery, with more staff to be available to give support and advice. Overall, they want greater patient involvement in decision-making making it feel like a partnership between the patient, midwife and consultant. Finally, they would like more comprehensive and longer term postnatal care.

Children's services

People were fairly accepting of travel for their children for specialist diagnosis and treatment. There were some instances quoted of staff lacking 'children skills' particularly in hospital which is seen as a daunting environment. Long waiting times were usually experienced by those with slightly older children and there were worries about staffing levels.

Key messages are:

- People are mainly happy with children's services. They don't feel there is a need for root and branch reform.
- If patients are to make more use of their GPs, for example, rather than A&E, there needs to be quicker access. This is a critical driver for satisfaction.
- Accessing GPs more rather than going to hospital would be a calmer environment for children as it is seen as calmer, cleaner and more convenient.
- People wondered if GPs and other staff would have the skills to take on more tasks and also would it not increase costs to provide more services outside hospitals.

- People are willing to travel to get the best care but prefer aftercare to happen closer to home.
- If aftercare happens more in community settings there would need to be quick access back to hospitals if care is needed again, rather than having to go through the whole referral process.
- Views about having video links are varied. In some circumstances, such as aftercare and less serious issues, it could be beneficial.

In terms of what people want from children's services, they are looking for regular communication between staff and parents/patient in layman's language and for there to be good communication between staff at all stages of the care pathway. They want personalised care and continuity of relationship to build trust. They want honest relationships and for staff to be open about any misdiagnosis or loss of note and for staff to take responsibility for actions and any errors. They also want competent staff at all levels and disciplines.

Unplanned care

There was a positive overall assessment of the emergency care system and staff expertise. Speed and accuracy of diagnosis and treatment were deemed crucial. There were some experiences quoted of being 'passed around' or kept in unsuitable situations due to lack of available space or staff shortages. There were also concerns about the future for West Cumberland.

Key messages are:

- The existing system for unplanned care is mainly working for patients so does not require major change.
- Travel is acceptable if the treatment needed is specialised and the patient's condition is not life threatening. But travel must mean that they receive quality treatment.
- If the condition is life threatening treatment should be as local as possible. Being in the hands of professionals as fast as possible is paramount. Transfer once in their care is acceptable.
- More could be provided outside of major hospitals i.e. community hospitals could provide minor injuries services if they do not already do so.
- A&E will continue to be used when patients want belt and braces reassurance. If in doubt, they will play it safe. There are doubts about how much GPs can do.
- Post A&E aftercare should be as local to home as possible.
- Care closer to home is preferable for some groups i.e. older people.

In terms of what people are looking for, they want to be communicated with regularly about how long they will be waiting and for staff to be effectively engaging with each other. They want to be kept informed about when they are being treated, what is the diagnosis and what is going to be done. Diagnosis should take place quickly and be accurate. Continuity of care is important. It is also important there are enough staff for them to be able to spend sufficient time with patients.

Planned care

Factors driving positive or negative experiences were communication and the propensity for administrative problems. Patients are able and willing to travel with prior notice and if

appointment details are appropriately communicated. Despite this travel was still inconvenient and expensive and could preferably be avoided for routine appointments/check-ups/aftercare.

Key messages are:

- Travel for particular specialisms is acceptable, particularly if it results in a higher quality outcome. Travelling is even more acceptable if it means day care surgery rather than an overnight stay.
- Moving services out of hospitals into community settings has significant advantages i.e. less time off work, family and friends available as a support network.
- The idea of a one stop shop is appealing but would it mean you get to spend less time with clinicians because your journey is being squeezed?
- There were mixed views about video links: it would hopefully mean less need to travel and could be used for consultations which do not require a physical examination and/or are not serious/complicated conditions. Video links could be very helpful for some patient groups i.e. those with mental health problems.
- There was some support for more specialised nurses if it means that burdens on GPs are eased.

In terms of what people are looking for they want to be treated like a human being, with staff spending time with patients, being friendly, compassionate and being proud of their work. They want to be confident that the staff seeing them are experts at what they do. They also want there to be sufficient numbers of staff so that they do not feel overworked and demoralised and also so that patient appointments can be longer.

Older and vulnerable people

There were positive overall experiences, particularly when dealing with GP surgeries. The default position is to use the GP rather than hospitals so the quality of this relationship is key. There was a noticeable difference in their perceptions and experiences of care. The care element was often described as being poor but staff capacity issues were acknowledged.

Key messages were:

- Travel is a big concern particularly for those on a low income and/or reliant on public transport. As many services as possible should be accessed close to home.
- This demographic group would prefer to access GPs rather than hospitals i.e. they are less likely to present at A&E. Any move towards more out of hospital services would be welcomed as long as it does not affect access to GPs.
- There is some scepticism about whether there would be sufficient staff numbers to deliver more services in the community.
- They like the idea of a one stop shop but how many would there be and where would they be located?
- There are mixed opinions about using pharmacists more. It would mean speedy access but they do not trust them as much as GPs.
- They are more sceptical about the use of video links than other population groups and worry that it will mean less face to face contact.
- If there are changes people would need clear signposting about where to go for what services.

In terms of what they are looking more, they would like continuity of care from start to finish and good communication from staff to the patient (and family) and between NHS staff. They want accurate, faster diagnosis and high quality treatment and staff knowing how to care for older people and conditions like dementia. They also want more permanent staff and fewer locums.

6.4 Key messages about providing care closer to home

The TNS report also highlighted key messages from across the focus group discussions about the concept of providing care closer to home.

They are as follows:

- Care closer to home as a concept was positively received across groups and was deemed a 'sensible' shift of services in response to key challenges being faced in North Cumbria.
- The hoped for benefits include: less need to travel, shorter waiting times, taking pressure of A&E and hospital, no parking challenges, a new lease of life for community hospitals and community focussed services in terms of building relationships and being more personalised.
- Possible drawbacks include: could be challenging logistically for travelling healthcare professionals i.e. travelling to different people's homes, could mean fewer consultants and nurses in hospital, could be labour intensive and costly and how qualified will staff be?
- There needs to be further clarification about which services would be delivered in the community and where – and would it reflect local demand. There was a feeling that the availability of services at the new Cockermouth community hospital are poorly communicated and that the facilities appear to be underused.
- Patients will need to be clear about where to go for what services.
- There were some concerns that more community services could be a precursor to a reduction/closer of existing hospitals (in particular, in relation to the concerns surrounding hospital services in Whitehaven including maternity services).
- Video links were deemed only suitable if clinically appropriate i.e. no physical examination required and was especially promising for those with mental health problems.
- There was some scope for telephone appointments for minor/procedural requirements i.e. test or scan results, repeat prescriptions. Text messaging has some potential for planned care (i.e. appointment reminders) and maternity (communicating with the midwife).
- Poor/unreliable internet connection was perceived to be an issue locally. Email was generally disregarded as an unsuitable method of communicating with the GP and could inundate the surgery causing further delays and admin issues.
- Services that could remain in hospital included 'anything major' that requires specialist staff, attention, equipment, A&E, cancer treatment (although some parts could be moved into the community i.e. tests, scans and chemotherapy).

8 Conclusion

This was a comprehensive period of engagement spanning ten weeks which reached out to patients, public and key stakeholders across North Cumbria. While information about the development of the five year plan was shared widely through existing networks and the media, more than 1,000 people were involved in actual discussions to seek their views about future services.

There was much support from Healthwatch Cumbria who facilitated 13 roadshows in towns and villages and from Cumbria CVS who brought together 80 people from frontline third sector organisations. Twelve meetings were held with county, district and parish councils, including four with the overview and scrutiny committee which has an important role in relation to consultation over any significant changes and therefore was keen to be involved in the process. And a leading market research company had detailed discussions with more than 160 people.

Overall, a huge amount of feedback has been received which has been valuable in terms of helping to shape the five year plan but which will also be extremely useful as the Programme Board moves towards implementation, which will involve further and ongoing local discussions and possibly formal public consultation.

While the engagement activity embraced people with different interests and from different geographical areas, there were some consistent themes. There were high levels of awareness of the challenges facing the NHS with many people referring to financial and recruitment difficulties. There was also a sense of loyalty to the local NHS with many people, particularly at the roadshows, talking positively about their own experiences of GP, community and hospital services. However, looking across all of the feedback it is clear that while there were many instances of positive experience, there were also some where people feel that the care they have received has not been what they would have expected.

The issues included speed of access to GP and hospital appointments with some complaining about cancellations for hospital outpatient appointments and operations. Associated with this were comments about the administrative arrangements in the hospitals which sometimes added to patients' frustrations around such cancellations. There were also comments about access in relation to people with specific needs, including access to translation services, both spoken foreign languages and British Sign Language.

The difficulty of travelling was a big issue in terms of availability of public transport, the cost of buses and taxis and how sometimes appointment times were not compatible with bus timetables. Many people expressed frustration about car parking at Whitehaven and Carlisle hospitals, with some saying how stressful it was when taking a poorly patient or a patient with disabilities to the hospitals for appointments because they even found it difficult to drop them off at the front entrance as those areas were also congested. There were comments that the challenges around transport could disadvantage some people and perhaps worsen health inequalities, for example, there were comments that young people in rural areas may not be able to travel for 'sensitive' health services. There were also comments, particularly at the roadshows which indicated that there was a lack of clarity about how patient transport services could be used.

Although travelling was a big issue there was recognition that it is sometimes necessary if patients need specialist care and in the focus groups in particular there were indications that quality was more important than distance. At the roadshows some talked about their own positive experiences of travelling to hospitals outside of Cumbria for specific procedures and at some of the council meetings there was recognition that not all services can be provided locally. However, some people commented that while they were willing to travel for some treatment and surgery, they would like aftercare to be provided closer to home.

There were mixed comments about ambulance services, with some saying they had received a fast response when they or a family member needed an ambulance, while others expressed concerns about response times and proposed reductions in cover.

There were also comments about services being taken out of Whitehaven and being moved to Carlisle with concerns about what services would be available on the redeveloped hospital site. There were many comments about the need for services to be more joined up particularly for older people and those with complex health needs and for there to be better communications across services and with patients. There were strong messages from the CVS events about the role that the third sector can play and about the need for a clear structure through which such local organisations can engage with the CCG. Third sector organisations also commented on expanding the use of hub coordinators to facilitate referral to support in the community.

The need for better communication with patients and their families and within and across organisations was also a recurring theme.

While there were many positive comments about local NHS staff, some felt that it was no longer a vocation but just a job and that the personal touch was increasingly missing. Some felt that this was due to staff shortages.

On the whole, people were welcoming of the concept of providing more care closer to where people live. In the focus groups it was deemed a 'sensible' shift of services in response to key challenges being faced in North Cumbria with hoped for benefits around less need to travel, shorter waiting times, taking pressure off A&E and hospital, no parking challenges and a new lease of life for community hospitals with more community focused services. However, there were also comments about the cost associated with more care being delivered closer to home and whether there would be the right staff to deliver these services.

Many commented on the importance of prevention and on providing more education in schools, more drop-in sessions in the community and more information about how to stay well. However, some people felt it was very much down to the individual and that there was sufficient information and support available.

Finally, in meetings with local councils it was clear that they wanted to be more involved with the NHS and the planning of future services and some saw real opportunities for tackling health inequalities.

Rachel Chapman

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Appendices

Appendix A Healthwatch Cumbria Together for a Healthier Future Engagement Findings

Appendix B Together for a Healthier Future Third Sector Report

Appendix C Full findings – TNS report