Better Care in Newcastle

The contribution from the voluntary and community sector in Newcastle

March 2014

Contents

This report has been put together by Sally Young from Newcastle Council for Voluntary Service (CVS), Ann McNulty from the Health and Race Equality Forum (HAREF), Kieran Conaty from Involve North East, Katie Dodd from Carers Centre Newcastle and Heidi Jobling from Deaflink. It aims to reflect the views of people who attended the events, who came from a broad spectrum of voluntary and community organisations active in Newcastle.

We would like to thank everyone who has contributed including staff, carers, people who use services and those people who volunteered their time to facilitate discussion and take notes at the event. We hope this is a true reflection of all the many views and opinions that were expressed.

Background

Newcastle upon Tyne is home to a thriving voluntary and community sector. There are more than 3,000 community and voluntary organisations. This includes nearly one thousand registered charities, Community Interest Companies (CICs), cooperatives, Industrial and Provident Societies, and Charitable Incorporated Organisations (CIOs). There are, at least, over 2,000 smaller community organisations.

There are a number of large organisations - some are 'home-grown' such as Changing Lives, which now has a national reach, others are affiliated or branches of large national charities such as Barnardos, others are more local such as Age UK Newcastle. These organisations are delivering services mainly through public sector contracts as well providing other activities.

There are many medium-sized organisations which exist on a mixture of grant aid, some contracts and earned income, as well as general fund-raising. Many of these organisations are based in an area of need and they focus on communities of interest and identity. Typical medium sized organisations include Riverside Community Health and the Carers Centre Newcastle.

The vast majority of community organisations in Newcastle have incomes under £10,000 a year, with 5% having no income at all. Most of these are run by unpaid volunteers.

Newcastle City Council and the NHS have historically invested in voluntary and community organisations through a mix of (mainly) contracts and grant aid. Many of the voluntary and community organisations classify themselves as social care organisations and / or supporting and promoting wellbeing. For a number of years the voluntary and community sector has benefitted from the generosity of the Northern Rock Foundation, the Big Lottery Fund, the Community Foundation (Tyne and Wear and Northumberland) as well as other trust funds.

It is estimated that Newcastle's voluntary and community organisations (excluding housing associations and private schools) have an income of at least £150 million (which includes public funding). There is also the generosity of the many volunteers who give their time freely, as well as the 6,500 people employed in the sector.

A key feature of the local voluntary sector is the networks which have existed for several years including VOLSAG (for organisations focussing on mental health), the Open Forum (for organisations focussing on health and social care) and CHYP IN (for organisations working with children and young people). There is an established Elders Council and the Quality of Life Partnership; BME forum through HAREF; the work of the Newcastle Disability Forum, Deaflink and many others. There is high quality information produced by many groups including Information Now, Newcastle CVS, HAREF and Involve North East.

There has also been investment in involvement mechanisms, which have supported this work. This means the voluntary and community sector has collected a lot of rich information over the years around what works in Newcastle, and what needs to work better. This report contains feedback from a short Open Forum event in February, and a dedicated Better Care Fund event in March, together with a literature review from Involve North East and HAREF, as well as a contribution from the Carers Centre Newcastle.

Newcastle has been home to many innovative voluntary sector partnerships and initiatives including Ways to Wellness and the Newcastle Voluntary Sector Consortium. The voluntary sector prides itself on its flexibility, responsiveness to need, identifying innovative solutions, being independent and being trusted by local people and communities.

Executive Summary

Throughout the Better Care sessions and from previous work, the following were identified as key factors that must be taken into account

- **Better Care principles**   The voluntary and community sector has long supported the principles of more integrated care, based within the community, using a variety of support including that provided by the voluntary and community sector

- **Cultural shift**   We all need to think holistically rather than clinically about health and wellbeing. This means trusting others, both paid staff and volunteers. The focus should be about the most appropriate support, rather than financial funding streams

- **Health, wellbeing and care** Care is the process to improve health and not an end in itself. The current discussion seemed to focus purely on process rather than the impact of the change. There needs to be greater focus on working with an individual, and their carer or family, and focussing on them rather than the organisation that provided particular services

- **Building on existing knowledge and what works**   Are we genuinely using the best information to design new systems and process? This report illustrates the depth and breadth of knowledge within the voluntary and community sector. There has been no discussion of any specific proposals, so it hard to comment on their effectiveness

- **High quality information**   There is a range of high quality information in Newcastle, but it needs to be used appropriately. Health and social care workers (in all settings) need be able to access it and use it with confidence

- **Information sharing**   It is impossible to provide appropriate care and support if all the necessary and appropriate information isn't shared with individuals, their carers and families, appropriate voluntary organisations and with health and social care workers

- **Process proofing**   Any new project / process should be checked against:
    - What does it mean to me?
    - What difference will it make to my life?
    - What would be the best outcome for me?
    - Does it mean giving me a say in my own care?

- **Appropriate timing**   Planning, involvement and communication should start as quickly as possible and the circle of support should be widened to include as many people and organisations as appropriate

- **Diversity of the voluntary sector**   There is a huge offer in Newcastle, but the NHS (in particular), needs to trust organisations and develop partnerships and relationships. This does happen, but it is through opportunistic rather than systematic contacts

- **Inequality in health**   All new systems should be established to minimise and reduce inequalities, rather than (unintentionally) increasing them

Report from the Open Forum held on 25 February 2014

At the Wellbeing and Health Open Forum held in February Rachel Baillie, Newcastle City Council and Julia Young, NHS Newcastle North and East Clinical Commissioning Group introduced the Better Care Fund in Newcastle. Following the presentation discussion groups were held about the Better Care Fund.

The presentations and papers are on Newcastle CVS website, visit http://www.cvsnewcastle.org.uk/networkinginvolving/adult-wellbeing-and-social-care/adult-wellbeing-forum

Discussion groups about the Better Care Fund

Networks
- How do we work together, through Newcastle CVS, two or three pieces of work
- Make solid suggestions from Health and Wellbeing and universities, e.g. for research support, innovation design etc.
- Collect evidence that short term decisions cost have and have long term consequences
- Who would cost a repository for evidence?
- Focus on good practice and info sharing
- Research on assisted living technology is medical led – not from service user perspective
- Wellbeing for Life academies – could usefully help us use our evidence. Could they contribute

Better Care Fund
- Seven day care 8 to 8 working – staff lives not geared up to do this. Childcare issues
- Pain management for people with dementia is a huge issue. Research bears out that they are being medicated with the wrong drugs, i.e. anti-psychotic drugs when in pain
- National Voices – why not use local info? We need to develop a clear local list
- End to end technology – mapping – talk to Eon about what electricity energy use.
- Need better mapping of what exists and what it look like for carers and users
- Mapping or services! (End to end diagrams www.mrasco.com)
- What will be lost with the £21 million that gets diverted into Better Care
- What does transforming mental health mean?
- Is there really a genuine commitment to move resources upstream?
- Worry – people being moved away from services who are most vulnerable – not use telecare etc.
- Health, care and housing needs to be in the Vision and Principles not just in the change schemes
- Link in with the findings from the Fulfilling Lives partnership between Changing Lives / Mental Health Concern and Acquila Way → people there have said what is needed and they are big users of resources
- Dementia diagnosis must be backed with local work on what follows diagnosis in terms of help and support

- Mental health – provider is bigger than any commissioner, as is the other Trust!
- Social care, health and housing needs to be linked earlier, in principle
- Dementia diagnosis <u>must</u> have a next step support linked to the measure
- People don't know where to go, especially in situation
- Are you going to test the 'system attributes' with the people of Newcastle?
- Who is responsible for explaining this to the people of Newcastle and when?
- Info sharing and consent needs agreeing – include covers – multi agency principles
- Seven day working – cannot do it
- Childcare – many women not in position to work outside child care
- At what point are you going to start talking to general public?
- Seven day services don't need to be physically staffed for seven days. They can be done through five day services producing signposting, action planning and preparing for the weekend
- Joint commissioning services should ensure that those with protected characteristics under the Equality Act are included in the budget

<u>Independence</u>
- Often commonality between/with

Consortia	Local	Organisations
	National	\
		Political

Should focus on the outcomes
(often hard with small organisations – holding onto clients
↓   holding onto information
   Change
   Creations
   New ways of working

- Sometimes lack of finance forces us to work together, e.g. moving street clutter affects all
- Recognition from larger organisations that smaller ones can work more flexibly and better outreach
- Decrease in funding – slash and burn
                   \ innovate
How to do this fairly across population?
Some cases heard at expense of others
Review Council in-house services – protectionism

<u>My own organisation</u>
Will work with members of my organisation (Elders Council) to speak up about what the integrated system, bringing together health, housing and care, should be like from the users, and would be users, services point of view – not just to save money in the providers of services – but to improve quality of life

<u>Linking up with NCVS</u>
In partnership with other organisations to be part of a collective source on behalf of all service users

Independent Living
- Develop a more inclusive community around those who have different needs, needs a change of attitude from the wider community for that to happen
- Put more stories of success in the media and stories of people who have been unable to achieve their dreams of independence
- Cost out your care plan based on the minimum age. If you need someone during the night that will cost you more
- Think about what you need to have help with on your worst day so that you can do your own care plan. If you do this you can argue for it in an assessment process
- People should not be considered on a "worth" basis, e.g. work/age etc or anything else, but individuals
- Make a public statement on how and where the services are being changed and how this will affect individuals
- Back-up systems should be in place to back systems for citizens in case of major problems, e.g. floods, electricity
- Inform public of the reasons for charge and this is not new money. Keep public on side
- All organisations join together and have an holistic viewpoint and comment for individual care
- There would be allowances for new citizen's care, and new patient care – not just those within the system
- Make sure there is a person in GP's practice who can be responsible for online care/responses for people who can do this themselves

Changes to practice/systems
- Insurrection and revolution
- Small things –
    Inclusivity
    Are you representative?
    Are you welcoming to different groups?
    Welcoming people, making a small effort
- "Evidence base" versus Innovation
- Nationally –
    Difficulty with funding – hard to rock the boat
    Local authorities, heads of care
    Need a shift
    Structures to push back
    Not just acquiesce
    Flag up when there's a problem and be clear about it
    Create dialogue
- Understand the funding available –
    Why do you need that?
    People will spend it
- Personalisation
    What do people want?
    What about people who don't want to and/or can't choose?

- Older people – perception of 'being deprived of (hospital) care

Assumes 'home' is suitable
Assume really ill if hospital
Cultural shift
Are family, friends, neighbours, community available?
If family, care in advance
Importance of care plan, planned care

- How do we manage joined up care
  Massive shift from where we are now
- Is home the right place for all?
  Will/is system competent to differentiate?
  Need a better holistic assessment
  Meant to be joined up service
  Concern care is free in NHS, but charged for in social care

- Like focus on prevention
  VCS could contribute a lot
- Too much jargon in information – avoid
  It is being used to hide   } What
  - 'Asset based approach to meeting needs' } does this
  - 'Risk stratification'   } mean
- Need more information on the measures
- Why dementia locally
  - Not against this, but why?
- Not a lot about equality
- What about the voluntary sector offer
- NHS doesn't see social care as equal partner
  Needs genuine shift
  Power based decision making
  Need attitudinal shift
  Too much NHS protectionism
  Should be who delivers best
- Change schemes
  Involving service users
  Ask the people
- Need a vision
  What does it look like?
  Has it made a difference?
- How does the JSNA/NFNA fit in?
- Issue of independence
  Getting out and about, e.g. sight loss / UK vision strategy
  80% 60 year eye condition
  Need a gate to open
  NHS should refer to VCS

Speakers and Participants

Sally	Young	Newcastle CVS
Rachel	Baillie	Newcastle City Council
Julia	Young	NHS Newcastle North and East CCG
Ruth	Abrahams	Disability North
Nick	Ball	NETS(work)
Suzie	Fothergill	NETS(work)
Paula	Barney	Action Befriending
Fran	O'Brien	Age UK Newcastle
Jacqueline	Robson	Alzheimer's Society
Rhona	Stanbury	Deaflink
Gillian	Stacey	Dementia Care
Mary	Nicholls	Elders Council of Newcastle
Vera	Bolter	Elders Council of Newcastle
Anya	Cook	Great Park Community Centre Association
Jill	Remnant	Healthwatch Newcastle
Bob	Dennis	Independent Living Zone
Julie	Marshall	Involve North East
Kieran	Conaty	Involve North East
Claire	Tritton	Mencap
Jean	Fraser	NALC
Pam	Jobbins	Newcastle CVS
Martin	Gollan	Newcastle CVS
Kate	Bradley	Newcastle United Foundation
Sam	McLoughlin	Newcastle United Foundation
Christianne	Ormston	Newcastle West CCG
Tom	Scott	North of England Refugee Service
Barbara	Douglas	Quality of Life Partnership
Mark	Shone	Rookie Sports
Johanne	Mears	Search
Barbra	Robson	Them Wifies
Maurice	Condie	Tyne Housing
Kate	Mukungu	Tyneside Women's Health
Ean	MacKellar	West End Befrienders
Violet	Rook	

Report of the Better Care Fund event, 12th March 2014

Rachel Baillie, Newcastle City Council and Julia Young, NHS Newcastle North and East Clinical Commissioning Group introduced the Better Care Fund in Newcastle. Following the presentation, discussion groups were held about the Better Care Fund.

Introduction

As part of the round table discussions participants were asked to consider two questions:

1. What would success look like to Newcastle's citizens?
2. How could the Voluntary Community Sector (VCS) contribute to the integration / transformation outlined in the plans for the Better Care Fund?

In terms of Question 2 each table was asked to consider their answer in relation to particular areas:
- Carers
- Mental Health – prevention, early intervention and support
- Prevention of people going into hospital unnecessarily
- Discharge/Rehabilitation/Reablement

1   Better care for carers

This section details the themes from the discussions of two tables from carers' perspectives

Focus on "what it means to me"
Make sure Better Care developments connect with daily lives, what being a carer means for individual people across communities, and what triggers crisis situations: "Being a carer for someone with serious mental ill-health can be a lonely experience".

Ensure the Batter Care Fund is used to develop clear actions that will directly benefit carers.

Monitor Better Care developments against what matters to people who are carers i.e. is it making a meaningful difference for them?

Use existing knowledge
Use what people have already said about 'good care': "How have local people's views been captured to inform Better Care?" Use information from Let's Talk Newcastle and other engagement processes e.g. who (from which communities, age groups etc) has said what about things like admission to/discharge from hospital - what worked well and what could be improved. In this way we can rigorously build our understanding of what people did and why (e.g. going straight to Accident and Emergency) and what will have biggest impact in terms of positive change, in order to concentrate effort in these areas.

Use information and expertise that VCS organisations working with carers already have e.g. Carers Centre Newcastle experience and data, information from condition specific organisations.

Learn from schemes like First Contact that bring everyone together around an individual, from social workers to health professionals to energy efficiency/money advice workers.

Use what was learnt from the NESTA social prescribing pilot and from initial stages of Ways to Wellness, in terms of supporting people to avoid unplanned hospital admission. Social prescribing approach has huge value as long as it includes people across communities.

Use examples of successful multi-agency initiatives from different areas e.g. Home from Hospital scheme in Bradford, co-ordinated by Carers Resource, shows significant reductions in hospital readmissions.

Offer support "just at the right time"
Focus on prevention and avoid input (respite care etc) only at crisis point, when "you catch carers too late, when they're already exhausted".

Future planning for carers is essential, and people need support, training and information to do this.

Good quality care for the cared for person will help the sustainability of the caring role for example, introducing people in the early stage of dementia, and their carer(s), to a day centre early on: "If you can take the person to the day centre when their dementia is less of a problem, they can get to know everyone, and get to know the centre and what goes on. When their condition worsens they are happy to be there. If they are introduced to the centre when their condition is already quite bad, it makes them stressed and confused".

A proactive "just at the right time" approach means that carers have easy access to the support/resources they need to help them keep going in their caring role, and maintain their own health and well-being, and agencies/organisations can target their resources in a timely way: "Anyone with elderly relatives knows how exhausting it is to get through the right door to access support … Better Care Fund is an opportunity to get it right".

Carers looking after someone who is not eligible for social care services, who choose to manage by themselves or who are self-funding, all need support services as well as those people who are caring for someone receiving social care services.

Build carers' confidence
Ensure services, including emergency and out of hours provision, recognise importance of increasing the confidence of carers through information, reassurance etc.

Recognise carers as people in their own right, not just 'tagged on' to the person for whom they care. They need to have a life of their own, a paid job, and good health/wellbeing and they have rights.

Develop responsive, flexible services of consistently good quality and tell people about them - this contributes hugely to carers' confidence and can reduce unnecessary hospital admissions.

Ensure the Carer Support Allocation is earmarked for carers to use for themselves, and not added to the cared for person's package e.g. for respite care.

Make involvement meaningful
Involve carers, i.e. the 'team around the person', appropriately in care planning e.g. a group participant discussed a family member who had fallen and been admitted to hospital for treatment. The person was desperate to be discharged as soon as possible and asked the occupational therapist what they needed to do to be discharged, and then worked very hard to pass the assessment and was discharged. Adaptations needed at home, to

ensure that the patient did not fall again, had not been made. It would have been helpful for the person's carer to be involved in discharge discussion.

Coordinate
The voluntary and community sector can coordinate overall care plans and involve the range of organisations needed, so that issues like "who's going to help with shopping? " aren't missed out.

The voluntary and community sector is well placed to develop broad understanding of need e.g. who is physically 'around' (friend, family member, neighbour) who can have some involvement as appropriate. This will avoid people getting home from hospital with nothing in fridge etc. VCS organisations often have level of trust to facilitate discussion with people about what they want and need

Coordinate access to information (of which there is enough in the city). Information Now is one of four websites that make up the 'Information in the city' partnership, with the aim of signposting everyone to appropriate sources of support. Many condition-specific organisations provide information or carers, and Carers Centre Newcastle has a dedicated website for carers.

2   Mental Health - prevention, early intervention and support

This section details the discussions of two tables around mental health issues, focussing in particularly around prevention, early intervention and support.

Barriers to accessing health and care services

Data sharing
This seems to be problematic; an example was given that if a patient went to the Freeman Hospital, but then went to receive services from the Northumberland, Tyne and Wear (NTW) NHS Foundation Trust, the NTW trust staff wouldn't get the information from the Freeman Hospital. "One foundation trust doesn't speak to another foundation trust".

Inflexible services
Some organisations in the voluntary sector were felt to get defensive when asked to provide services to support people with acute health conditions, as they didn't always have the resources in place.

Integration between specialist and generalist support
Specialist services can lead to being treated in a silo - a more integrated approach is needed. Integration into mainstream settings was highlighted as a key issue. It was felt that where specialist support was needed (e.g. for specific groups), it was important that it *wasn't* delivered in a way that it became so specialised, that it acted as a barrier in access to a broad range of services. The example was given of deaf people who weren't directed to services in a standard way, so deliverers of mainstream services were less likely to have a broader understanding of problems and issues impacting on deaf people.

There was a big risk that there wasn't the specialist support in place for certain groups (Deaf, Minority groups etc) and also when there was specialist support in place, they would get put down a route which could lead to exclusion from mainstream services.

Location of health and care services
Specialist support does have its place e.g. mental health day centres were felt to be more 'safe' as a place to access support by those people needing the services.

Admissions
It was noted that Newcastle had a better track record of reducing the number of people being admitted to an acute psychiatric setting. There was a focus on reducing re-admissions to the Accident and Emergency (A and E) Department – readmissions were high for a small group of individuals who kept going to A and E. There was a targeted approach tackling issues around drugs and alcohol.

Communications
Within the deaf community, there were some issues arising when interpreters weren't present at consultations. Barriers were created and it was put forward that individuals ended up placed within mental health institutions without proper diagnoses.

The social model
A broader understanding was needed by organisations and services of who is physically around (friend, family member, neighbour), who they can share information about a patient with. There needed to be questions around medication and clinical support but also about the levels of community and social support.

Solutions to improving mental health and wellbeing

The Whole Picture
"This is a much bigger picture – need to start to define those roles a bit more". There are the core health providers, NTW, Primary Care and the Local Authority and the services respond to what is commissioned, so the commissioning processes need to take connections, partnerships and the social picture into account. It's important to meet the diversity of need. One respondent put forward that they were puzzled about the role of the social worker in the future; in particular they were concerned about the impact of the budget cuts and whether Social Workers were also expected to manage care plans? It was also noted that GPs were expected to develop/coordinate a plan for people aged over 65; this involved looking at risk and identifying high risks. "It's a worry in the future – where's the resources to support it".

There were many specialist community based mental health support groups (for users and carer) that had developed over the years. These needed to be better integrated into the whole picture. Although many organisations had tried to promote themselves to statutory services, there was still a long way to go. Newcastle was fortunate in having VOLSAG (mental health voluntary organisations network), and this provided a good route into local organisations.

User-led organisations
In terms of mental health, the service user/carer led resources in the VCS need to be strengthened. It was noted that there was an issue around how little support was given to mental health user-led services. If there is a stronger user/carer voice, it affects commissioning. "Is this captured in the (BCF) attributes?" People need to be part of designing their own care.

Access and equality
A key issue highlighted by the group was about changing the mind-set of the providers in relation to specialist need – there was discrimination within the services that needed to change. For example, funding around interpreters had not been built into budgets, had not been offered to deaf patients or family members had been asked to interpret. However, it was noted that Ways to Wellness had a specific budget line for access and equality.

3   Prevention of people going into hospital unnecessarily

This section details the discussions of two tables around the prevention of people going into hospital unnecessarily.

Barriers to accessing health and care services

Data sharing
Data sharing was seen as key to reducing unnecessary admissions to hospital. "The NHS is very precious about patient data" and this does not facilitate seamless care. People who are essential to keeping the patient out of hospital are not given vital information about the patient or not included in discussions about their care because they are a friend or carer, but not next of kin. Sharing information about the patient should not be restricted to next of kin but should be considered in relation to the circumstances of the patient.

Inflexible health services
Rigid services and appointment systems that have been designed at the convenience of the healthcare professional were also seen as a reason for unnecessary admissions to hospital. It was felt that to ensure accessibility, they need to be patient-focussed and flexible.

There is also an issue around when a patient is first diagnosed with a condition and what initial care pathway they choose or is chosen for them. For example, when a person is first diagnosed with sight loss they are offered lots of different support from health and care services such as psychological support. But if they choose not to take this up when it is first offered, they are often lost from the system and not offered the support again. "Once you've lost someone in the system you can't get them back". This could result in the patient's mental health deteriorating over time and ultimately a hospital admission.

Location of health and care services
In terms of preventing homeless people from going into hospital unnecessarily, it was highlighted that this group found it difficult to access health services and in particular a GP practice or walk-in centres. To support homeless people to access these services they need to be able to see a health worker in a familiar setting that they feel comfortable in. At Crisis the GPs come into the centre or do the checks in a venue that the homeless person feels comfortable in. It was suggested that this model could be used for other groups where the location of the service may act as a barrier to access.

Information about health and care services
The health and social care system is very complex and in order for people to use services appropriately, they need information about what services are available and when they should use them. It was felt by some that there needs to be more information available for citizens to make informed choices. However others felt that there was enough information about services but the issue was people finding it. It was suggested that all available

information resources be examined in terms of content and format to ensure that it is accessible for all.

Solutions to preventing people from going into hospital unnecessarily

Care homes support
Care homes were seen as a contributor to unnecessary admissions to hospital and it was felt that training was needed to give care home staff the confidence to deal with falls and minor injuries, rather than calling an ambulance to take them to hospital.

Out of Hours GP services
It was also felt that the referral process for out of hours GPs should be examined as most Accident and Emergency admissions are in the evenings and weekends.

Over 75s health checks
Health checks for the over 75s were also identified as a way of preventing people from going into hospital unnecessarily. A GP practice in the east of Newcastle was cited as an example of good practice as they took a very holistic approach to carrying out their health checks ('Holistic Health Check'). Those checks however no longer take place and it was felt that they should be reinstated across the city.

Monitoring patients
It was suggested that GPs should be proactive in monitoring their patients and that they should not assume that if they had not had contact with a patient for a period of time that their health is alright. They should periodically make contact with patients to assess their physical and mental health.

Social isolation assessments
When carrying out any medical assessment it was suggested that a social isolation assessment be carried out alongside so that any issues are identified before a person ends up in hospital.

Considering social isolation further, it was felt that community networks were vital for prevention. It was suggested that the Voluntary and Community sector (VCS) could develop a Good Neighbours project where for example, people living on a street could all agree to look after each other and help out with shopping etc. for neighbours who needed support. Overall though, it was felt that greater community development within neighbourhoods was needed to ensure that the community looked out for each other.

Reactive services
In terms of older people, it was felt that this group often end up in hospital unnecessarily, when there is no medical reason for that admission. For this group "hospital [is] not the first choice but seen as safest bet" and they are 'tipped' into hospital by 'fear'. However it was suggested that this could be avoided if people were able to get a fast response from primary care and access to community support networks.

Key workers
It was felt that there are too many isolated health and social care assessments and also that professionals do not share the assessments. It was suggested that patients need one key person to co-ordinate and direct their health and social care to make sure that services and support is joined-up, to ensure patients are not admitted to hospital unnecessarily. It was felt that the VCS could do so, from bringing in specialists to coordinating the overall

plan, so that issues such as who is going to help with their shopping, are not missed off someone's plan.

'First Contact' was highlighted as a good example of this type of scheme and it was suggested that it should rolled-out further. It brings everyone together around an individual from social workers and health professionals to energy efficiency in the home and money advice.

Hybrid care workers
The idea of a hybrid care worker i.e. someone who had a reasonable awareness of bandages, dressing, making tea and talking to people rather than just specialists was also put forward. It was suggested that this model was in place some years ago in North Tyneside to support dementia patients. It was a joint position between the NHS and social care services, and staff were recruited from a social care background, supported by two managers, one a nurse and one a social worker. They supported people with small things like dry dressings and making cups of tea. It was felt that the project ended due to costs.

Social prescribing
Social prescribing was seen as an excellent example of the NHS considering a non-clinical approach to care and using VCS resources to support patients to stay out of hospital. It is the connection between primary care and the patient's real lives. In the west of the city the social prescribing project is called Ways to Wellness.

However, it was felt that health professionals should think more outside of the box about the social activities available to patients and also offer things like showing patients how to climb the stairs safely after having a fall.

There were also concerns however that some patients do not have confidence in treatment that is non-clinical or provided within a non-clinical setting. It was felt that a culture change is needed so that citizens accept that socially prescribed activities and locally provided services are equal to clinical healthcare provided in a hospital for example.

Telecare
Telecare was seen as having a vital role in preventing people from being admitted to hospital but there was a warning that older people needed support to use it – "technology is only good if it is enabling".

4   Discharge / Rehabilitation / Reablement

This section details the discussions of two tables around people being discharged from hospitals, and their rehabilitation and Reablement in the community

Barriers to good discharge, rehabilitation and reablement

Organisational structures or person focussed care
Services are seen as focussing around organisations and not individuals, with some organisations keen to transfer the individual because of resource imperatives for the organisation rather than the needs of the individual. This is sometimes reflected in the language of 'frequent flyers' and 'delayed discharges'. People's place in the system is not their fault, but the consequences of decisions taken by others.

Specialist or generic services
It was recognised that there was a place for both, and staff need sufficient knowledge to support everyone. Some of the barriers were at the interfaces between staff and the person needing services and / or their carer were expected to navigate the system without being given sufficient information

Data sharing
This was poor, even between NHS trusts "one Foundation Trust doesn't speak to another Foundation Trust'. How can this be good care? This can lead to resources wasted as duplication in taking and collecting information, the individual having to tell their story many times and the greater potential for mistakes being made.   Pregnant women have held their notes for over twenty five years with more notes lost in the NHS system than by the women. This was felt to illustrate a lack of trust and protectionism between organisations.

Duplication of effort
The lack of trust between organisations and the problems in sharing information lead to repetitive and duplicated processes. There are too many isolated assessments, which lead to incomplete care packages and care plans and assessments, as they don't always contain the full information. These need to include information from the individual and the family member / carer. There could be an input from the voluntary and community organisations, as appropriate.

'Consultants aren't interested in what happens next'
Hospital staff need to think beyond their role in treating the patient, and consider their whole lifestyle and circumstances and the consequences of treating them in hospital. This discussion needs to involve the patient's family and / or carers. There can be different perspectives on ability to cope between patients and their carers. Part of the discharge should include and voluntary and community sector support that can support transition.

Nuts and bolts
There remain delays in hospital discharge with people waiting for consultants to sign off discharges, getting medication and getting transport. These issues have been raised for over 25 years, and even with modern technology, still remain.

Perception of the Voluntary Sector
The voluntary and community sector is often not seen as being sufficiently professional by both public sector staff and citizens. NHS and social care staff worry about risks, safeguarding, sharing information, quality of services, and have a low understanding of the breadth and depth of the voluntary sector offer. For some citizens, they could feel they were getting 'fobbed off' and it is 'their right to see a doctor'.

Role of Primary Care
There were mixed messages that more care has to be delivered in the community, but that demands on GPs were increasing. The role of other primary care team members wasn't clear and the integration (or lack of it) with community health services. Because of rising demands, there was little scope for checks on frail elderly people who hadn't been seen for some time (and the assumption was they were fine).

The medical model
There continued to be over-reliance on the medical model and scepticism around social prescribing. Ways to Wellness could provide an innovative approach, but that meant

clinicians letting go of their power and trusting others. Would we ever see hospital consultants signed up to social prescribing?

Solutions for a good discharge, rehabilitation and reablement, including a voluntary sector contribution

Clear and appropriate information
There is enough information provided in Newcastle, the problem is about people finding it. There is the 'Information in the City Partnership' – does every care worker know of this? There are a number of websites, directories and newsletters including Information Now, Health Signpost Directory, CVS Directory of organisations, and the Families Information Service. Professionals needed to use this information and support their patients and clients to use it as well.

Teams of support
If most people over 80 have long term conditions, an approach could be multi-agency team around the individual / family so that people can dip in and out. This should include voluntary and community organisations, similar to the Circles of Care approach for people with learning disabilities. This could be delivered by a Link Worker approach (such as with Ways to Wellness), but the focus should be the individual needing support, and not staff attending loads of unnecessary meetings.

Genuine Enablement
It is vital to give people and their carers and families sufficient skills and information to do things for themselves. Sometimes people needed a safety net – just knowing something was there could be enough. Resources available needed to include voluntary and community initiatives. The approach could be 'just enough support' – providing a lighter touch, less medical and more social. The NHS and social care workers need to trust the voluntary sector as a provider and let go of people.

Who's buying the bread?
In the rush to discharge people from services, sometimes the emphasis is on medical support rather than social care. There are many organisations in Newcastle e.g. West End Befrienders, faith groups etc, which can provide volunteer carers as well as other organisations that have paid carers. There could be clearer linkages, using IT, between these organisations and the public sector so, for instance if an person aged over 80 was discharged from hospital, they would get a visit in 36 hours from a volunteer carer. This is intended to complement professional services.

Imaginative discharge
As well as patients being discharged from hospital with medication and food, could they be discharged with a basic food package (including bread and milk? This could be focussed at people living alone or with a carer and in a vulnerable situation. The North Tyneside 'Hospital at Home' scheme is funded through Northumbria Healthcare and operated by Age UK Volunteers. The volunteers help patients to be safely discharged from hospital as quickly as possible by ensuring that there is, for example, food in their fridge when they go home or they might go to collection medication from the pharmacy for them.

Good neighbours and communities
The voluntary sector could be given resources to develop a Good Neighbours project based at a street level and involving local community groups and faith organisations. This could mean help with shopping, or popping in to see someone is alright. However what is

really needed is greater community development within neighbourhood to ensure that communities looked after each other.

Telecare
Telecare and telehealth could be used imaginatively to support people in communities, both from prevention and aftercare aspects. Voluntary and community organisations could be linked into systems.   Carers and families need to be involved.

Seven day working
Services are still delivered around staff and not individuals. There is concern that some people aren't discharged or get an inappropriate discharge because of the time of the week. However this means a shift in resources as well as supporting the voluntary and community sector to work at weekends, as appropriate.

Closer working between the NHS, social care and housing
Housing has a major impact on wellbeing and health and should be considered as part of the whole package. There needed to be more choice of housing for older people and vulnerable people. The need for more intermediate care was recognised, there were insufficient step up/step down options.

Understanding the individual
Often people were blamed for taking certain actions e.g. turning up at the Accident and Emergency Department, without understanding why they did this e.g. they couldn't get to see a GP within the next three days. Clinical care is obviously important, but so is the 'softer intelligence' that we get from individuals. As independent organisations, voluntary organisations can often develop relationships based on trust with individuals. People can tell their stories in a no-blame environment. The voluntary sector is well-placed to collect evidence and stories from people that illustrate the reasons for behavioural decisions and these can be fed back (anonymously) to decision-makers.

Care Homes
A number of residents will need support from residential and care homes. Most of these have minimal contact with voluntary organisations. Could this be built into the contracts? Could there be visits from volunteers and faith groups to residents in care homes; some of the more enlightened homes encourage this. There could be greater linkages with arts and cultural activities, schools and young people. There have been projects in recent years to have GP practices associated with specific homes and this was thought to have increased understanding and improved relationships. The care homes were often large, separately operated organisations; there could be projects to support people across homes e.g. yoga sessions, singing and art classes. Those homes offering more activities and working with voluntary organisations would be eligible for higher premiums.

The long haul
There are certain schemes that offer intensive input when someone is discharged from hospital, e.g. the Rapid Intervention model delivered by the Community Intervention Team, but longer term reablement doesn't match up with the discharge. The voluntary and community sector has a role to play in long term reablement but people need to be referred to appropriate organisations and those organisations need to be properly informed and resourced to support people appropriately. A good example of this is after-care for stroke support.

Participants at event

Lynn	Johnson	Age UK Newcastle
Rachel	Parsons	Carers Centre Newcastle
Katie	Dodd	Carers Centre Newcastle
Donna	Bell	Crisis
Rhona	Stanbury	Deaflink
Chris	Shrubb	Edward Lloyd Trust
Craig	Duerden	Healthwatch Newcastle
Jill	Remnant	Healthwatch Newcastle
Jen	Marriott	Involve North East
Leah	Lamb	Involve North East
Nicci	Donnelly	Involve North East
Mandy	Taylor	Streetwise/Newcastle West CCG
Hilary	Bellwood	NHS Alliance
Julia	Young	Newcastle North and East CCG
John	Lawson	MESMAC NE
Kevin	Coombs	Newcastle City Council
Clare	Hodgson	Newcastle City Council
Rachel	Baillie	Newcastle City Council
Cathy	Bull	Newcastle City Council
Fiona	Richardson	Newcastle City Council
Felicity	Mendelson	Newcastle City Council
Rachel	Baillie	Newcastle City Council
Pam	Jobbins	Newcastle CVS
Sally	Young	Newcastle CVS
Alison	Walton	Newcastle Healthwatch
Hilary	Bellwood	NHS Newcastle Gateshead Alliance
Julia	Young	NHS Newcastle North and East CCG
Alison	Sweeney	NHS Newcastle North and East CCG
Jackie	Cairns	NHS Newcastle West CCG
Christianne	Ormston	NHS Newcastle West CCG
Ann	Dymyd	NIWE Eating Distress Service
Olwen	Pollinger	PARKINSONS UK
Barbara	Douglas	Quality of Life Partnership
Lucy	Dixon	RNIB
Johanne	Mears	Search
Jackie	Cairns	Newcastle West CCG
Pauline	Bishop	St Anthony of Padua Community Association
Peter	Moore	Stroke Association
Matthew	Henderson	Taking Part Workshop
Victoria	Hildreth	Taking Part Workshop
Irene	brown	Under the Bridge
Steve	Nash	VOLSAG
Ann	Dymyd	NIWEEDS
Ean	MacKellar	West End Befrienders
Sarah	Cowling	Healthworks

Carers and the Better Care Fund - Submission from Carers Centre Newcastle

Carers Centre Newcastle (CCN) welcomes the inclusion of carers in the Better Care Fund. Carers are the main providers of health and social care in the UK often bridging the gap between the two and acting as a 'lynch pin' – holding it altogether. Carers epitomise the 'Big Society', community and social assets.

The care and support provided by carers in the UK is worth an estimated £119 billion per year. Therefore the economic value of Newcastle carers can be estimated at £521 million per year. The NHS spend for 2012/13 was £105 billion.

CCN attended the NHS and LA event at the Centre for Life on 12th March and there was a carer specific question:

How could the VCS contribute to integration/transformation in the plans for the Better Care Fund, particularly in relation to:-

- *Carers*
- *Mental health – prevention, early intervention and support?*

The two points are inextricably linked. Carers care for people with mental health conditions but also frequently suffer from greater health inequalities, including mental health, than non-carers (see evidence below).

The Better Care Fund for carers includes:

- Funding for carers breaks / carer specific support
- Funding for carers assessments
- Funding for meeting more carers needs
- Funding for provision of information and advice
- Funding for advocacy services
- Funding for services that prevent needs for support
- Funding for safeguarding

The Carers Centre Newcastle (CCN) is the only organisation in Newcastle solely dedicated to supporting and representing adult carers. With a proven track record and a sustained presence in the City for over 15 years CCN is confident in being able to actively contribute to the desired outcomes and specific plans for carers as part of the BCF. This longevity, consistency of service, and a commitment to carers has resulted in a strong trust in CCN and their work (98% of carers said they would recommend CCN to other carers). Their Social Return on Investment figure for 2012/13 was £5.8 million for an income of £460,000.

CCN has a much wider role than being a service provider for carers. It promote carers' needs and issues, it provides services and support and enables carers to have choice and control and to have a voice. It works with local organisations across sectorial boundaries to develop better support services for carers and recognition of their vital role in the delivery of health and social care.

Carers' rights and needs
Carers have rights in law and needs of their own. These will be strengthened in 2015 with the introduction of the Care Bill and the Children's and Families Bill. Carers rights and needs cannot be met only by providing services to the person(s) they care for.

- They need to be considered and their rights respected.
- Information relevant to their role as a carer and not just about the condition and/or age of the person(s) they care for.
- Services and support for *themselves*; not just as a consequence of the person(s) they care for care package e.g. advocacy and mediation.
- Support to 'navigate the system'.
- Involvement – to be valued and respected as care partners.
- A break from caring.
- Good quality services for the person(s) they care for.
- Emotional support and help to handle stress.
- Training, for example, to be shown how to move and handle or planning for the future.
- Referrals to other services.

There are many self-funded patients/service users/carers and those who manage their own situation without involvement from formal services. They are often unknown to social care providers but are likely to be known to health services. Not all service users/carers will appear on the LA radar until the service user has reached 'substantial' under FACS, therefore the opportunity to provide a service under early intervention or with a preventative approach can be lost.

Building on experience and best practice the Voluntary and Community sector(VCS) are well placed to independently or in partnership with statutory or other VCS providers deliver the carer specific outputs and expected outcomes sought. The VCS offers value for money and added value, often through the extensive use of volunteers. With a history and track record of being able to reach and engage with citizens/patients/people, the VCS has a significant and positive contribution to an early intervention and prevention agenda as these are the organisations people and communities turn to at a time of need.

Impact of caring and why carers need services and support
There is strong evidence that demonstrates that as a community of identity carers suffer from greater inequalities that the general population; becoming a carer can be one of the worst things you can do for your health. CCN's experience and expertise reflects the national picture, including:

- Whilst caring can be very rewarding, the impact of caring can be detrimental to carers health. Findings by Carers UK found that the 84% of carers said that caring has had a negative impact on their; 92% reported it had a negative impact on their mental health[1]. These findings are reflected in Newcastle. In response to the Carers Centre annual survey for 2012/13 Newcastle carers were asked what their top 5 concerns were:

    1. 76% said loneliness, stress and anxiety
    2. 65% said their own health
    3. 57% said managing to care as they got older
    4. 55% said planning for the future
    5. 54% said being listened to by professionals.

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[1] Carers UK. The State of Caring 2013.

- The Government has highlighted carers as a group experiencing comparative poor health within their plans to promote public health.[2]

- 13.2% of carers caring for over 50 hours a week were in 'bad' or 'very bad' health. This compares to 5.3% of people without caring responsibilities. So full-time carers are two and half times more likely to be in bad health.[3]

- 40% of carers have significant distress and depression levels.[4]

- Carers providing more than 20 hours of care per week over extended periods have twice the risk of experiencing psychological distress over a two year period than non-carers; the risk of distress increases progressively with the amount of time devoted to caring each week and adverse effects of caring are evident beyond the end of caring episodes.[5]

- A four year study of 392 carers and 427 non-carers aged 66-92 found that carers who were reporting feelings of strain had a 60% higher likelihood of death in that period that non-carers or carers not reporting strain.[6]

- Carers providing high levels of care associated with a 23% higher risk of stroke.[7]

- On average, carers retire eight years early[8] and one in five gives up employment to care.[9]

Impact and benefits of supporting carers

Newcastle faces significant and unparalleled financial pressures and the situation is likely to get worse. Carers should be viewed as an 'assets' and investment in carers should be seen as an opportunity. There is a wealth of evidence to show that supporting carers:

- Improves health and wellbeing outcomes for patients and recipients of care.

- Improves health and wellbeing outcomes for carers who suffer disproportionately high levels of ill health.

- Reduces unwanted admissions, readmissions and delayed discharges from hospital

- Reduces unwanted residential care admissions and length of stays.

- Patients are able to remain in their own home or family home for longer.

- Improves social isolation, thereby promoting social inclusion.

- Improves their access to universal services, for example supporting them to remain in paid employment or training and therefore less likely to suffer financial hardship.

- The opportunity to take a break enables carers to have a life outside caring and be more involved in their community.

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[2] HM Government. Healthy lives, healthy people: a strategy for public health in England (2010)
[3] 2011 Census
[4] Pinquart M, Sorensen S. Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. Psychology and Aging (2003) 18 (2), p. 250-267
[5] Hirst M. Carer Distress: A prospective, population-based study. Social Science & Medicine (2005) 61,
[6] Schulz, R, Beach, S 'Caregiving as a Risk Factor for Mortality'. Journal of American Medical Association, Dec 1999, vol. 282 (23), 2215-2219.
[7] Haley, W et al (2010), 'Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers'. Stroke, 41:331-336
[8] 'Real Change, Not Short Change: Time to Deliver for Carers' (2007). Carers UK
[9] Buckner, L, Yeandle, S (2007a), 'Carers and Caring in EU Member States'. Eurocarers.

Better Care Fund – Review of existing consultation reports

Introduction

As part of the Better Care Fund consultation Involve North East and the Health and Race Equality Forum were tasked with reviewing previous consultations around health and social care that had been carried out in Newcastle in recent years. The aim of this review was to identify any pieces of work that support the principles and benefits, attributes and transformation schemes put forward in the draft Better Care Fund proposal.

Involve North East examined reports held within its Resource Bank and previous Local Involvement Network (LINk) consultations and any information to support the proposal is detailed below.

The evidence below supports the proposed transformation schemes, addressing the question:

> *Do the proposed transformation schemes deliver what our communities have told us that they need to support them to have positive health and care?*

Reports

This section details the reports we have identified which provide evidence to support the proposed transformation schemes.

Breast, Bowel and Lung Cancer - What do we Know about these Diseases? Involve North East (2008)

Research was carried out by Involve North East to inform the Healthy Communities Collaborative's 'Promoting the Early Presentation of Cancer Symptoms' project with 21 people living in Byker, Walker and Elswick. The research gauged their existing knowledge, health beliefs and attitudes towards breast, bowel and lung cancer.

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)

Newcastle LINk carried out research on what the priority for health and social care issues were in Newcastle. A total of 203 people from 27 organisations provided feedback to the consultation.

The research identified the top three health and adult social care priorities and identified people's reasons for choosing their health priorities. It also explored people's experiences of using health and adult social care services with findings relating to mental health, healthy living, drugs and alcohol, support to access services, obesity, smoking, long term conditions, sexual health, carers, teenage pregnancy and breastfeeding.

NHS North of Tyne Older People's Services Review 2009-10: Report of the patient, carer and public consultation, Involve North East (2010)

The Older People's Services review was one of five reviews which took place after 2007. In partnership with Newcastle City Council and the Newcastle Hospitals NHS Foundation Trust its aim was to take a comprehensive look at all aspects of older people's services commissioned or provided by Newcastle Primary Care Trust (PCT) and consider how

effective the services were, how efficiently they operated and most importantly, whether they were meeting the needs of older people living in the city.

As part of the review Involve North East carried out engagement to gather the views of patients, their carers and the general public. Forty-three people gave their experiences and views of the services they had received over the previous three years.

Health Action Network Consultation Report - Exploring Awareness and Knowledge of Bowel, Breast, Lung, Oesophageal, Prostate and Skin Cancer in Newcastle, Involve North East (2011)
Involve North East's Health Action Network carried out consultation work to explore peoples' awareness and knowledge of Bowel, Breast, Lung, Oesophageal, Prostate and Skin Cancer in Newcastle. One hundred and twenty-three people gave their views.

Health Action Network Consultation Report - Exploring Awareness and Use of Health Services in Newcastle if you are Injured or Unwell, Involve North East (2011)
Involve North East's Health Action Network carried out consultation work to explore peoples' awareness and knowledge of the range of NHS services available and the most appropriate service to use when they become unwell or are injured. Eighty-eight people took part in the consultation.

People's Experiences of Mental Health Services, Newcastle LINk (2011)
Research was carried out on behalf of Newcastle LINk by Launchpad to explore the experiences of people in Newcastle that use mental health services. Views were collected using word clouds to gather thoughts on mental health services with over 100 responses were received, as well as 20 interviews, at least 14 activities with local groups, and a focus group with 16 participants.

The main findings from the research include:
- the length of time waiting for appointments
- the inconsistency in seeing the same health professional
- the lack of choice around services
- the lack of information available about alternative services
- not enough information sharing and communication between workers and agencies
- the lack of community care
- the inconsistent experience across service users in accessing social workers, community psychiatric nurses and other such services
- issues around access to funding

There were broadly six recommendations developed to improve mental health services, including:
- the need to embrace recovery in the approach of service
- reducing the gap between primary and secondary care
- the need for a greater knowledge of preventative and maintenance services available, particularly in community settings
- greater communication across agencies to avoid fragmentation
- cultural sensitivity training and outreach to improve take-up of services
- ensuring service users are treat fairly in assessments

Our Health, Our Voice, Newcastle LINk (2011)

Newcastle LINk commissioned a peer research project to examine the opinions and experiences of young people in health issues and services. WEYES and Streetwise were involved in recruiting ten young people to be trained as peer researchers. An introductory health questionnaire received 208 responses; a participatory appraisal sticker board gathered a further 117 views and nine focus groups were held.

The report evidenced a whole range of findings including:
- the need for easy to understand information in leaflet form and from internet sites
- young people are very interested in being more involved in health decisions
- barriers currently prevent young people from having a role in decision-making around their health, such as being treat differently to adults.

Ten recommendations were developed around the availability of information on access to health professionals and health services as well as information on what health concerns do practices offer help and advice on, how to make appointments, confidentiality, consent and information sharing, and young people's rights. There were also recommendations around opportunities for advocacy support to young people.

The Views of Relatives and Carers on the Information given to them when a Patient is Discharged from Hospital, Newcastle LINk (2011)

Newcastle LINk carried out research to capture the views of carers/relatives about the information they receive when a person they care for is discharged from hospital. The research stemmed from the findings of the Newcastle upon Tyne Hospitals NHS Foundation Trust inpatient survey from 2010 which identified the issue. A total of 74 people took part in the research.

Some of the main findings from the research include:
- most patients received some form of information upon discharge
- the majority were satisfied with the information, however, almost one quarter felt there was not enough information
- the need for more and improved information for relatives and carers around the patient's condition, after-care, additional support and loan equipment

Recommendations from the research included the need for the information distributed to be reviewed, ensuring relatives and carers are fully informed, ensuring relatives or carers were involved in the discharge process, consider additional support and provide more support for relatives and carers to understand the after-care process, particularly when social services are involved.

Carers' Perspectives on Getting a Break, Newcastle LINk (2012)

Research was carried out on behalf of Newcastle LINk by the Elders Council of Newcastle to understand how carers take a break and what taking a break means to them and their ability to continue their caring role. To collect views a steering group was set up which included five key organisations working with carers; a questionnaire was distributed widely around networks and received 32 responses; a series of focus groups were arranged with a total of 24 people attending; and two providers of services allowing carers to take a break were also contacted.

The main findings from the research included:
- there is a stigma attached to seeking help
- economic considerations, such as low income, play a large part in carers' lives

- there is a need for timely information to be available for carers
- there is a need for formal care services to work side by side to provide services that are sensitive to the needs of the person being cared for.

Fourteen recommendations were developed under the headings of:
- mutual/peer support
- information, guidance and support
- the impact of economic pressures
- quality of care

Mental Health: Access and Interfaces between Primary and Secondary Care in Newcastle, Newcastle LINk (2012)

Research was carried out on behalf of Newcastle LINk by Launchpad, Carers Centre Newcastle and Newcastle Advocacy Centre to explore issues around a perceived gap in primary and secondary care as well as a lack of clarity as to the function and purpose of different agencies and the transitions between them. The views of service users and carers were captured by the ongoing operations of the three organisations undertaking the work along with nine one-to-one interviews, an event organised by Newcastle Advocacy Centre and a specific event for this report.

The main issues presented in the report from service user and carer experience included:
- difficulties in accessing certain types of help
- transition problems between services
- lack of clarity for users, carers and workers about services' availability
- eligibility criteria and remits

Four recommendations were provided which aim to improve mental health services including:
- the need to adapt or refine the recovery model for mental health so that services must accommodate variable rates of progress/recovery
- adapting to issues relating to cultural diversity and co-existing sensory disabilities
- there should be dedicated partnership working to ensure an outward-looking approach to make the Newcastle system work rather than prioritising internal processes as well as a recommendation to provide a role around a field worker/mental health trainer
- the need for information, in terms of access, sharing and publicity, between services as well as the need for services and their staff to know about each other too

Student Health Needs Assessment - Perceptions of Health and use of Health Services in Newcastle, Involve North East (2012)

A Student Health Needs Assessment was carried out in Newcastle in 2012 by Public Health at NHS North of Tyne in collaboration with the Students in Newcastle Forum (a working group which brings together representatives from Newcastle University, Northumbria University and Newcastle College with the City Council). As part of the assessment Involve North East was asked to gather students' perceptions of health and use of health care services whilst living in the city. One hundred and forty-six students gave their views.

Transformation schemes

This section provides evidence using narrative and quotations to support the proposed transformation schemes.

Systemic transformation

A3 Facilitate data sharing and use of technology to engage patients and service users
Fulfil data sharing obligations and introduce interoperable IT systems including secure web access for patient and telecare and telehealth functionality. This scheme includes actions to define and embed supportive information governance arrangements, and builds on existing partnership work on technologically enabled care through the DALLAS programme. It will be supported through the Active Age AZTECH programme, drawing on input from a group of international IT companies.

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)
The community priorities research highlighted a large range of issues across a variety of topics including data sharing between organisations and agencies. Specific consultation responses include:

> "Access to social care is not joined-up with health care. For example, going to the GP with your husband and becoming an unpaid carer but not being given a social worker to help you with benefits and services specifically designed for carers."

> "Because of patient confidentiality a carer is often unaware of care plan put into action and the discussions that take place with GPs and specialist."

Mental Health: Access and Interfaces between Primary and Secondary Care in Newcastle, Newcastle LINk (2012)
As part of this research, the need for sharing data between health and social care services was highlighted. Issues around patients repeating their stories to multiple agencies and professionals and the need for more joined-up working were also identified. Specific consultation responses include:

> "Issues can arise where people have needs identified by others which they do not want to address. These have an impact on others, but local authority services do not have duty/power to address"

> "Stop unwillingness to share information"

A5 Enable self-care
Enhance health literacy, information availability advice and advocacy to support prevention, enable self-care and facilitate access. Our approach which will promote shared decision making and care planning will build upon the Ways to Wellness model of social prescribing to ensure a holistic approach to self-care. The NHS "111" Directory of Services will be marketed and utilised to facilitate active signposting to services which utilise individual and community assets.

Breast, Bowel and Lung Cancer - What do we Know about these Diseases? Involve North East (2008)

The findings from the report included the need for more information around the signs and symptoms of breast, bowel and lung cancer:

- What to look out for in terms of breast cancer, in addition to a growth or lump
- The differences between symptoms of the cancers and long-term illness people suffer from (e.g. targeting IBS sufferers)
- How to distinguish cancer symptoms from those associated with old age
- Men's risk of getting breast cancer
- Bowel cancer screening

"[You might think it was] just changes in what you're eating or getting older"
"Many people might get symptoms but it's to do with lifestyle"

Dissemination was suggested via:
- Leaflets through the door
- Local newspapers and magazine articles
- Information stands in community venues e.g. bingo
- Schools
- Group sessions in surgeries
- Models - for breast cancer, a model available to people so they could feel what a lump was like, so would know what to look out for should be available to people use
- Celebrity endorsements

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)

The community priorities research highlighted a large range of issues across a variety of topics. There was a large response around the need for better information availability and the need for advocacy support as well as the need for improved signposting and making use of community services. Specific consultation responses include:

"There is not enough promotion of available services".

"BME communities find it difficult to access services and find out what is actually available".

"Information and knowing how to access a service is important as well as what is there".

"Funding is needed for an advocacy worker (a local person, with local knowledge) situated within GP surgeries to signpost to relevant services".

"One person asked for a referral from their GP to East End Health to access some of the available therapies they offer. The GP refused to refer them as the organisation was not run by the NHS or a private health provider".

"Often people working in health services don't know what services are available. There is a lack of communication. This also means that they can't pass information on to the public".

Health Action Network Consultation Report - Exploring Awareness and Knowledge of Bowel, Breast, Lung, Oesophageal, Prostate and Skin Cancer in Newcastle, Involve North East (2011)

From the findings of the research it was recommended that there should be continued promotion of the signs and symptoms of the six cancers but in particular bowel, prostate and oesophageal.

Promotional materials should be considered for male and female audiences separately and for men, there needs to be more encouragement to go to their GP practice with any of the symptoms. Additional promotional materials should also be considered for BME communities.

Materials should use local people with both positive and negative stories and in large organisations; the experiences of colleagues could be shared.
Formats should include:
- Leaflets
- TV advertisements
- Radio advertisements
- Newspapers, e.g. Metro
- Billboards
- Face-to-face discussions with community groups

Messages should be displayed in:
- Workplaces
- Occupational health services
- Community centres
- Schools
- GP waiting rooms
- Health centres
- Hospitals
- Metro
- Buses
- Internet

There should be greater promotion around:
- Higher risks due to a family history of the disease
- Higher risks due to age
- Unexplained weight loss being a symptom that should be acted upon

Specific messages around bowel cancer should include:
- Getting checked out for tiredness, loss of appetite and weight loss

Specific messages around prostate cancer should include:
- Increased risk through being Black African or Black Caribbean
- A weak flow of urine and a feeling like the bladder has not emptied is a symptom of the disease
- Pain when passing urine and blood in the urine are very rare symptoms of the disease
- Promotional materials should include a diagram of where the prostate is

Specific messages around oesophageal cancer should include:
- Increased risk through being male, having long term acid reflux, having a diet low in fresh fruit and vegetables and being overweight

- Hoarseness or chronic cough and persistent vomiting or regurgitation are symptoms of the disease
- Getting checked out if you have new and persistent acid reflux/indigestion/heartburn

Health Action Network Consultation Report - Exploring Awareness and Use of Health Services in Newcastle if you are Injured or Unwell, Involve North East (2011)
This report found that levels of awareness of what actions to take when people become unwell and the NHS services available are generally high. However, a need was identified for greater promotion of all of the services and more information about particular services and when to use them. Moreover, in addition to generic promotion, specific groups were identified to receive tailored information in appropriate formats:
- Older people and particularly those who do not have access to the internet
- BME communities
- Cyrenians Service Users and NECA Housing

Walk-in Centres and Minor Injuries Units
There was demand for more information about when to use and how to access walk- in centres or minor injury units. In terms of the location of services, people wanted to know where the walk-in centres were, which ones had closed and which ones had relocated.

The following information should be considered for inclusion in any promotional materials:
- What to use the service for
- Who can be treated at each facility
- Who they are run by e.g. GP-led or Nurse Practitioner-led
- Where they are located and which ones have recently closed or relocated
- How to access them i.e. walk in and wait to be seen
- Opening times
- No direct access to x-ray facilities – although they may be situated within buildings which have x-ray machines

A & E or 999
- Consider developing specific promotional materials covering the appropriate use of this service
- Advertise penalties for inappropriate 999 calls
- Consider a targeted campaign for parents of young children covering other actions that could be taken when their child is ill and particularly at night
- Consider assisting the promotion of the Press Don't Panic scheme provided for epilepsy patients

In terms of format, the following suggestions were made:
- Face-to-face discussions
- Fridge magnets through the post
- Leaflets
- Online advertisements e.g. Facebook, computer pop-ups
- Posters
- Single non-emergency telephone number
- Specialist GPs for addicts
- Television advertisements
- Text messages
- Website

Our Health, Our Voice, Newcastle LINk (2011)

This research had a very wide remit in terms of the issues and topics covered however it did highlight issues around information, advocacy and shared decision-making which were found to be important to young people in accessing health and social care services. Extracts from the report and specific consultation responses demonstrate this:

'When asked how important they felt their involvement was, 62% of young people felt it was very important to be involved in decision-making around their health, 22% felt it was quite important, 14% a bit important and just 2% felt it was not at all important' (page 11).

"You should be involved in everything. You should always be given all the information and options…because it's your health."

'Two young women suggested having an advocacy worker to support young people in accessing health services, "maybe someone who I knew, who is close to you but not that close"…"My doctor's lovely but I just can't go on my own".'

Carers' Perspectives on Getting a Break, Newcastle LINk (2012)

The research highlighted the need for more and better information for carers around services that could help with their caring responsibilities or information around taking a break and what their options were. An extract from the report highlights this issue:

"Carers commented on the need for timely information, which might come through a variety of sources…They also talked about the need for a person to talk things through and write things down" (page 8).

Mental Health: Access and Interfaces between Primary and Secondary Care in Newcastle, Newcastle LINk (2012)

As part of this research, the need for better information availability to mental health service users and between mental health services was one of the main issues discussed in the report. Specific consultation responses include:

"Central information hub with knowledge of services".

"CHMT; primary care; voluntary sector – there is no single pathway between them and no referral criteria easily accessible. Lack of knowledge of what is available throughout the city".

"Issue keeps coming up that those who work in the 'system' don't know about all of its component parts and how they fit together".

Student Health Needs Assessment - Perceptions of Health and use of Health Services in Newcastle, Involve North East (2012)

Half of students offered suggestions for things that organisations could do to support students' health needs and the five most frequently mentioned included provision of information about GP services and provision of information about all NHS health services.

Students requested information about GP services as follows:
- How to register with a GP practice and what happens to your old doctor and medical record
- Where all of the GP practices are located
- What services each GP practice offers

- For Chinese students this information should be available in Mandarin if possible and should also include instructions about using interpreters.

"I'm not sure but when I arrived to uni I didn't really have much guidance on where to go and what sort of GP to sign up for or anything like that so…more information on that would have been useful because I didn't really know where to look".

"I think maybe a more coherent approach, because at the moment it's really confusing, like you said you didn't know where to go and there's just loads of different GPs with different names - some are called surgeries, some are called medical groups, what's a medical group? What's a surgery? Like, the only thing you recognise is 'well I know what a pharmacy is, I get that, I know what that's going to do for me', but when it comes to doctors it doesn't say in big letters on the outside 'doctors' you know, so then you just kind of like 'well what's the difference between a medical group and a doctor, or a surgery or a…'"

Students requested information about other NHS health services:
- Both UK based and international students requested information about the different health services available in the city however for international students there was also a need for general information about how the National Health Service works.
- For Chinese students, additional information on how to use A & E appropriately should also be considered as there was a tendency to use this service as a first port of call when they need to seek medical attention.

"Make us more aware of what is available in the city. I have no idea where to go for things".

"During fresher's week there should be a talk about where the local hospitals are etc. and where A&E is. They should also give information about how to get free prescriptions".

"The university and the NHS cold provide more information about how the NHS system works".

"Sometimes me and my friends just go to GP in Boots as well and some just go to RVI emergency departments…they like to see the doctors that day...Because in China we just go to the medical – the hospital…for anything".

Needs Specific Transformation

B1 Facilitate 7 day working
Work with patients, citizens and partners to analyse available data, including seasonal variation and to diagnose where 7 day working can add value across the full health and care system,

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)
The community priorities research highlighted a variety of issues. The need for better access to health and care services was highlighted across a range of areas including mental health, GPs and supporting access to services. Specific consultation responses include:

"Services are only open 9-5. That only leaves the Tyne Bridge after that".

"I work in mental health and there is a need for more provision at the weekend like an out of hour's service."

"I care for a person suffering from dementia and he only wants to see a specific GP, but when I ring up for an appointment it takes weeks!"

"It can take weeks to get an appointment".

"There is a long wait (2-3 months) for counselling services at my GP surgery".

"When I was ill on a Friday I had to use the walk-in centre on the Saturday".

Breast, Bowel and Lung Cancer - What do we Know about these Diseases? Involve North East (2008)
Research was carried out to inform the Healthy Communities Collaborative's 'Promoting the Early Presentation of Cancer Symptoms' project with 21 people living in Byker, Walker and Elswick. The research gauged their existing knowledge, health beliefs and attitudes towards breast, bowel and lung cancer. It also sought to identify any barriers to, or reasons why participants would not go to their doctor when ill.

Participants provided examples of not being able to actually get through to their doctor to make an appointment or not being able to speak to or see their doctor very quickly when ill and there were also strong feelings expressed by workers about the need for appointment times and clinics to cater for those who work full-time.

"I know there's a girl in my office it took her, she rang the doctors forty times before she even got through…it was just ridiculous, she couldn't even get through so I think that is a major barrier to it"

"I think there's a major issue actually with doctors…my husband has been thinking you know, 'well I'm getting to that age where I should be having a check on my health' so next time I was calling in at the doctors I said 'oh have you got a well men clinic?' And they said 'oh we started one but nobody came' well they'd had it in the afternoon and men you know like some jobs you've got flexi time but a lot of jobs you can't you lose money em, so it's generally the same you know as you described trying to get an appointment out of working hours is really, really difficult".

Health Action Network Consultation Report - Exploring Awareness and Knowledge of Bowel, Breast, Lung, Oesophageal, Prostate and Skin Cancer in Newcastle, Involve North East (2011)
One of the report's recommendations was that appointments should be more readily available, particularly for shift-workers:

"Accessible appointments for working people who do shift work. I can't pre book appointments at my GP surgery".

B2 Prioritise reablement and rehabilitation
Maintain and enhance community rehabilitation and reablement services, including embedding reabling approaches across the whole system

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)

The community priorities research highlighted a large range of issues across a variety of topics. Accessing support services and the need for more information was highlighted in relation to reablement and rehabilitation. Specific consultation responses include:

"The help I was offered wasn't what I needed. I need help lifting and moving my husband at home but the helper wouldn't help. They were only there to do my washing".

"The person who came to help after my operation was not much help".

"They only do specific tasks".

The Views of Relatives and Carers on the Information given to them when a Patient is Discharged from Hospital, Newcastle LINk (2011)

This research highlights the need for better after-care on discharge from hospital, particularly around reablement and rehabilitation. The need for better information and support was also highlighted. Specific consultation responses include:

"More specific information about rehabilitation at home specific to the condition".

"Information about an OT's role".

"Who to contact, what happens next, who will help me".

"I would have liked to have been informed on help I could gain at home and some after care groups to get involved with".

"A home assessment would have helped at time of discharge…the patient couldn't even walk unaided and fell within an hour of return".

"I asked for mother to be referred to the social work team for reablement services the day after the operation. I was told by the nurse that an OT or physiotherapist would arrange it. Two days after the op there was still no social worker visit. I asked again and was told she hadn't been referred. The nurse agreed to refer her but I was informed there would be a delay. This never happened and mother was discharged with no social worker and no help when arriving home. No one discussed my mother's capabilities or home even with me".

"My experience wasn't brilliant due to the patient being alcohol dependent, little patience or understanding from the nurse discharging him, I had to challenge her attitude".

B5 Prioritise out of hospital options

Redesign pathways to ensure primary response for intervention is delivered through ambulatory care. Review community service specifications to enhance competencies of staff roles and skill mix to meet the needs of the older person with complex care needs and to maximise preventative impact. Remodel older people's resource centres and assess design and capacity of appliance and equipment services to ensure they are able to respond to increasing numbers of people cared for outside of hospital.

NHS North of Tyne Older People's Services Review 2009-10: Report of the patient, carer and public consultation, Involve North East (2010)

Six patients of Chirton Resource Centre took part in the review. Patients were generally very happy with the service but offered the following suggestions for improvements:

- Having the TV on at night time - they could provide headphones as a lot of people in the Centre are deaf and have to have the volume very loud which stops people being able to sleep
- Provide newspapers - I would be willing to pay for one that I want (two patients)
- Having more engaging activities, things that use your brain
- One patient commented that the toilets were too low and they needed to install some higher seats instead

B6 Recognise and support role of carers

Ensure that carers' mental and physical health needs are recognised and responded to as individuals in their own right by supporting access to mainstream services. Develop a joined up approach to carer identification and support, including promoting access to information and advice on balancing their employment and education with their caring role, facilitation of carer breaks and promoting opportunities, for training in areas such as first aid, moving and handling and stress management.

Mental health: access and interfaces between primary and secondary care in Newcastle, Newcastle LINk (2012)

Although carers were not the main focus of this report, issues around carers' mental health was discussed and issues identified around carers being able to access mental health services. Specific consultation responses include:

"How do carers with mental health issues themselves access support for themselves whilst still caring? At the moment they don't fit current criteria/gate-keeping though there may be some help from VCS services. There is a gap in services for carer respite to help carers with mental health issues".

Carers' Perspectives on Getting a Break, Newcastle LINk (2012)

The research highlighted the issues carers face in their day-to-day lives from the importance of family and friends and social networks to the need to know about and trust the services that are on offer. An extract from the report highlights this issue:

"You have to learn to safeguard yourself. It takes time. You have to swallow your pride and ask for help. It's often at a crisis point".

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)

The community priorities research highlighted a large range of issues across a variety of topics. The need for support for carers was highlighted across a number of topics both in terms of supporting existing carers and identifying new carers. Specific consultation responses include:

"There is a lack of provision for keeping carers mentally healthy".

"People are often unaware they are a carer and unless services are on board and recognise this, those people won't be offered the support available".

"Nobody told me I was a carer. I had no idea that I was entitled to an allowance".

> "Services need to be trained to recognise the presence of carers. They need to look at the patient's situation as a whole and ask: who's looking after them when they go home?"

> "Carers are often unwell themselves or have long term conditions, but they don't seek help. Their health is put to the side whilst they care for someone else."

B9   Transform mental health services
Model the future configuration of in hospital and out of hospital care for people with mental health needs.

Community Health and Adult Social Care Priorities in Newcastle, Newcastle LINk (2009)
The community priorities research highlighted a large range of issues across a variety of topics. The need for better access to mental health services was highlighted and the need for improved support. Specific consultation responses include:

> "It can be difficult to access mental health services due to the criteria that have been set".

> "There is not enough support after the initial episode to help people cope. There is not enough community or long term support".

Mental Health: Access and Interfaces between Primary and Secondary Care in Newcastle, Newcastle LINk (2012)
Mental health services were discussed in detail within this research and, although the focus was on the gap between primary and secondary care, issues around the gaps between health and social care were also highlighted with service users encountering a number of problems. Specific consultation responses include:

> "Need clear information regarding the system and points of entry".

> "Gaps in inclusion/exclusion criteria – no agreed transition criteria".

> "Greater clarity regarding change from GP/primary care level to high steps/levels of service including access to appropriate forms of mental health assessment and co-operation within Asylum process as appropriate. There are examples of really good and creative practice across mental health professions, but this is really based on good will/care/compassion and unfortunately this does not allow for a uniform standard".

> "The system is not joined-up and is not co-ordinated".

> "Workers in both sectors only have a small frame of reference as to what services are out there. Inconsistent service that often depends on the individual worker. Systems have developed independently of each other".

HAREF Briefing: Better Care

1. For an **asset based approach** to work effectively people need enough information to be able to take personal responsibility for their wellbeing and health. People in minority ethnic communities have consistently identified gaps in knowledge about how to stay as healthy as possible for as long as possible:
- Young people from some black and minority ethnic communities in North East England share their views of health services: Research and report commissioned by Government Office for the North East, 2010, HAREF – research involving 24 young people who described their backgrounds as Arabic, Bangladeshi, British Asian, Iraqi, Kurdish and Pakistani
- Conference Report, 2010, HAREF – conference involving 120 people from Afghani, African, Bangladeshi, Chinese, Czech, Filipino, Indian, Pakistani, Slovak communities
- Contribution to Newcastle Joint Strategic Needs Assessment, 2011, HAREF – local and national literature review
- Exploring health and social care needs of people in black and minority ethnic communities in North Tyneside: Report commissioned by North Tyneside LINk, 2011, HAREF – research involving 43 people from African, Bangladeshi, Chinese, Indian, Iranian and Pakistani communities
- Long Term Conditions Workshop Briefing, 2011, Bridges GP Consortium Conference

2. For a **lifecourse approach** to be effective services need to take quality of life and life expectancies in to consideration e.g. linked to conditions such as diabetes which disproportionately affects people from south Asian communities:
- Demystifying Diabetes, 2014, HAREF, HISEM, HealthWORKS, Diabetes Centre and Newcastle West Diabetes Lead

3. For effective **access** to, and use of, integrated services people need to know how the whole system works, including when/how to access emergency care. Adequate and consistent advocacy and/or communication support is also vital, and this can be more important than 7 day availability (extending availability extends inequality unless services are fully accessible):
- Young people from some black and minority ethnic communities in North East England share their views of health services: Report commissioned by Government Office for the North East, 2010, HAREF – research involving 24 young people who described their backgrounds as Arabic, Bangladeshi, British Asian, Iraqi, Kurdish and Pakistani
- Conference Report, 2010, HAREF – conference involving 120 people from Afghani, African, Bangladeshi, Chinese, Czech, Filipino, Indian, Pakistani, Slovak communities
- Exploring health and social care needs of people in black and minority ethnic communities in North Tyneside: Report commissioned by North Tyneside LINk, 2011, HAREF – research with 43 people from African, Bangladeshi, Chinese, Indian, Iranian and Pakistani communities
- Accessibility Workshop Briefing, 2011, Bridges GP Consortium Conference

4. For **change plans** to be effective there needs to be a commitment from all partners to join things up:

- Cycle City: Report of group discussions with people from minority ethnic communities, and with members of Elders Council, 2014, HAREF

5. For **carers** from black and minority ethnic communities to be recognised and supported there is a need for awareness of cultural barriers to their recognising themselves as carers and getting the help they need:
- The Princes Royal Trust for Carers, 2010, Caring for all carers: A survey of services for BME and seldom heard carers in Carers Centres and Crossroads Care Schemes
- Carers Workshop Briefing, 2011, Bridges GP Consortium Conference
- Who cares?: Experiences of some men in black and minority ethnic communities in Newcastle, on each of whom another person depends, 2011, HAREF – in-depth interviews with 14 men from Bangladeshi, Chinese, Indian and Pakistani communities, age range from teens through mid-twenties, thirties, forties, fifties, sixties to early seventies

6. For **dementia diagnosis** to be improved for people in black and minority ethnic communities there is a need for outreach in terms of information and advocacy/communication support:
- Department of Health, 2009, Managing Better Mental Health Care for BME Elders, Interim Report on National Seminars held for BME Elders, DH with University of Central Lancashire and Policy Research Institute on Ageing and Ethnicity
- People in Black and minority ethnic communities and dementia care, 2010, HAREF - literature review
- Awareness-raising sessions on dementia at Grainger Park Mosque, 2014, Carers Centre with HAREF, 2014

7. **HAREF's contribution**: HAREF began as a network from 2000 when people worked together under the umbrella of the Newcastle Health Action Zone (Race Equality Area of Special Action). HAREF is about joining things up to reduce health inequalities. Following quotes are from health professionals interviewed for the report commissioned by North Tyneside LINk, 2011 (referenced above). They illustrate people's enthusiasm for making a difference together:

- My hope for the future is that we work together, for example to keep people out of hospital when they can be cared for at home … We've started talking now and we can go on to plan and take action. We can produce a joint picture of people's needs, rather than assuming we know what's needed, and services can then fit that picture

- We need to identify groups of people and their health needs and, in parallel to that, scope non-traditional service providers, looking to see what's around, particularly in relation to long term conditions. This would mean integrated work and community involvement. We need to be more creative and innovative in opening up a menu of services, and do it flexibly and quickly in partnership with others