Better Health Programme Joint Health Scrutiny Committee

Special Meeting on Thursday 1 December 2016 at 1.30 pm in the Council Chamber, Hambleton District Council, Northallerton DL6 2UU

Agenda

1. **Apologies for Absence**
2. **Substitute Members**
3. **To receive any Declarations of Interest by Members**
4. **Minutes (Pages 3 - 8)**

   To receive and approve the minutes of the Better Health Programme Joint Health Scrutiny Committee held on 13 October 2016

5. **Sustainability and Transformation Plans - Publication (Pages 9 - 12)**

   To consider the attached cover report of the Principal Overview and Scrutiny Officer, Durham County Council and an associated presentation by Alan Foster, Chief Executive of North Tees and Hartlepool NHS Foundation Trust and STP lead for Durham, Darlington and Tees ;Hambleton, Richmondshire and Whitby STP

6. **Better Health Programme - Phase 4 Engagement Feedback (Pages 13 - 92)**

   To consider the attached engagement summary reports from the Better Health programme engagement events.

   Presentation – Representatives of the Better Health Programme will give a presentation to the Joint Committee updating members in respect of the key findings and issues identified as part of the Phase 4 Engagement

7. **Chairman's urgent items**
8. **Any other business**
9. **Date and time of next meeting**

   Thursday 19 January 2017 at 2.00 p.m. – Redcar and Cleveland Council – Venue to be confirmed

Published:

23 November 2016

Contact Officer: Stephen Gwillym, Principal Overview and Scrutiny Officer, Durham County Council **Tel:** 03000 268 140

Membership:

DARLINGTON BOROUGH COUNCIL
Councillor Wendy Newall
Councillor Jan Taylor
Councillor Heather Scott

DURHAM COUNTY COUNCIL
Councillor John Robinson
Councillor Jan Blakey
Councillor Watts Stelling

HARTLEPOOL BOROUGH COUNCIL
Councillor Ray Martin-Wells
Councillor Stephen Akers-Belcher
Councillor Rob Cook

MIDDLESBROUGH COUNCIL
Councillor Eddie Dryden
Councillor Bob Brady
Councillor Jeanette Walker

NORTH YORKSHIRE COUNTY COUNCIL
Councillor John Blackie
Councillor Jim Clark
Councillor Caroline Dickinson

REDCAR AND CLEVELAND BOROUGH COUNCIL
Councillor Ray Goddard
Councillor Mary Ovens
Councillor Norah Cooney

STOCKTON-ON-TEES BOROUGH COUNCIL
Councillor Sonia Bailey
Councillor Allan Mitchell
Councillor Lynn Hall

Better Health Programme Joint Health Scrutiny Committee

At a meeting of **Better Health Programme Joint Health Scrutiny Committee** held in the Jim Cooke Conference Suite, Municipal Buildings, Church Road, Stockton on Tees **Thursday 13th October 2016 at 1.00pm.**

Present:

Cllr J Robinson (Durham County Council) Chair

Councillors –

Councillors W Newall, J Taylor and L Tostevin (Darlington Borough Council)
Councillors O Temple (Durham County Council)
Councillors B Brady (Middlesbrough Council)
Councillors J Blackie, J Clark, C Dickinson (North Yorkshire County Council)
Councillors R Goddard, M Ovens, N Cooney (Redcar and Cleveland Borough Council)

Officers –

Peter Mennear, Kirsty Wannop (Stockton-on-Tees Borough Council)
Stephen Gwillym (Durham County Council)
Joan Stevens (Hartlepool Borough Council)
Alison Pearson (Redcar and Cleveland Council)
Daniel Harry (North Yorkshire County Council)

Better Health Programme –

Alan Foster
Dr Nick Roper
Dr Boleslaw Posmyk
Edmund Lovell
Ali Wilson
Dr Neil O'Brien
Derek Cruikshank

Also in attendance – Members of the Public

1. **Apologies for Absence**

   Apologies for absence were received from:-

   Councillor S Akers-Belcher (Hartlepool BC)
   Councillor J Blakey (Durham County Council)

2. **Substitute Members**

   L Tostevin for H Scott, Darlington BC and O Temple for W Stelling

3. **To Receive any Declarations of Interest by Members**

   There were no interests declared

4. **Minutes**

   The minutes of the meeting held on 8th September 2016 were confirmed by the Committee as a correct record and signed by the Chairman.

5. **Accident and emergency Services – Performance against waiting times**

   The Committee considered a presentation that gave further explanation to the presentation received at the meeting on 8th September 2016 regarding A&E performance standards. Members were informed that emergency department across the UK were categorised into three types and the performance indicators varied depending on the type of department it was.

   Type 1 were consultant led units open 24 hours with full resuscitation facilities. Type 3 were units such as Minor Injury Units which may be doctor or nurse led.

   North Tees and Hartlepool NHS Foundation Trust had a type 1 and type 3 units.

   Type 2 Units were consultant led single speciality units, for example the unit at Sunderland Eye Infirmary.

   Resolved that the information be noted

6. **Sustainability and Transformation Plans – Update**

   Members were provided with a report that gave background information in respect of the development of health and care system Sustainability and Transformation Plans.

   The Committee then received a presentation that updated Members on the progress made to date in respect of their development and submission to NHS England. The main information provided could be summarised as follows:-

   - Better Health Programme had become a key part of the local Sustainability and Transformation Plan covering the sub-region. The STP Footprints had been determined nationally.

- Organisations agreed that North Durham CCG would move into the Northumberland Tyne and Wear STP, and so no longer be part of the Better Health programme.

- STPs were designed to address the health and wellbeing gap, quality of care, and finance and efficiency. Local challenges included the need to reduce variation, ensuring success in relation to cancer mortality was repeated for other diseases, and standardising the approach to care across the area, including the care that was already available seven days a week. This could for example mean increased access to specialists, and often involved the frail elderly.

- STP needed to add value and stop variation. Existing plans would be used and built upon wherever possible.

- Details of the BHP model of care and the possible scenarios that were being considered.

- The Better Health Programme proposals included provision for a reconfiguration of acute care, but it was not planned that any hospital would close. All sites would stay open but would deliver care differently.

- Specialist hospitals would allow for patients to see a consultant who was a specialist in their condition or in that service. Currently this did not happen; patients may see an experienced doctor who would not always be a specialist in the condition the patient was at hospital for.

- A timetable for the STP was provided with consultation on service change beginning in June 2017. Also provided were October's public engagement event dates. Consultation had been moved back to 2017 in line with other STP timetables and no decisions had been made.

- Some capital funding would be needed to change services, and each STP would be making bids to the national Investment Committee. The local STP needed to be realistic about what it could secure. National approvals would therefore not be given until March 2017.

Members were given opportunity to ask questions/make comments that could be summarised as follows:-

- Representatives from North Yorkshire highlighted that during previous service reviews, residents had been reassured that although some services may be moved from the Friarage Hospital, Northallerton, they would still be accessible at Darlington Memorial Hospital. It was noted that under the options being put forward, this may not be the case in future. It was noted by the Programme Team that the CCGs in North Yorkshire were being engaged through the process.

- Members queried the process of securing capital funding through the STP process. It was noted that a bid would need to be made for funding for the period covered by the STP, although this would need to be ambitious but realistic. Other sources of funding including via CCGs and money that individual Trusts could generate would also continue to be explored.

- If no changes were made, the current estimated gap in funding between resources and demand would be £259m by 2020/21. The STP would need to include both efficiencies and service improvements. The detailed finances of the local STP were still being finalised, but the local NHS would need to work within the overall financial limits imposed nationally.

- It was important that consultation described all scenarios so the public were fully informed on what each would mean.

- It was noted that future presentations should make clear that the Major Trauma Unit at James Cook was being retained, as this was not clear in the version presented to the Committee. It was agreed that better descriptions of current and future services needed to be used.

- Thought needed to be given to the different scenarios and how it would impact on some of the more rural areas in terms of distances to services. It was agreed that distance would need to be factor in the options analysis. It was explained that a big driver regarding services was the work force available to give a better 7 day service.

- Engagement on the STP and BHP needed to be continually improved, including more events in the North Yorkshire area.

- Members noted that workforce pressures had been a continual theme in recent years and queried whether there would be a concerted effort to attract staff. The STP lead noted that there was a national training programme and that the local NHS was recruiting from the same pool as the rest of country. There were not enough training places nationally, but efforts were being made to attract people to this area.

- When considering the different scenarios, parking at the hospitals needed to be taken into consideration.

- Members highlighted the importance of promoting genuine choice in maternity care, for example home births.

The Committee recorded the concerns of a Durham County Councillor in relation to the future place of North Durham within the region's planning processes. The area would in future be covered by the Northumberland and Tyne and Wear STP, but had previously been considered as part of the Better Health Programme, and would continue to be covered by an acute provider Trust that spanned both STP areas.

It was noted that 85% of North Durham patient contacts were via North Durham Hospital, and the next highest used providers were Gateshead and Sunderland. For future planning processes it was suggested by the BHP that it made sense to include the area in the northern STP.

North Durham CCG would continue to engage with both the regional STPs.

Resolved that the information be noted.

7. Better Health Programme – Phase 4 Engagement Plan

A timetable for the STP was provided with consultation on service change beginning in June 2017. Also provided were October's public engagement event dates and the engagement themes.

8. Better Health Programme – Not in Hospital Services

The Committee considered a presentation updating on the development of a Not in Hospital Strategy. The main information provided included:-

- Better Health: Principles of care ensuring people were only in hospital when they needed to be.
- The 4 principles were Prevention, Responsive & Accessible, Co-ordination and Proactive and the Standards and outcomes.
- The out of hospital model of care.
- The enablers, person centred outcomes, system outcomes and priorities for this year.

It was noted that 90% of health contacts took place out of hospital, and therefore it was only right to make this a major focus of service improvements.

A community hub approach would be developed, with hubs of services based on populations sized thirty to fifty thousand people. These would have a physical base or be co-ordinated virtually, depending on the geographical location. Teams would be sized appropriately for the local population.

Members raised concerns regarding having the right services in the community hubs, and ensuring good practice was repeated across the region, for example stroke care.

Members queried the lack of involvement of mental health series in the Programme. It was noted that the original focus was on acute services, but the out of hospital workstream was increasingly involving mental health services. These services were however mainly based in the community already.

It was noted that increased use of technology (eg. remote monitoring of patients) had not been covered in detail in the presentation and the Programme Team would bring further details to a future meeting.

It was noted that there was a need to align the plans for acute and community care, and ensure that there was a transfer of resources to match any transfer of activity.

A member of the public noted the important role of nurses and this was agreed by all. They also highlighted issues with community dental care in Hartlepool, and the representative of the CCG was surprised at this as access should be available via NHS111. This was to be followed up outside of the meeting.

Resolved that the report be received and a further report on the use of technology be brought to a future meeting of the BHP Joint OSC.

9. Chairman's Urgent Items

The Chairman had no urgent items.

10. Any other Business

There had been no items identified.

11. Date and Time of Next Meeting

The date of the next meeting was Thursday 1st December 2016 at 1.30pm in the Council Chamber, Hambleton District Council, Northallerton.

Better Health Programme Joint Health Scrutiny Committee

Special meeting of the Better Health Programme Joint Health Scrutiny Committee

1 December 2016

Durham, Darlington and Tees; Hambleton, Richmondshire and Whitby Sustainability and Transformation Plan

Report of Principal Overview and Scrutiny Officer, Durham County Council

Purpose of the Report

1 This report provides members with further information in respect of the publication of the Durham, Darlington and Tees; Hambleton, Richmondshire and Whitby Sustainability and Transformation Plans in advance of a presentation updating members on the STP submission and feedback from NHS England.

Background – Durham, Darlington and Tees; Hambleton, Richmondshire and Whitby Sustainability and Transformation Plan

2 At the previous meeting of the Better Health Programme Joint Overview and Scrutiny Committee, members received a presentation by Alan Foster, Chief Executive of North Tees and Hartlepool NHS Foundation Trust and lead officer for the Durham, Darlington and Tees; Hambleton Richmondshire and Whitby Sustainability and Transformation Plan detailing the development of the STP prior to its formal submission for consideration by NHS England.

Sustainability and Transformation Plan – Feedback from NHS England and next steps

3 Mr Foster will give a presentation updating members on the progress made to date in respect of the feedback from NHS England to the Durham, Darlington and Tees ;Hambleton, Richmondshire and Whitby STP and next steps in terms of the development of consultation options for statutory consultation and associated communication and engagement plans and timeframes.

4 The Durham, Darlington and Tees ;Hambleton, Richmondshire and Whitby STP has not been formally published at the time of writing this report, but it is

expected that copies of the finalised STP will be available for members on the day of the meeting.

Recommendations

5 The Better Health Programme Joint Health Scrutiny Committee is recommended to:-

(a) receive this report, and

(b) consider and comment upon the contents of the presentation in respect of the STP publication and associated consultation options, communication and engagement plans.

Background papers

- NHS England Guidance – Sustainability and Transformation Plans
- Report and presentation to Better Health Programme Joint Health OSC and minutes of the meeting held on 13 October 2016

Contact: Stephen Gwillym, Principal Overview and Scrutiny Officer, Durham County Council Tel: 03000 268140

Appendix 1: Implications

Finance - None

Staffing - None

Risk - None

Equality and Diversity / Public Sector Equality Duty - None

Accommodation - None

Crime and Disorder - None

Human Rights - None

Consultation – None

Procurement - None

Disability Issues - None

Legal Implications – None

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Better health programme

NHS

The NHS in Darlington, Durham and Tees

VONNE voluntary organisations' network north east

NHS Better Health Programme

Engagement with the Voluntary and Community Sector Report

November 2016

NHS Better Health Programme

Engagement with the voluntary and community sector

1. Background to 100 conversations:

The NHS Better Health Programme (BHP) committed to having conversations with over 100 voluntary and community sector groups and organisations across County Durham, Darlington and Tees Valley. The aim was to have these ‘conversations between August and the end of October 2016 as part of the BHP Phase 3 Engagement plan to inform the formal public consultation options.

NHS Better Health Programme particularly wanted to encourage smaller community-based groups and organisations to engage in conversations about the NHS Better Health Programme representing the following: .

- Groups whose members identified themselves as having ‘protected characteristics,’ as defined in current equalities legislation (sex, disability, race, age, religion & belief, sexual orientation, gender reassignment, pregnancy & maternity)
- Groups that may meet regularly but do not normally choose, or have the opportunity, to engage in discussions around this type of health issue.

This work will enable NHS Better Health Programme to build a full picture of the needs of all parts of the community, particularly groups that experience health and wellbeing inequalities and enable members of those groups and communities to influence the health services they use.

2. The structure for voluntary and community sector engagement

VONNE as a regional infrastructure organisation representing and supporting the voluntary sector with significant reach over the BHP area acted as the lead body and worked with other CVS/ LDA (Local development agencies), Healthwatch and key special interest group organisations as '**Delivery Partners'** to support delivery of the 100 conversations across County Durham and Tees Valley. The delivery partners were as follows:

	Partner Organisation	**Area delivered**	**Interest group**
1.	Redcar & Cleveland VDA	Redcar & Cleveland	Mixed
2.	Catalyst Stockton	Stockton & Hartlepool	Mixed
3.	Women's Commissioning Support Unit hosted by Women's' Resource Centre	Durham & Tees Valley	Women's groups
4.	East Durham Trust	East Durham	Mixed
5.	Stroke Association	Durham & Tees Valley	Stroke
6.	Tees Valley, Durham & North Yorks Neurological Alliance	Tees Valley, Durham & North Yorks	Neurological conditions
7.	Age UK Darlington	Darlington	Older People
8.	Healthwatch Darlington	Darlington	Mixed
9.	Middleborough VDA	Middlesbrough	Mixed
10.	Durham Community Action	Co. Durham	Mixed
11.	Darlington Association on Disability	Tees Valley & Durham	Learning Disability

Each delivery partner identified smaller community and voluntary sector groups within the target communities and approached those groups about having a discussion with their members/participants. The final list of groups was agreed with VONNE and the NHS North of England Commissioning Support Communications and Engagement Team. (See full list at Appendix A).

Groups participating in a discussion were offered a 'supported' conversation facilitated by the local delivery partner organisation.

A facilitators engagement pack including information about the NHS Better Health Programme, advice on how to facilitate the discussion and information on how to feedback the responses from the discussion group was developed with input from VONNE and key representatives of delivery partners. Darlington Association on Disability (DAD) were commissioned to produce an Easy Read presentation for delivery partners engaging people with learning disabilities.

Facilitators from each local delivery partner attended briefing sessions organised by VONNE working with the BHP Communications and Engagement Team. Each delivery partner was issued with an NHS Better Health Programme engagement pack and briefed accordingly. Standard feedback templates were agreed to ensure the format of feedback was standard across all partners.

The facilitated discussions with groups then took place between August and November 2016 either at one of the regular meetings of the group or at a special separate meeting in venues that were accessible and local to the group and interpreters and support provided where required. Once the discussion had taken place, each delivery partner organisation provided VONNE with numbers of the people who were involved in the discussion and the key feedback from the discussion on the feedback template provided by NECS.

94 group conversations had taken place by mid November 2016 with over 1060 participants providing their feedback. The profile of group's participants in terms of equality and diversity was as follows:

Carers = 4% Children, Families and Young People =7% Disabled People = 12% Gender Specific Groups: Women= 15% Men=3% General /Mixed =15% LGBT= 2% Long Term Conditions =11% Older People =12% Young People =10%

People of a Particular Ethnic / Racial Origin = 9%

VONNE has managed the collation of the conversation feedback notes via delivery partners and produced this feedback report summarising and analysing the feedback from the 94 conversations so far. A further 6 conversations are underway. Appendix A sets out the full list and profile of groups engaged and Appendix B contains each individual feedback form for each group.

3. NHS Better Health Programme – 100 Conversations Executive Summary Feedback:

Top 3 Issues:

The top 3 key issues that the majority of groups identified are summarised as follows(see section 4 question 5 for further summary feedback on issues):

1. **Travel and Transport**

   There was widespread concern about transport issues for families and carers visiting their relatives in specialist hospitals if these were to be further away from their homes than current arrangements. There was also concern about the lack of availability and cost of hospital parking in general.

   There was concern about the capacity of ambulance services in transporting patients to specialist hospitals greater distances than currently as there was a common view that ambulance services were already under significant pressure and struggling to maintain a responsive service.

2. **Communication, capacity and skills across services**

   Pressures on GP and Community Services

   There was a significant amount of feedback on the current challenges for patients in accessing GP services and difficulties in getting appointments and a strong view than planned changes to provide more care out of hospital and closer to patient's homes would exacerbate this problem.

   There was also a common view that community services and social care were under significant pressure and unable to cope with demand currently and that this needed to be addressed before any new arrangements were put in place.

Greater communication between services

There was a commonly expressed concern about lack of or poor communication currently and that improved communication between services at hospital, GP and at wider community services level needed to be put in place along with increased capacity locally for BHP to work.

Staffing levels and skills

There was a view that staffing levels needed to be improved and staff needed the right skills for the BHP model to work, both in hospitals and in the community. The NHS needed to train and recruit appropriate staff and this should be a priority in these changes .

3. **Awareness, education and access & information for minority and interest groups**

Awareness & education

There was a strong view that there was a need to educate the public as to what health services to use and when and that before these changes take place an education campaign needs to take place. People needed to feel confident in new systems.

There was also a view that professionals need to learn from those who have lived experience of ill health, care and accessing services.

Access for minority groups and interest groups:

There was significant concerns expressed about barriers such as language, physical access and lack of support mechanisms such as interpreters for a number of minority groups and interest groups.

4. Key summary feedback from conversations:

Below is a summary analysis of the majority of the feedback from the conversations including a selection of representative quotes. The full feedback can be found at Appendix B (click on relevant question links at bottom of excel spreadsheet to access all responses to a particular question).

Question 1 Do you understand the issues raised in the video?

The majority of groups said they understood the issues being raised.

Some BME groups required a translator to explain the content, for example:

'We discussed the slides and NHS BHP leaflets via the Chinese Association facilitator who translated questions and responses. We shared the NHS Leaflets in Mandarin and Cantonese. The Association members present stated that they had not heard of the Better Health Programme and were not aware of a review of how services are provided.'

A group of older people and people with learning disabilities had difficulties both hearing and understanding the video. However DAD's Easy Read presentation was used with the majority of groups with learning disabilities.

The AAPNA group of older Asian males who have early onset dementia facilitator feedback was as follows: 'As would be expected their understanding of the details was less than other groups, but they understood the basic principles'

BID Services Deafened Adults group said 'Video is very interesting but all I need is a BSL interpreter' .

We had some feedback that the leaflet was hard to understand and we had a comment that Mental Health is not covered in the leaflet or the video.

'There should be a separate consultation on mental health services and where they will fit into BHP. This is a very specific subject and not covered by Better Health Programme'

In terms of feedback from Gypsies and travellers groups the point was made that 'Literacy is an issue within this group which needs to be recognised in both the Better Health Programme proposals and the consultation/engagement process. They do not on the

whole understand that they can be involved in discussions about health services. They feel information leaflets are not for them and so this needs to be explained to them'. Direct feedback from these groups included:

' Lots of words in the leaflet. Not very good if you have trouble reading'

' Don't understand some of the words…. trauma…. clinicians…...? '

' What exactly is a hub?? '

DASH (Durham Association Social Housing) Vulnerable Women's Group facilitator feedback was: 'Generally most of the group said understood what the video and leaflet talked about but it didn't really apply to them' Direct feedback from the group included:

'Most of what the BHP talks about doesn't affect me as it is community services provided by other organisations that I access and hardly anything mentioned in the video'

Question 2. What effect do you think it will have for your hospital services?

Common issues raised:

Travel:

There was widespread concern about travel times to hospital for appointments if they were to be further away. Challenges for those who don't drive including cost and lack of public transport/hospital transport/volunteer drivers were highlighted in addition to parking and access issues for those who do drive.

'Further to travel if the specialist hospital is further away or if the hospital where you continue your care is further away, how will family support you?'

'People/patients can feel isolated if specialist centre is too far away to visit'

'Car parking is horrendous in hospitals as well as paying to park'

‘It is difficult to travel further and costs more money when we rely on a pension.’

‘James Cook is bordering on inaccessible for people with complex neuro needs because of lack of transport, parking difficulties and repeated cancelled appointments’

Concern was widely expressed around families trying to visit- distances and access to transport & car parking fees:

‘Local hospitals are important to people living in the local area. Families/patients can get to them easily. Having people who care being able to visit can vastly improve life chances. Patients to do not feel isolated or depressed. ‘

Concerns were expressed about distances to access emergency care and the strain on ambulance services already overstretched:

‘Paramedics – they need to know travel distances and where to send people. Paramedic’s knowledge is extremely important and they also need to be available to transport you.’

However, some groups felt that as long as you could be triaged in an ambulance, it would not matter if you had to travel a bit further.

Services:

Below are a selection of comments on the perceived impact on hospital services:

There were a number of concerns expressed around the potential loss of A & E departments at local hospitals, particularly from Darlington groups:

‘Don’t wish to lose the local hospital’

There was concern that NHS hospitals were already overstretched and have staff shortages and these proposals could make things worse:

‘More pressure on staff and resources’

‘ What happens if no specialist beds available’

‘How will this happen if there is no more money?’

‘Accident and emergency is a concern if you have to wait 12 hours to be seen’

‘Hyper-specialisation will deskill a lot of secondary care staff who will not look after the person as a whole.’

However, some felt that specialist hospitals would improve services:

‘Specific specialist help would be improved - The group liked the fact and hoped that in future parents would still be able to stay with a child in specialist care.’

‘If the hospital is properly staffed then having consultants there 24/7 could be a good thing.’

‘It is very important/good idea to have centralised services and experts.’

‘Older people do end up bed blocking as can’t go home. If there had been proper respite care rather than hospital for my mother it would have been so much more suitable. My mother ended up in hospital for 6 months. I hope BHP will improve care for elderly people and bring them home for care.’

Public Awareness & Information:

There was a common view that there needed to be a public awareness campaign and more information on where to go and how to access different services. Wide view that the current range and complexity of services was hard to navigate:

‘People will need to be educated about where to go for which services as many still struggle when to use 99 and 111 or walk in centre or urgent care centres and when they are open and when not open’

‘People don’t know where to go now so how will new system be different and how will you inform people so they know when they are in crisis?’

‘The group felt that it would be important for the Community to know the details of the changes when they are decided with translated leaflets etc. Older people particularly would need to know and this will have to be through other methods than just leaflets as reading is an issue.’

'Gypsies and travellers only know and use A&E departments. They do not understand the wider health provisions and will not be engaged by traditional methods'.

'Lots of barriers caused by culture, language, childcare, transport'

Question 3. What effect do you think it will have for your GP and community services?

Discharge

There were a number of concerns expressed about continuity of care and support on discharge and the need for greater capacity in the community if people were to be discharged earlier:

'Specialist centres – how would you cross over into Local Authority areas? You would have to make sure that there is knowledge and liaison between medical teams, discharge teams and community resources. It is difficult already going into hospital in another area as resources do not link up when you get out as information is not shared. This could make it worse.'

'Communication between hospitals and community services is not good now so with extra pressure how will it cope.'

'If medication can be gained from local pharmacists – particularly on discharge this would speed up the process as people have experienced discharge delays due to waiting for medicines being dispensed by hospital pharmacy.'

'The group was very concerned about older people being released from hospital without the appropriate support. It was felt that the move to support people within their homes would be a positive move with the caveat that this support would have to be properly co-ordinated between hospitals, GPs and social care services.'

'Need qualified staff to provide quality care in local area and they need to look at how this provision is currently met as some of this is not happening.'

‘People can’t survive at home without proper facilities like ramps, beds, shower aids. They need to be well looked after. They are sending people home when home isn’t ready. This is not a good idea. Resources must be in place for your discharge.’

Access to Community Services

Common concerns were expressed about access to community services and the lack of capacity currently:

Bad communication & availability of community services

People are already struggling in the community with very little support

GP already at full capacity who will run these hubs?

Community services very inconsistent. People have experienced poor after care and felt until this was addressed nothing else would improve and bed blocking would continue.

Community care is at breaking point already.

‘My GP knows nothing about Stonham or rest of voluntary sector groups. No communication now so will it be better because of BHP or will it just be about hospital and GP services again?’

Community staff are so pushed for time how will they manage so many more people.

‘Not enough of the right community services. Want more day services to help with mental health issues.’

‘It was generally felt that if other services could be accessed from their GP surgery or the “hubs” then they themselves and their families would find it easier to access them. They would also welcome other trained clinical staff taking on GP roles.’

A number of Hartlepool group respondents felt that The One Life Centre in Hartlepool was ineffective and ‘should be closed and put better services in the hospital’

However, groups felt accessing appropriate health services in local GP surgeries and “hubs” was considered to be a positive and welcome move if capacity was strengthened:

‘Hopefully will help more access nearby as most people who have had a stroke are unable to drive so local hubs would be better’

‘The changes will hopefully see linkages with appropriate services such as physios/OT’s, voluntary and community groups such as the Staying Put Agency (equipment for the home etc) and smaller community groups/charities and self-help groups’.

‘Need to involve expertise of the voluntary sector who often provide needed support for marginalised community members such as our community members’

‘More pressure on voluntary services even though there has been loads of cuts on the wrong services already’

‘A lot of people come to voluntary sector for care as it is not there elsewhere. Voluntary sector hasn’t got the money to pick this up’

‘Anything that makes getting several people together in one place for my autistic child is a benefit’

‘Does GP service know all the community services to be able to signpost? I struggled to find the women’s refuge’

‘Hindu men are too proud to ask for help and so obtaining these services in the community would be good. The Hindu Centre used to have sessions for measuring cholesterol levels, diabetic nurses etc, but these stopped sometime ago. This is also true if men are discharged from hospital – often they will not identify themselves as needing support or help. Professionals need to understand this’

Access to GP Services:

The majority of groups felt that access to GP’s was already challenging and could get worse if BHP proposals were implemented:

‘Transport was a huge issue; some women have to change buses at least twice in order to get to an appointment (rural)’

‘Longer waiting times for appointments’

‘It is already problematic accessing GP and community services – it will make things much worse!’

‘GP’s should be the first port of call but you cannot get an appointment for 3 weeks’

‘They were concerned that overstretched GPs could not cope with extra services unless extra staff are employed – and not just clinical staff, but also administrative staff who could run effective appointment systems’

‘Currently there are difficulties getting appointments with GPs, so if there isn’t investment in getting new GPs and surgeries in general then it is difficult to know how this will improve services.’

‘There is an initiative to train 25% more doctors nationally, but these won’t be fully trained for another 7 years, so what happens to this programme until then.’

‘Could have more pressure on our GP’s but if our GP knows where to signpost to these community services this could benefit patients’

‘Members stated that they struggle to get timely appointments now and are concerned that it would take longer to get an appointment’

‘Six attempts to gain appointment to see named GP’

‘GP is really not proactive now. Usual prescriptive messages but absolutely no awareness of services available outside of the practice so people can make a choice, decision or help themselves’

‘Gypsies and travellers need to be engaged carefully and appropriately so that they use facilities such as GP surgeries’

‘Triage at GP practices: The group made this a first priority because they believed services should be streamlined from GP practices’

Question 4. What impact (positive or negative) do you think changes to hospital, GP and community services might have on you, your family, carers and your wider local community?

A representative selection of feedback and comments from groups is set out below:

‘There is confusion at the moment as to what the roles of different NHS services are e.g. walk-in centres, urgent care centres, one-life centre, and GP surgeries. More details on the changes need to be given before views and opinions can be given. For example, if a person has been admitted to the regional trauma centre what happens when the person is recovering? At what stage are they transferred back closer to home – if at all? And what provisions will be made for family and carers to visit the person if they don’t live locally? If this is not considered many patients may end up with no visitors from family and friends which may have an impact on their recovery’

‘Lots of worries about travelling to and from appointments. Concerns about parking and petrol costs. Ambulance issues already, this will make it even worse’

‘The changes may mean more travel to and from specialist hospitals for both the patient and their families. In urgent care situations there would be less of an impact as those attending suggested they would want to be treated in the best place possible – wherever this was located. However they will have to be convinced that decisions by paramedics etc will be the appropriate ones’

‘Isolation from age, chronic illness, living alone, not having access to a car, create a situation where you dread appointment letters because of the extreme amount of energy and cost it takes to attend’

‘Everyone felt that the new changes would only add to the pressure for carers and families as they will be expected to pick up the slack with hospital visits and community transport. Who will fight for those who don’t have families?’

‘BME communities know how to get to local hospital but are not confident using public transport anywhere else’

‘Transport and expense also came up as to how people will be able to visit regularly and that without regular family support a lot of patients will suffer emotionally’

‘The group were supportive of providing support and services either into people’s homes or within easy access as long as these services were planned, integrated and delivered by appropriate staff. The benchmark of current provision of social care in people’s homes is skewing people’s confidence in this move, i.e. people cannot distinguish between 10 minute calls from carers and provision of community health services’

‘The group agree that it will be a positive to have appropriate services provided both in community settings and in people’s homes provided that there is sufficient support available and that family and carers are also supported. People in the community will accept these changes if they prove to be beneficial’

‘More strain on community services. Who’s going to look after the hubs and keep them in order? Travel expenses to a specialist hospital, especially for families on low income. Communication is poor at the moment’

‘Hindu - Social services and care services need to be reviewed alongside this Programme. Social services do not have a good reputation in some communities so there would be some distrust of these services linked to discharge from hospitals. The experience of some of the group was that either they did not know of any home support services or that these services were limited. Also older people like to have the same and familiar carer for their welfare’

‘Care at home :I think for people like myself with different background who has no relatives around themselves would be more difficult if they are supposed to be treated at home as they might not have any family to support them during the time when they don't receive immediate care”’

‘Carers will have much more work to do, people will be out of hospital sooner so the pressures on carers will be greater, especially following initial discharge’

‘The consensus here was that no-one would really mind if anything worked properly. Everything is about cutting services to save money but if it was reinvested to make community services work better no-one would mind and would save money longer term. People just want to know what they need to be doing and the lack of meaningful communication means people are very frustrated at how much time it takes to get the right person who is able to make a decision’

All in One Youth: Young people:

Positive: There will be better care due to specialist clinicians being together in one place. Also all modern equipment will be located in this hospital.

Care for patients will be continuous with all professionals aware of the persons needs. There will be a smooth transition from hospital to home.

Extended GP and Community Services are a positive and will be beneficial as long as funded and integrated.

Family Help Network:

Positive – The community hubs could have a more person centred approach and community spirit. Could stop using up hospital time and money. Have people from different organisations on hand instead of getting treated at hospitals and then getting signposted to them.

More services in the community will mean people do not have to travel as far for less serious appointments and follow ups.

Negatives:

Hospitals: The issue of distance. Too far to travel leads to a decline in health during travel and leads to higher death rates. Makes it difficult for family and friends to visit if the hospital is further away. Transport is a big issue.

What about single people with children, if they need to go to hospital, how will they arrange childcare for other siblings etc.

Community Services & Hubs - If not planned appropriately and funded then GPs and other professionals will become stressed.

Question 5. General Comments:

‘The BHP is idealistic and not realistic’

‘If there is not enough staff or money now it does not matter what they say in the video it won’t work’

‘Many felt cynical’:

- Felt it has all been suggested before
- decision had already been made
- Felt to be unrealistic

‘People don’t use A&E properly now so how will they learn where to go for what and in which circumstances. When you are in a crisis situation your brain doesn’t think logically but just about specific factors so it needs to be simple to remember’

“In theory it sounds like a wonderful idea…but in practice”, the group were very doubtful as they felt that there is a lack of infrastructure to support the local community and communication is not effective’

‘Most of the group felt that there was a danger of not treating the whole patient if services became too specialised and that often there is a need for multiple specialism’s in the treatment of a patient. They all expressed concerns about the ability to resource services at all levels, i.e. specialist, community hospitals and GP services as there was consensus that current GP services are fully stretched but that local community hospitals are under used’

‘Lack of funding is a worry as there doesn’t seem to be money attached to BHP’

A Number of people expressed a view that people who don’t turn up to appointments should be fined.

Carers have to work and caring has an impact on their life and health. BHP need to consider the impact it will have on carers. Not enough is done to support carers’

Access to services

‘Voluntary Sector provide a lot of unseen and unsupported services for people with mental health issues and barriers. Mental Health voluntary support groups should receive mainstream funding’

‘Understanding for Mental Health should be an integral aspect for BHP as it underpins the rest of our health. There are real problems with lack of access to Mental Health Services. Particularly crisis situations’

‘People feel generally frustrated at being able to get around and access services when visually impaired’

‘NHS service should be accessible and they are not for everyone. Will the specialist centres and community services put accessibility as a priority please?’

Travel:

‘Transport is still not going to be good as the shuttle bus can take up to 2 hours to get to the hospital depending which one you go to and you have to remember that you have to travel to either Peterlee or Hartlepool hospital before hand to catch the shuttle bus. One lady gave an example of when her husband had to go to Hartlepool hospital for a week, the cost was £6 per day (£42) in total’

‘Whoever dreams up these schemes does not have to catch 3 buses to attend an appointment. Living alone on a state pension is terrible when you need monthly injections at hospital to stop you from going blind. Wish they would do it at my GP’s’

‘When undergoing chemo transport is critical as we can’t drive afterwards and we don’t all have family and friends close by to take us. Getting a bus after a session can make you very ill waiting around in the cold and damp’

‘Long waiting times for ambulance’

Hospital:

‘Lots of people wasting time in A&E now because they can’t get an appointment or don’t know where else to go’

‘The NHS cancels appointments to stick to targets and this is very frustrating for people who rely on others for transport, especially if the person has had to take time off work. Accessing hospital transport is nearly impossible even if you live alone. One person in

the group had 5 appointments cancelled and then was told off by the clinician for not being seen for nearly a year instead of 6 months.

'There should be more right to choose where you can have your baby. I had to fight for a home birth and had to be assertive to get it. I was told if there was no midwife cover then I would have to go to hospital which is not what I wanted. I have more than one child so know the process'

Discharge procedures need to be improved with family considered more and professionals (hospital staff, social care staff, district nurses) working together more than they are currently. People are scared of the gaps in discharge, but if the changes mean that patients are transferred from hospitals to "home" or community provision in a manageable way and not when there is no support available then it will be good. If it also stops early re-admissions particularly from older people then this would be a positive. Experience of this stroke group is that often those with strokes often have to be re-admitted to hospital and this again begins with another trip to A&E. If an alternative pathway could be established through community or GP services or even through the specialist stroke ward, then this would be a positive change. Also if the after-care for people with strokes is put in place through community services then people would prefer to stop at home rather than be re-admitted to hospital.

As soon as the treatment is finished (Chemo) there is no support after for the patient and hopefully BHP can implement this by liaising with other sectors

Integration/communication between health and care services:

'No reality between Physical and Mental Health services. Poor understanding of co-morbidities and how many appointments you have to attend'

'The group were keen to express their experiences over complete breakdown of the relationship between Health and Social Care, publicity was all about Integrated care. They felt reality of Integrated services was a long way off unless the NHS stopped gate keeping and stopped the messing about with service redesign just to suit commissioners'

'Need to link social care with health care far better and this includes digital data systems'

‘GP: There is too much emphasis on duplicating everything from hospital clinics. GP’s repeat blood tests for diabetes done at the hospital. These could be done at local level and shared. Nothing is done to prevent or stop you deteriorate, annual reviews would at least give you some chance to consult with a GP’

‘All systems and procedures need to be reviewed and integrated including the 111 telephone system’

Community Hubs:

‘Hope this is not just about cost-cutting but a real realignment of services which can be properly staffed and importantly, co-ordinated’

Recognising services had to be re-shaped the group felt aggrieved that Hartlepool was not given what they needed. One of the key priorities for this group was access to specialists closer to home, either at the hospital or clinics at the One Life Centre but only if the NHS ran the One Life Centre, not as it was now.

‘It is better to recover in own home but only when care is there and presently it is not’

‘What about a mobile community care hub like the mobile library?’ (rural group)

‘Many more services should be in the community as part of a prevention programme that relates to the needs of real people, not hospital numbers’

‘Before the actual changes take place the support in the community around discharge and support in the home and community needs to take place. Also GP services needs to be improved so that people have confidence in the changes’

‘We definitely need more nurses out in the community who can keep an eye on older people better and not let things deteriorate badly before people are treated. If this could happen people would not need to go to hospital so much’

‘Could do with more mobile services visiting the Dales rather than having them in one place. Minor injuries for example could you have one session each day or a couple of days at each GP surgery and then move it around the area’

‘The One Life Centre was a good idea but at the moment is better off shut. All they do is call an ambulance anyway which is often not needed. They pass the buck all the time and never give you any respect.’

‘The walk in centre at Peterlee is not functioning properly at the moment. Services are moving to the general hospital’

Question 6. From your discussion, what three things did group members think were most important?

Facilitators worked with the groups to draw out the three main things the groups felt were most important. Key representative feedback is set out below and primarily falls into three categories:

1. Transport and travel

Transport for carers and families – need to ensure that there are adequate schemes in place if changes are made

Travel for patients and family members is the most important issue that needs to be looked into as a priority.

If hospitals are changed to specialist hospitals this will ultimately lead to longer travelling time for family members and carers. This needs to be considered as older and vulnerable people may suffer due to this (with no visitors etc) which would prolong their recovery.

Joined up transport system which include public buses, community transport to include vetted taxi firms and plenty of free parking is essential if looking at putting things into central hubs

Local people are resilient and realistic and know about travel but feel they can’t travel any further than they do now without it being detrimental to the final outcome, especially in an emergency situation (Teesdale)

Not everyone drives, has access to a car or can be given a lift so consider these people

Transport – reduction in parking costs.

Parking is expensive at hospitals and often no spaces

Transport for Relatives to visit and then people going home after a stay in hospital if not near home.

Transport for family members and numbers of ambulances

Travelling or parking can both be very difficult at present. Will this be taken into consideration with future plans?.

Public transport is ok during the day but not on evenings and weekends so what happens when you need services then?

Patient transport is important for people who don't drive or have people to drive them there.

Taking my autistic daughter on public transport would be impossible unless I had support.

Epilepsy Group: Hospital transport is inaccessible and unreliable if you cannot drive. No-one could afford a taxi to James Cook and back.

Ambulance Services:

Ambulance services are already under great pressure

Transport for patients – Need to ensure there is a strong service and enough ambulances

Ambulance service? Will it be able to cope? What will happen to the golden hour?

Need to improve waiting times.

Currently the way the ambulance service is manned, will they have enough vehicles to manage, especially if they are taking people further away?

Ambulance services need to be reviewed in light of delays experienced.

Concerns regarding the ambulance service and how far it has to come, paramedics are out of the area and don't know roads and farm tracks.

More funding for the Air Ambulance was mentioned every time as it is not core but local people feel it should come from central funding (Teesdale)

The presumption is that James Cook Hospital will be the Regional Trauma Unit and be developed further. Makes sense to centralise equipment/staff, but still a concern about travelling from outlying areas. Ambulance and other transport services need to be developed appropriately. Also invest in paramedics – aware voluntary organisations used (St.John's ambulance etc), but are these trustworthy?

Speed that people would access the right treatment from the right staff was seen as a good step forward on paper, lots of concerns as to whether this can be done, but the idea was met with positivity.

Most people who have been through domestic abuse and moved to a place of safety have no car and worry if they will be recognised on public transport. This needs consideration if the person has mobility barriers or other health needs as travel and access are vital in helping that person gain the treatment and service when required.

2. Communication, capacity and skills across services

Hospital:

Actually being able to staff the specialist hospitals 24/7 realistically and efficiently

Only if all hospitals have appropriate equipment, staffing and access to patient details will this work.

Hospitals deal with medical needs but not with emotional or social needs. Social interaction for those following a stroke is very important

Future of A&E at DMH

Communication and continuity of care:

Communication, can the services between hospitals, rehab, community services and GPs stand up to the huge increase in demand that will be needed.

Great communication between services – joining up services

Improve communication between services and increase capacity locally and in the community first

Sharing data is essential but it has to be confidential and only with people who are delivering the health care

This was referred to a number of times as the group felt that communications within the NHS were hopeless, faulty and bordering on dangerous because of buck-passing and lack of accountability.

Lack of communication with family and friends at all levels of the pyramid. Lots of organisations working together – they need to communicate better as it is poor already without the additional load this new systems will bring.

Community capacity and resources :

Concerns regarding care in the community or discharged to home without adequate support, will there be enough trained staff to make the proposals work

Accessibility and availability especially with GP's and aftercare. After care – there should be uniformity of care. Quality standards of care.

Have community services in place before changes are made to get rid of the backlog and to have them running successfully before trailing new things

Integration of support services (social care, GP services, community services and voluntary/charitable and self-help groups) should be planned before the changes occur.

There also needs to be far greater awareness of what parity means and community staff need mental health awareness training. At the moment mental and physical health are kept apart and separate so there is always a delay in getting appropriate care.

Proper follow ups following a stroke. Good physio at home. Need consistency of staff, we often see different people every day

The use of community centres to provide appropriate health and social care services is supported by this group and they would use these services.

In Teesdale- Local people go to the Richardson for specific treatments but feel it should be a community hub

Pressures on GP and Community Services

After care services and discharge procedures need also to be a priority.

Older people in particular should not be discharged from hospital without correct support in place.

Continuity of care from hospital to home should be a priority in the proposals.

Moving out from Hospitals into the community means more people like care coordinators or nurse practitioners need to be available and able to make decisions quickly for prescriptions, supplies, equipment or aids or liaise with other services.

Community resources are already under a lot of pressure. They can't cope with more people without extra funding and resources

Involve third sector and social services so centre around patient needs first

GP's :

would they be able to cope, would these proposals make the wait for an appointment worse – could IT help (but issues re lack of coverage in East Cleveland)

Much about the changes made sense but the group felt unless GP practice capacity was addressed, the system would implode

A reduction in waiting times for GP appointments – easier access.

Getting a GP appointment is already difficult so if all services come into a hub then surely this will make it more difficult?

Emphasis on the community. We can't get in to see a GP at present.

Important to be able to trust doctor and to see the same one. Someone with health issues does not want to be passed around to access all the care that they need.

the group felt strongly that GP's needed more nurse practitioners who you could get to know and who be available to see.

Staffing levels:

It is impossible to implement without more qualified, knowledgeable, experienced and willing staff.

For Better Health to work you will need more better trained, qualified and caring staff in all sectors

Staffing and retention policies to train and recruit appropriate staff should be a priority in these changes.

Staffing – Stress, more pressures on them, fear of a reduction in morale

Essential that the services that are going to be available in the community and at GP surgeries are properly staffed, equipped and accessible to all within a short timescale.

Qualified staff providing care in the local area. Need to ensure that this is sustainable and is working adequately before making changes

Some of the greatest problems in the NHS are lack of suitably skilled, informed staff. Community services could be far more efficient with more pairs of hands who were able to make decisions and get on with the job.

If BHP is to work then more service providers need more holistic knowledge as well as their specialism as most people have more than one condition. This is especially so for cancer patients as often we have conflicting information.

3. Awareness, education, access & information

Awareness & education

Need to educate the public as to what services to use when. We need training for professionals and education for the general public. Professionals need to learn from those who have lived through the experiences.

Before these changes take place an education campaign needs to occur so the general public understands which services are used. People need to feel confident in the new systems – people are scared now that the NHS is failing.

Timescales – people in the community are unaware of these changes so this group suggest that the consultation/awareness raising takes place over a long a period as possible rather than rushing the proposals.

People feel very confused as to what is out there and what they are eligible for.

Education and awareness raising will be critical. We are not sure where to go now and only really pay attention when there is a crisis.

Making it easy to decide where to go in a crisis (GP, hospital, 111)

Education/Training about where to go and when. Who provides what service etc.

Asking for information can be quite intimidating. Supermarket might be good idea to get information from.

Digital records: Need to have option for all information or specific information to be available to be shared across all health providers in a confidential manner so service user doesn't need to repeat their story or information. E.g. mental health needs, medication needs,

People are never given right time and place information to make decisions or manage their healthcare.

A lot of the problems in the NHS are lack of explanation and technical language. People tend to hear different things from different people and become confused over what they should be doing.

Access for minority groups and interest groups:

Information about services which operate after hours is essential especially for mental health and crisis situations for both the service user and the people who are supporting the service user.

Language, physical access, support mechanisms such as interpreters and confidence all need to be central for local health services as many ethnic minority women don't feel able to access local services.

The group said translation from Chinese dialects into English and back is a big concern and acts as a barrier when trying to make appointments with hospitals and surgeries so puts them off trying. the elderly members said they could only access health services if a family member attended with them.

General feedback included requests from the group to consider translation machines in GP surgeries and hospitals for appointment bookings.

Language barriers already take a long time. Language line leaves communities in Darlington frustrated. The dialect used is a much 'posher' one than the communities use and sometimes people feel 'looked down on.' (Bengali focus group)

Ethnic minorities are not sure or aware of breast screening/menopause.

GP full of generic leaflets but if you have a mental health impairment or learning disability such as dyslexia you stand no chance of being able to read any of them. If you ask for something accessible you are ignored because they do not know what that means.

Learning Disability/Autism:

Where a person needs to have their own (paid) support with them in hospital it could cost more than the current support package in place (i.e. to cover staff travel time to/from the specialist hospital or to provide 1:1 support to a person who doesn't always have this).

Will there be enough learning disability nurses available at specialist hospitals.

'If I was in an ambulance I would want my Dad to come with me'.

A number of comments about health professionals being hard to understand (what is said to them) because they talk too fast or they have heavy accent.

It was generally felt all staff (health) and support staff should have some/a better understanding of autism and learning disability

Visual impairment/hearing impairment/deafened

The lack of suitable information and regular information for visually impaired people came out time and time again especially about letting people know what BHP is and what it will do.

'Doctors don't know sign language. It's annoying when appointment letters are not in an accessible format; they won't email because it's not safe and secure but will allow online ordering of medication. Email or text notifications would be better for people with visual impairments. Only find out about services through word of mouth.'

Joining up of safe digital information systems is needed to help people who can't communicate.

Accessing services after 5pm for a visually impaired person has immense restrictions if they don't have family or friends to transport them as public transport is not available and services are usually a good travel.

Specialist hospitals don't get it right – for example the eye hospital sent out ordinary letters to people. They do not use the correct format such as audio and Braille.

It may be helpful to be asked, 'In what format would you prefer to receive the information?' or 'How would you like to be contacted?' – Text reminders of appointments should be used more.

Interpreters are essential for all deafened people regardless of where the service is provided

Plain English - Many deafened people have limited vocabulary so plain, concise and jargon free language is vital during appointments, consultations, treatments etc

There is a lot of information out there which many deafened service users are unaware of as leaflets, radio campaigns, and posters are unhelpful for deafened community members.

Disability

GP services were generally very hard to access if you had a physical disability and could not wait 3 weeks for a non-urgent appointment.

Epilepsy Group: Always an assumption that you drive but people with uncontrolled epilepsy cannot drive and always have to rely on someone else or public transport which is unreliable. If you have a limited income with a health condition now you are sent round all over by people who do not care or how much it costs.

The group wanted to support other people in similar situations and felt the NHS could do more to refer people to community groups where they could access support and information without fear of being judged.

There is no Neurology Department at North Tees Hospital and the group felt there should be outreach clinic at Hartlepool to help people who could not drive or who lived alone and had no-one to help them get to clinic appointments.

Gypsies & travellers

Gap in knowledge and understanding of what health services are available in general by gypsies and travellers. They are aware and use main services such as A&E and maternity services, but are unaware of what support they can get for things like caring for older people, Alzheimer's etc

Access to care in custody- A lot of discussion about vulnerability, lack of interpersonal skills and lack of eye contact by health professionals led to this priority. Proper healthcare when in custody or on remand was very fragmented and when services felt like it not the person needed it.

Victims of domestic abuse

Many of the domestic abuse service users felt some services needed to be taken to safe hubs as well as community hubs such as smoking cessation to the women's shelter or home visits for counselling if on a protection programme etc

BME/Dementia/Older

AAPNA –(older Asian males who have early onset dementia) This group of users have a high level of trust with their own GPs and are even reluctant to use other GPs in their practices. This is the same for other specialist clinicians they have seen If changes are made then this group will need extra support in both understanding these changes and in trusting that they are getting the appropriate services

5. Lived Experience Case Studies

In addition to the feedback submitted from groups, we had 4 individual case studies submitted from various group sessions as follows:

Lived Experience Individual from LGBT group

Hospital services

Endorsing the general view that communication between Health and Social care was currently at a very low point, Mr A reported on a circumstance over care of terminally ill people whilst supporting a parent through cancer. The NHS did not offer information about therapies or other services. By chance, the family sourced information on services available through Macmillan Cancer Care which also led to a therapeutic intervention that made a huge difference to the overall ability to manage a rapidly deteriorating condition.

The NHS did not offer support at source where families can most benefit from right time and place information. There is no onward referral and the family did not receive any respect for the role they were adjusting to.

Lived Experience Individual from neurological condition group

Ambulance Patient Transport

Mrs B lives with ME and 4 other co-morbidities, a wheelchair user who lives alone and cannot drive.

She needed regular appointments at a clinic only offered 30 miles from home. She was waiting for ambulance transport to attend the clinic when the Ambulance stopped for an accident en route to fetch her. The Ambulance service contacted her to say they would be late. Mrs B said that was no good and had to contact the clinic to say she had no transport. She was advised to cancel the appointment which she did but the Ambulance turned up anyway. She then received a letter from her GP explaining that as she had not attended the appointment it would be registered as a deliberate 'not attend'.

An appointment was rearranged and the Ambulance transport service arrived 15mins before the appointment time, presuming travel was to the local hospital. They needed 45minutes travel time. They had not read the log before the journey. Mrs B has missed several appointments because of this lack of scrutiny.

She had to chase the issue for some time in order not to be labelled a 'serial offender'.

Lived Experience

Individual from ARC Staying out group

Sensory loss awareness

An 80-year old lady with acute hearing loss had a stroke with short term paralysis on one side. Widowed and not able to drive, the lady tried for 4 days to access a GP by asking a neighbour to help make an appointment to check 'dizzy spells'.

The only appointment for 3 weeks was a telephone appointment. She was unable to use the telephone at that point and was then offered an email contact to arrange an appointment in the future. There was no recognition that she did not have a computer or mobile phone. The receptionist was very unhelpful so the lady gave up.

A week later the lady fell through a dizzy spell and broke her arm.

Lived Experience Individual from LGBT group

Co-morbidities in young people

A person with adult-diagnosed Type 1 diabetes also had a genetic condition and 2 other co-morbidities with chronic depression. The person had disengaged with NHS services because of poor professional attitudes shown, there was always a level of blame towards obesity. Health care was arbitrary with no connection between physical and mental health. Services were fragmented with communication either non-existent or patients were referred on with no consultation notice or support. Clinic appointments were often made on the same day or cancelled several times yet they were a young person trying to maintain employment.

The person recognised the lack of understanding contributed to poor self-esteem and confidence. NHS professionals needed to be proactive about moving people to recovery programmes which could prevent further diagnoses in later life. There is no impetus to understand the impact of co-morbidity or stop people deteriorating.

Appendix A

Partner Organisation	Combined Feedback Form number	Groups	Description	Beneficiaries	Geographical area	Number of people attended
Redcar & Cleveland VDA	86	Ladies of Steel	Community group initially made up of the wives of steel workers	Gender specific - women	Redcar & Cleveland	10
	91	Living Sober	Addiction Recovery & Family support group	General public - carers	Redcar & Cleveland	12
	93	Dormanstown Community Sport and Social Group	Community Sport and Social Group: Umbrella group for a number of sports with strong disability focus.	General public & Disabled people	Redcar & Cleveland	14
	88	53' Society of Amateur Dramatics	Community theatre group	General public	Redcar & Cleveland	18
	89	Saltburn Scouts Parents Group	Parents Group	Children, Families and Young People	Redcar & Cleveland	10

	87	The Old Co-Op Building Loftus Community Group	Community hub in East Cleveland	General public	Redcar & Cleveland	12
	2	Helping Hands	Luncheon Club	Older Disabled people	Redcar & Cleveland	18
	85	Friends of Westfield Farm	Community group - ecology focus	General public	Redcar & Cleveland	10
	92	Guisborough Bridge Discussion	Mixed	General public	Redcar & Cleveland	16
	4	Saltburn Arts Group	Arts Group	General public	Redcar & Cleveland	15
Catalyst Stockton	14	Epilepsy Outlook	Epilepsy Support	Disabled people	Hartlepool	15
	22	Hartlepool Families First	Young People	Young people	Hartlepool	8
	15	Home Group Project	Homelessness / Ex Offenders	General public	Hartlepool	3
Catalyst Stockton	**18**	Age UK Teesside	65+	Older people	Stockton	**7**
	16	Staying Out Group - ARC	Arts/Older People	Older people	Stockton	**14**
	23	Focus on Vision	Sight Impaired	Disabled people	Stockton	**8**
	19	LGBT - Catalyst	LGBT	LGBT	Stockton	**5**
	24	Stockton Over 50s Forum	Over 50s	Older people	Stockton	**12**
	20	Little Sprouts Cafe	Parents & Children	Children, Families and Young People	Stockton	**5**

Women's Commissioning Support Unit	**73**	Aspire Learning, Support and Wellbeing CIC	Women's Groups	Gender specific - women	Durham	12 females ages 24-69
	79	Wear Valley Women's Aid	Women's Groups	Gender specific - women	Durham	8 females ages 24-58
	77	Diverse women's Network	Women's Groups	Gender specific - women	Durham	11 females ages 25-60
	84	Allington House Young Women's Group	Women's Groups / Youth	Gender specific - women	Durham	4 females
	72	Allington House Women's Group	Women's Groups	Gender specific - women	Durham	5 females
	74	DASH Durham	Women with complex needs	Gender specific - women	Durham	5 females ages 20-39
Women's Commissioning	**80**	A Way Out - Stockton	Women at risk of sexual exploitation	Gender specific - women	Stockton	8

Support Unit						
(Tees Valley)	**81**	My Sister's Place - Middlesbrough	Women at risk of sexual exploitation	Gender specific - women	Middlesbrough	9
East Durham Trust	**39**	Dawdon CA Youth Group	Young people 16+. Incl. Disabled people	Young People / Disabled people	Durham	10
	41	Horden Heritage Group	Mixed	General public	Durham	10
	42	JPEG (Joint Photography Easington Group)	Primarily older people	Older people	Durham	10
	43	Peterlee Methodist Church Ladies Circle Focus Group	Primarily older women	Older people / Gender specific: women	Durham	10
	37	B12 Group	B12 Deficiency Support	General public	Durham	25
	45	Shotton Women's CREE	Womens' group	Gender specific - women	Durham	20
	38	Blackhall WI	Women's' group	Gender specific - women	Durham	10
	40	Eastlea IT Focus Group	Mixed	General public	Durham	4
	44	Seaham Physical Disability Focus Group	Mixed including members with physical disabilities	Disabled people	Durham	11
	46	Wheatley Hill Mothers Club	Mothers	Gender specific - women	Durham	45
Stroke Association	64	County Durham Stroke Club	Stroke Support Group	Long term conditions	Durham	24
	68	Positive Strokes Club	Stroke Support Group	Long term conditions	Durham	20
	62	Pelton communication group	Stroke Support Group	Long term conditions	Durham	7

		2				
	63	Communication support group Durham	Stroke Support Group	Long term conditions	Durham	7
	67	Newton Aycliffe Stroke Support Group	Stroke Support Group	Long term conditions	Durham	4
	70	Wingate Craft Group	Arts Group	General public	Durham	13
	71	Wingate Mothers Group	Mothers	Children, Families and Young People	Durham	8
	66	Happy Talk	Stroke Support Group	Long term conditions	Durham	18
	69	Stroke Prevention Group	Stroke Support Group	Long term conditions	Durham	9
	65	Grandparents Durham	Grandparents	Children, Families and Young People	Durham	9
Tees Valley, Durham & North Yorkshire Neurological Alliance	**17**	**TVDNY Pain Group**	Neurological conditions	Long term conditions		18
	21	**TVDNY multi-neuro FRIENDS group**	Neurological conditions	Long term conditions		18
Age UK Darlington	**1**	Autumn Years	Older people	Older people	Darlington	25

	6	Carers Club	Carers	Carers	Darlington	24
	12	Stroke Club	Stroke Support Group	Long term conditions	Darlington	32
	7	OLGBT	Older lesbian, gay, bisexual, and transgender	Older LGBT	Darlington	5
	13	Veterans Café	Veterans	Older people	Darlington	28
	5	Branksome Lunch Club	Older people	Older people	Darlington	18
	8	Elm Ridge Lunch Club	Older people	Older people	Darlington	24
	9	Corporation Lunch Club	Older people	Older people	Darlington	22
	10	Skerne Park Lunch Club	Older people	Older people	Darlington	5
	11	Zumba	Older people	Older people	Darlington	8
Healthwatch	3	Chinese Association	Chinese Community	People of a particular ethnic / racial origin	Darlington	7

Darlington	48	Bengali Community	Bengali Community/Women	People of a particular ethnic / racial origin/ Gender specific women	Darlington	11
	50	Darlington BME Project - Healthwatch	BME	People of a particular ethnic / racial origin	Darlington	16
	52	Polish Community	Polish Community	People of a particular ethnic / racial origin	Darlington	6
	90	FReNDS - Family Resource Network Darlington	Parents/Families	Children, Families and Young People	Darlington	5
	53	Stepping Stones	Post Natal Group	Children, Families and Young People	Darlington	7
	49	Borrowed Angels – Support Group	People affected by miscarriage, pregnancy loss, still birth and infant loss	General public	Darlington	4
	54	Tea and Toast Group	Mixed	General public	Darlington	7
	51	Ladies Night	Women's' group	Gender specific - women	Darlington	7
	47	Baby Lounge	Parents	Children, Families and Young People	Darlington	12
Middlesbrough MVDA	**56**	Breckon Hill Community Enterprise	Mixed	General public	Middlesbrough	11
	60	Tees Stroke Club	Stroke Support Group	Long term conditions	Tees Valley	28

	83	All in one youth project	Young people	Young People	Tees Valley	17
	59	SPARCs (Travellers)	Gypsy Roma Travellers	People of a particular ethnic / racial origin	Tees Valley	9
	61	Tees Valley Chinese Community Centre	Chinese	People of a particular ethnic / racial origin	Tees Valley	43
	57	Hindu Cultural Association	Hindu Community	People of a particular ethnic / racial origin	Middlesbrough	17
	58	Kinship Carers – Middlesbrough	Carers	Carers	Middlesbrough	14
	55	AAPNA Services	BME/ Asian males with early onset dementia	People of a particular ethnic / racial origin / Long term conditions	Middlesbrough	12
	82	Branches	(Substance misuse carers)	Carers	Middlesbrough	11
	94	Straightforward- English for speakers of other languages group	BME	People of a particular ethnic / racial origin	Middlesbrough	12
Durham Community Action	**76**	BID services	(deafened, hearing impaired and some with learning disabilities and deafened)	Disabled people	Durham	6 females

33	Stonham	Mental health	Disabled people	Durham	5 males, 6 females ages 26-65
29	North East Autistic Support Toddler Group (NEAS)	Autistic children and their carers	Disabled children & Family Carers	Durham	5 females
30	Durham and Districts Women's Cancer Support Group	Cancer	Gender specific - women	Durham	8 females ages 49-82
32	Consett Stroke Club	Stroke	Long term conditions	Durham	5 female, 1 male ages 44-94)
35	UTASS Young Farmers	Mixed rural	General public	Durham	34 people aged 13-59
36	West Rainton Wellbeing Group	Mixed	General public	Durham	
31	St John's Chapel Farmers Cree	Men	Gender specific - men	Durham	8 men ages 60-89
34	Middleton in Teesdale Men's Cree	Men	Gender specific - men	Durham	19 men ages 61-89

	75	Gypsy Roma Travellers	Gypsy Roma Travellers	People of a particular ethnic / racial origin	Durham	3 females, 4 males
	78	Allington House Visual Impairment Group	Visually impaired	Disabled people	Durham	1 male 11 females
DAD	25	Middlesbrough 1st Women's Group	Learning Disability Women's group	Disabled people & Gender specific - women	Tees Valley	tbc
	26	Middlesbrough 1st Men's Group	Learning Disability Men's group	Disabled people & Gender specific - men	Tees Valley	tbc
	28	Durham Peoples Parliament	Disabled people	Disabled people	Tees Valley	tbc
	27	Darlington Peoples Parliament	Disabled people	Disabled people	Tees Valley	tbc

Total Attendees: 1061

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Better Health Programme

Delivered by
Groundwork NE & Cumbria on behalf of
North East Commissioning Support (NECS)

Public engagement report to inform the Better Health Programme: Engagement with frail elderly people living in care setting.

November 2016

Contents

Executive Summary

This report outlines the main findings from the public engagement process carried out by Groundwork North East & Cumbria on behalf of **North of England Commissioning Support (NECS)** for the Better Health Programme. This engagement targeted elderly and frail people in care settings to gather experiences on the discharge process throughout five Clinical Commissioning Groups (CCG's) in the area. These CCG's were Darlington, Hartlepool and Stockton, South Tees, North Durham and Durham Dales Easington and Sedgefield.

In total, 85 conversations were carried out across the five CCG's. These conversations yielded mixed experiences from patients. 50% expressed positive experiences of the service, whilst the other half of participants (43 out of 85) expressed negative remarks about the service they had received when being discharged from hospital. In particular, 22% of participants (19 out of 85) made specific reference to the discharge process.

The main messages that can be taken away from this public engagement with older people in care settings about the discharge process are;

I. Discharge is taking too long due to missing paperwork and medication (17%) – patient perceptions are that they are being left waiting for too long after they have been told they are ready to be discharged. Of those who did have perceptions of long waiting times the average was 4-5 hours, this figure is from across the service and not limited to one or two CCG's. Examples given include the discharge letter not being signed by the doctor on time or medication taking hours to be dispensed.

II. Waiting for transportation - patient transport was noted as a one of the main cause of delays (5%). Two people that we spoke to suggested that patients are given a time window of 2-3 hours so they know roughly when they will be collected. Further to this, waiting time and pressure on the service could also be reduced if more patients were made aware that they can be collected by a family member and do not need to be taken by patient transport.

III. Lack of communication between staff and patients/families (13%) - patients feel staff need to be communicating more, not only with the families, but also with the patient if they have the capacity to understand. Many told us they are left confused and frightened because they don't understand what is happening to them. They feel staff often leave them 'in the dark' even when it is their own care that is being discussed. Finally it was also expressed that medical staff should be more understanding and attentive of additional patient needs so they are treated appropriately; such as those with Alzheimer's or physical disabilities.

IV. Lack of communication between hospitals, the primary care setting and other departments' e.g. social workers/other hospital departments (3.5%) - People expressed that the communication between the departments is too disjointed leading to miscommunications, delayed discharge and not all the necessary provisions being made for patients to ensure seamless care. Please see case study from an Anonymous Man in Darlington which demonstrates this point.

V. There is a lack of support being offered to some patients (8% - Many expressed the view that if they were given further support after being discharged, such as referrals to other services like Occupational Therapy or Physiotherapy, it would have greatly improved their speed of recovery and quality of life. An example of this can be seen in a case study from an anonymous man from the North Durham CCG.

1. Introduction

1.1 North of England Commissioning Support (NECS)

NECS was established on the 1 April 2013. It is based in the North East of England and delivers high quality innovative commissioning support services to a range of clients who consist of 11 Clinical Commissioning Groups who between them serve the communities of County Durham and Darlington, North of Tyne, South of Tyne and Wear, Teesside and Cumbria. NECS also provide a healthcare procurement service for the NHS England North.

One of the service offerings that NECS deliver is healthcare procurement in order to improve the quality of people's lives and as a result drive up quality, value and service to stakeholders and customers through innovative practice.

NECS approached Groundwork North East and Cumbria to support with the public engagement around the Better Health programme.

1.2 Better Health Programme

Across County Durham and the Tees Valley, around 35,000 NHS staff serve a population of 1.2 million people in specialist and local hospitals, in GP practices and community settings, and at home.

Our care needs are changing. People are living longer and have different conditions and health needs: dementia, obesity and alcohol-related disease have become major challenges and more people have long-term health conditions and need support and management, often for many years.

Thanks to better care, we are surviving illnesses and living with conditions for much longer than we used to. This means that our health services need to change too. More services can be provided in community settings or GP practices, without the need for hospital visits, and the service can reduce the length of stay of any planned hospital admissions.

There is disparity between the quality of care across the area because of a lack of uniformity in provision or because services aren't available or have reduced staffing levels at different times of the day, or at weekends.

The Better Health programme aims to review the services that are provided across Durham and Tees Valley to make sure that these services are meeting the needs of our population, are of a consistently high standard across all our providers, and have the staffing and resources to be sustainable into the future.

The programme aims to deliver:

- Improved results for patients
- Consistency of a high standard of care wherever, and whenever it is provided
- Sustainable services resourced for the next 10 -15 years
- Services provided 7 days a week where necessary
- Services that are easier for patients to understand and use
- Improved life expectancy and quality of life for everyone in Darlington, Durham and Tees Valley.

1.3 Groundwork North East & Cumbria

Groundwork NE & Cumbria were approached to undertake this work due to successfully managing community-led environmental projects for over 30 years in the North East. Groundwork NE & Cumbria is a region wide organisation committed to local delivery.

What stands us apart if our ability to be in touch with local communities across the whole region and we pride ourselves on delivering grass roots projects in partnership with others. We have an experienced team of dedicated staff and a proven track record in the delivery of high quality community-led programmes across the region.

Community engagement is an area in which we have vast experience, adapting the techniques used in each project to ensure the relevant stakeholders are involved and the correct information is gathered from the process. The aim is to ensure the communities' opinions are captured in order to provide information that can be used by the client. We find that a "bottom up", community driven approach results in more sustainable projects as they are truly supported by the community.

2. Approach to Community Engagement

NECS approached Groundwork to focus on engagement of the frail or elderly, predominantly living in care homes or sheltered accommodation. The brief was to capture patient experience of being discharged from hospital and capture individual accounts and opinions around the discharge process, quality and continuity of care upon discharge. This work will supplement the findings of the wider public engagement.

The proposal aimed to have conversations with 20 people in each CCG area (100 in total) predominantly living in a range of care settings across the area (a target of 25 care homes). Where appropriate Groundwork will provide, or signpost participants to, additional information about the Better Health programme (as provided by NECS).

Groundwork Land and Neighbourhoods teams, covering Durham, Darlington and the Tees Valley carried out a series of one to one conversations to collect a range of quantitative and qualitative data from people who had recent experience of the local care and discharge process.

A prompt sheet was created for interviewers, to ensure that key points were covered, however the conversations were conducted in an informal manner which allowed the patient to share their experiences and offer opinions on the current process and suggestions for improvement.

3. Methodology

To ensure the data could be easily collated and common themes could be gathered a standard format was agreed for gathering the information from the conversations.

Desktop research allowed us to map the care homes and sheltered accommodation across the identified areas. Teams then approached the staff at the settings in the first instance to help identify participants. Participants were then asked whether they would be willing to take part in a conversation, and a meeting time was arranged. Staff members then carried out the conversations on a one to one basis in the home setting.

Groundwork produced a registration document to capture details of participants partaking in the conversations. This included demographic information and was completed at beginning of each conversation with interviewer supporting as necessary.

All conversations were captured with detailed notes taken to record people's views and opinions. Prompt questions were provided to help the interviewer gain useful information.

The participants were then engaged in discussions around their experience. Conversations were individual, but in general covered topics such as;

- Nature of admission
- Duration of admission
- Circumstances around discharge
- Communication
- Quality of Care
- Quality of experience
- Suggested improvements

Groundwork staff recorded the conversations on discussion sheets.

1. Engagement process

In total we approached, 176 settings across the area, as broken down in the table below.

Area	Number of settings approach	Number of settings who identified appropriate participants
North Durham	31	4
DDES	30	6
HaST	43	10
South Tees	41	13
Darlington	31	9

It was challenging to locate appropriate people in the identified demographic who had the capacity to speak to us about their experiences. Many settings reported not having people with capacity to partake in the conversations or not having people with the necessary experiences, with care home staff reporting not having a high volume of people who they care for after a hospital admission.

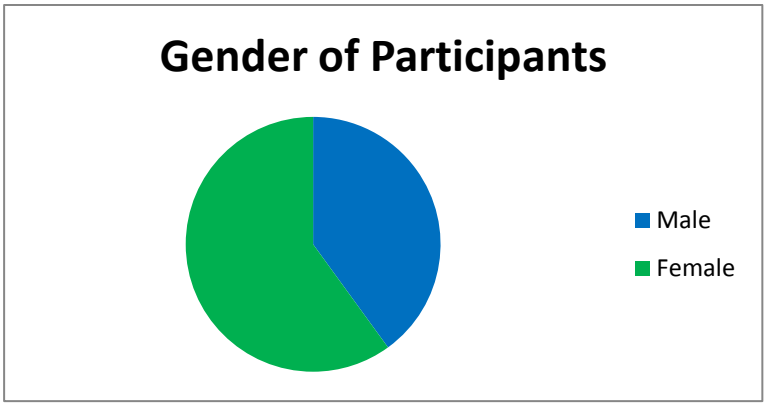
The following is a list of the settings who identified individuals and where conversations took place.

North Durham	DDES	HaST	South Tees	Darlington
Rosemount Residential Care Home	Defoe Court Care Home	Dinsdale Lodge Care Home	Prospect Place	Eden Cottage
Brockwell Court	Lothian House	Bramley Court	Clayton House	Eastbourne Care Home
St Andrews Nursing and Residential Home	Brancepeth Court	Park House Rest Home	Pembroke Residential Home	Elderwood Care Home
Westerleigh Care Home	Barrington Lodge	Ingleby Care Home	Belmont View	Oak Lodge
	Tenlands	Greenlodge Care Home	St Peter's Court	Riverside View Care Home
	Jack Dormand Care Home	Green Links Group	Primrose Court	Rosemary Court
		Kathleen McNamee	Yew Tree Care Home	Rockliffe Hall Care Home
		Robert Dalton	Burlam Road Care Home	Greencroft Court
		Wynyard Woods	Cleveland View	Branksome Hall
		Hartfields Retirement Village	Parkville Care Home	
			Ascot Care Home	
			Bramble Lodge	
			The Gable Care Home	

In total we spoke to 85 participants across the area of interest. The table below sub divides the number of participants per CCG area.

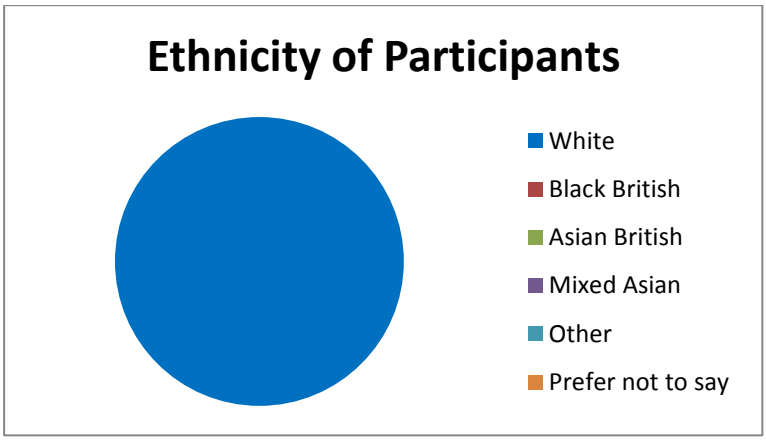
Area	Number of conversations
North Durham	10
DDES	16
HaST	20
South Tees	20
Darlington	19
Total	**85**

Gender



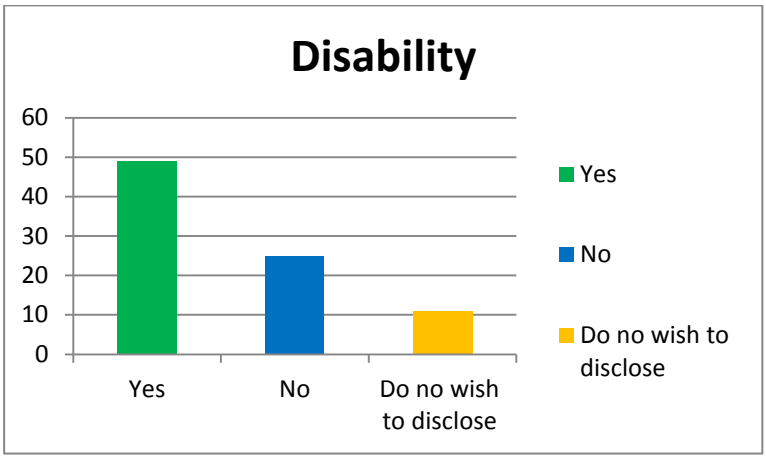
In total we spoke to 31 males and 54 females across the area of interest.

Ethnicity of participants



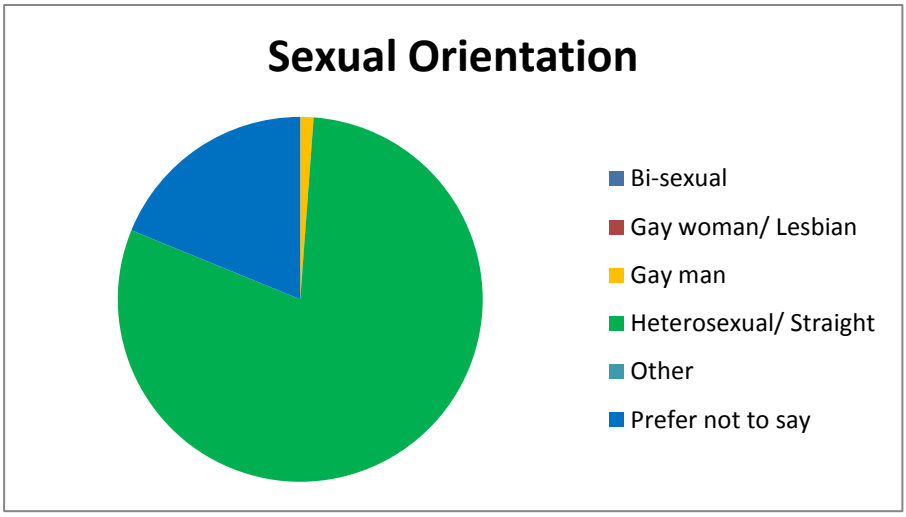
In total all 85 participants that we spoke to described themselves as white

Disability



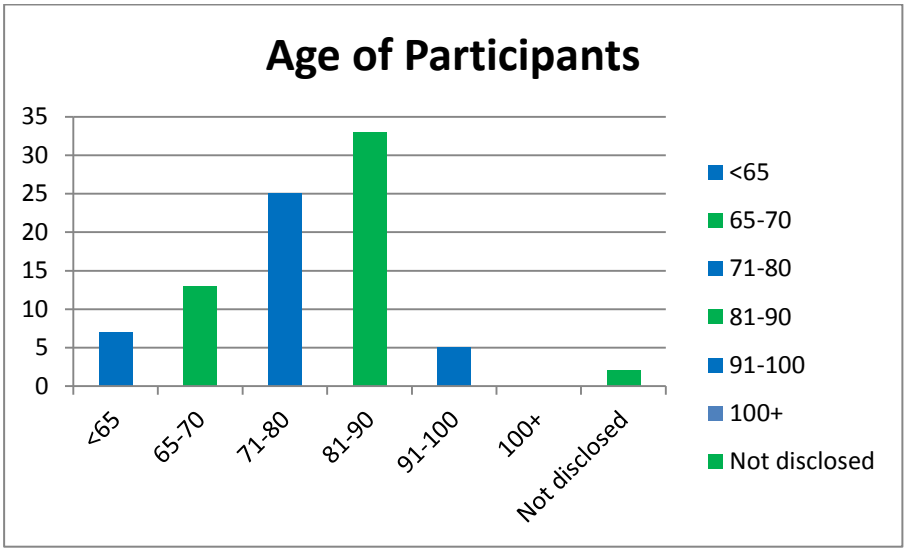
In total of the 85 people we spoke to, 45 people considered themselves to have a disability, whilst 25 people said they didn't and 11 did not want to disclose that information to us.

Sexual Orientation



Of the 85 people spoken to 68 people described themselves as heterosexual/straight, 1 person described themselves as gay and 16 people preferred not to say.

Age



As show in the above graph, in total we spoke to 7 people aged 65 and under,13 people aged 65-70, 25 people aged 71-80, 33 people aged 81-90, 5 people aged 91-100, 0 people aged over 100 and 2 people who did not wish to give their age.

5. Key themes from the conversations

5.1 North Durham

Patients in this CCG area reported receiving treatment from a number of hospitals including Darlington, Freeman's Hospital and Durham and the majority of the 10 people spoken to reported positive experiences. The majority of participants reported having positive experiences and being satisfied with the service they have received.

"I feel the care has been brilliant, joined up and seamless"

"I feel that the services and care I've had in both hospitals [Durham and Stanhope Cottage] was very good, in particular Stanhope was excellent."

However, 2 participants did tell us about their negative experiences of the discharge process. One participant reported being transferred to different hospitals multiple times, explaining that he was unsatisfied with the level of service as he felt excluded from the decision making process.

"I wasn't told why I had to be transferred to different hospitals and found the staff often spoke about me rather than to me. I was moved from place to place without being told why."

Another respondent reported missing personal items and a lack of paperwork on discharge, which made it difficult for care home staff to accommodate her needs.

5.2 DDES

Again, the people we spoke to had had mixed experiences of their time in primary care settings and the discharge process, with over half of the 16 people engaged sharing with us negative comments about their experience .

One person reported feeling that staff shortages resulted in poor quality care whilst in hospital. In particular one participant reported feeling that the staff on the wards lack of understanding about additional needs of patients with dementia.

Two participants in this area shared experiences of extended stays in hospital (primary care setting) due to lack of arranged care provision. They felt the stay was due to the need for appropriate accommodation and not for any extended requirement for medical treatment, and therefore questioned if this was the best use of the resources.

One participant spoken to in this area felt that there was very little support for families when caring for a patient immediately after discharge. When a family member released home with different care requirements, very little information or support was provided and it was left to families to sort care in the

short term resulting in the family feel quite alone in dealing with the patient's needs. They felt the process was less than seamless and were very clear than care should not end when the person leaves hospital.

Throughout the conversations multiple participants highlighted the need for better communication. 25% felt that direct communication with the patient was lacking, despite the patient still having adequate capacity to understand and make decisions for themselves. Examples include a lack of communication around the cause of illness and course of treatment, reasons and requirements for transferring to alternative settings and a lack of information regarding support services, leaving people feeling 'out of the loop' when it came to their own care.

Others reported that better communication could have made their experience better, for example one patient reported having a planned admission arranged for the early morning, but upon arrival having no beds available resulting in an extended wait time for treatment, which they felt could have been avoided and the treatment could have been rescheduled.

Others stressed the need for family members to be more informed. Again this materialised in a number of examples through the conversations, including families not being informed regarding transfer and discharge arrangements and not being given enough information on discharge to support the care of the patient.

Some people did report receiving follow up care and support; however one participant reported delays in getting the follow up referrals recommended upon discharge. Of the 16 spoken to, 4 explained that if more support had been offered it would have aided their recovery.

Another participant felt that the service was not individual enough. They reported receiving OT support on discharge, but only for a set period, which is not long enough in some cases. The duration of the support provided should be based on the individual need and not predetermined.

Another participant felt there was a lack of communication between the care home setting and the OT. In their case a brace and support was issued, however the care home staff were unsure how to fit them properly as there had not been any handover or explanation from the OT.

In this area there were fewer issues regarding the discharge transportation system, with some participants specifically commenting positively on the system. However one participant experienced a delay in discharge due to vehicles not being able to accommodate their wheelchair and felt better communication, so that everyone knew what had to be accommodated, could have prevented this. Poor communication whilst in hospital regarding cause of illness and what course of treatment will occur were the main themes in this area.

5.3 HAST

People engaged in this area reported mixed opinions when it came to their 'in hospital' experiences, with 2 main hospitals being mentioned in the conversations (North Tees and James Cook). A couple of examples were given of planned admissions which were reported on positively, and the process was portrayed as well managed and seamless.

"I've had some great hospital experiences and some very good nurses – I am very lucky"

"I don't know what I would have done without them – the nurses during my stay in hospital".

However, of the 20 people engaged in this area, on three occasions attitudes and behaviours of ward staff have left respondents feeling unsatisfied and anxious about future experiences. In addition two people mentioned feeling 'loneliness and isolation' during their stay.

People commented on several occasions regarding a lack of information at points throughout their hospital /discharge period. 3 reported feeling there was a lack of information provided regarding the causes of the illness and two people reported being discharged without finding out the reason, which in turn has resulted in negative feelings.

Some respondents felt there was a lack of information and support upon discharge, with a sense that information was only provided 'if you knew the right questions to ask', whilst another reported feeling like they weren't being listened too. Patients also highlighted the need for better communication between the hospitals and the care homes.

Again, some patients reported being transferred to another care setting prior to returning to their usual residency. People we spoke seemed to appreciate this 'stepping stone' to allow them to fully recover and had a positive experience of this.

5.4 South Tees

In general the majority of people spoken to in the South Tees area reported positive experiences of their time in James Cook with 50% of people reporting that they were satisfied with their length of stay and felt they were discharged at the right time. One individual reported feeling that it was a ***"seamless service with a range of support"***. Another patient reported she was ***"delighted with the treatment [at James Cook], the staff were all friendly" and I have no complaints at all"***. Only one individual reported feeling like they were 'being pushed home' without the right support.

Some of the participants had experience of being transferred to alternative Primary Care settings after their initial admission, for support with extended care, rehabilitation or in their opinion 'bed shortages'. Whilst some people reported this as a positive step in their journey (i.e. getting support to arrange care home accommodation for release) others found the transfer process 'unsettling' and 'upsetting' with individuals reporting that they felt there should be more choice in the discharge process and others.

Again participants reported mixed reviews on the on-going support and care they received upon discharge. Some participants reported being discharged with support from Occupational Therapists and Physiotherapists which helped them to be more independent.

One participant felt the he had been let down by the after care, with discussions with OT's not being followed up on resulting in the individual not being able to return home and having to find supported accommodation.

¼ of the 20 people spoken to in this area reported were around the lack of discharge notes and / or medication upon release, which in some cases delayed the discharge process and in other cases resulted in confusion and upset upon arrival at care setting.

5.5 Darlington

Through these conversations we received some good reviews regarding the care and satisfaction with the service at Darlington Memorial and Bishop Auckland hospital.

"The hospital was marvellous and that I received a great service. I would also give the discharge process a 9/10 and felt that no improvements need to be made."

We also received some negative patient feedback on their in hospital experience with one person reporting ***"laid waiting the corridor for a bed to be free"*** for a long time and another reporting poor quality care having been *'left unwashed for days'* and felt that better communication between staff in the hospital was required as things were being missed.

Some of the people we spoke to had experience of receiving specialist treatment in other hospitals elsewhere in the North East (Durham and James Cook). On both of these occasions the patients commented that they felt the distance from their home and the hospital was too far and that they found this unsettling, especially when staying in for a longer period of time, as the distance can be a barrier to visitors.

"I did not like being so far away from family. I felt isolated as everyone else was getting visitors and I wasn't."

6 people complained about the delays in the discharge process, and the long time spent waiting for transportation. One person reported not being discharged until 9.30pm, which they felt was too late to be going home (to a care home) and felt they had been left waiting too long for the transport. The nurses allowed him to stay in his own bed until this happened. However, it wasn't until 9.30pm that night that he was actually discharged and taken back to the care home where carers were waiting for him. The man explained he felt that 9.30pm is too late to be going home and he had been left waiting too long for the ambulance.

The delay in discharge also affected people who were being discharged home to family.

"It took 4 to 5 hours to be discharged as they had to get my medication sorted and wait for discharge letter. It was annoying to have to wait so long because my wife was waiting for me, so it was frustrating to both of us"

Again 5 people experienced what they felt was poor communication with the patients whilst in hospital and after being discharged. One patient reported being admitted for what she thought was a straight forward planned surgery and was told she would only be in hospital for a couple of days, but ended up staying in for three weeks without an explanation to why this was the case. She feels that something went wrong in the surgery that was not explained to her. Another patient reported;

"I felt that the staff there did not communicate with me enough and I had many questions that went unanswered."

Others felt that better communication was needed between in hospital departments and out of hospital support to prevent delays in on-going treatment after discharge. There were also reports of services which were recommended on discharge having long waiting lists to access.

Some people reported feeling that the problems identified were the result of overworked and overburdened front line staff. They felt there need to be less administrators and more money spent on nurses so that everything takes less time and no one is left waiting.

However some people did report the system working, and when it did patients reported being very satisfied with the services they received.

"I felt better at home [in a care home] and was able to get better quickly. I was given a lot of support after both by the hospital and the care home; I felt that I could talk to the nurses at the Breast Clinic at any time and this helped me to recover well."

"On discharge I was taken home to my husband. The district nurses came out to make sure everything was alright and before I came home they check the house to see if I could manage. The aids I needed were brought within the hour."

5.6 Additional conversation with staff

In addition to the conversations we had with individuals, some staff in the care settings wanted to share their opinions. We recorded conversations with 7 staff members at various settings across the area.

The main concern was around the lack of direct contact the homes have with the hospital. Often staff lack clear information regarding changes to medication and they felt the current system of recording a patient's medication made it difficult to identify changes required after discharge. Improved, or more direct, conversations between the hospital staff and care home staff would save a lot of time and reduce the chances of incorrect medication being given.

Staff reported medication being wasted. They said the medication the patients are discharged with is packaged in a form that the care homes are not allowed to administer under their regulations. This often results in the medication which has been sent to the care home with the patient from hospital being wasted as it cannot be administered, neither can it be returned to be re-used.

There were several reported cases of missing discharge paperwork, medication or mobility aids and personal items (i.e. dentures or glasses) on the person's arrival at, or return to, the home. Some staff reported that discharge notes sometime directed staff to contact GP in order to find out about the medication instead of providing the information directly to them. This resulted in the staff members lacking clarity around the care required, and patients lacking the prescribed aids for living outside of a primary care setting. Staff also felt it made their roles more difficult and onerous, with time wasted chasing up missing items.

Staff felt patients were often left too long in the discharge room waiting for transportation, which can result in safeguarding issues and inadequate care. They reported instances where patients had arrived at the home in the evening, despite clear rules around cut off periods for admissions, leaving the staff unable to plan and arrange the necessary care on arrival, again potentially resulting in inconsistency of care. In other instances patients from the same hospital due for discharge have arrived at different times in different vehicles.

Staff also reported feeling that patients are released too early due to bed shortages. They reported instances when patients still required medical care, but were discharged to a care homes, which in their opinions increased the pressure on them beyond the remit of their role or expertise. Other staff felt that there is a delay in admitting patients (either due to delays in admission transportation or due to doctors dismissing reported changes in symptoms), putting more responsibility on the care home to manage the medical needs of their residents. There seems to be a lack of understanding by hospital staff around the level of care and support available in different types of settings.

6. Summary

Throughout the process we were able to capture the views, opinions and experiences of 85 older people. People often provided information about their in hospital experiences, alongside discussing the discharge process and satisfaction of services and this information collected has been presented in the report. This has been supplemented by information provided from care home staff at 7 settings.

It was challenging to identify suitable participants in a care setting, as in multiple instances homes reported having no residents with in-hospital/discharge experiences, whilst others reporting that residents had advanced stages of dementia resulting in them having a lack of capacity to be able to consent or cooperate. Even when we were able to identify people, we experienced barriers to being able to collect a full, accurate account of their experience including:

- Limited information as family members or care home staff are now taking responsibility for their health care and have received information on their behalf.
- Memory issues, preventing some people from being able to present a complete account.

Despite this, we were able to engage with a range of people across a large geographic area to provide insight into how older people feel, what is important to them and improvements they believe are needed in the services discussed.

As expected, the information we collected was very individual and no two experiences being the same. Satisfaction levels of the care and services received also varied due to the personal experiences. The most common concerns were;

Discharge Process

- The discharge process from wards is often subject to delays due to waiting for medication and notes.
- Linked to this, people then experience delays in being provided with discharge transportation, in multiple instances, resulting in older people waiting for long periods in a discharge lounge and potentially not receiving the appropriate care during this period.
- Late discharges resulting in the care home not having time to make the appropriate arrangements for the patient on arrival. In addition, there have been multiple reports of patients arriving without essential medications, paperwork and personal items.
- There are reports from staff that medicines are wasted due to patients being discharged with medication in a form that the homes are not authorised to administer.

Communication

- Communication with elderly people whilst in hospital could be improved, especially around transferring of patients and discharge options.
- Support offered upon discharge is inconsistent, with some people feeling like they lacked appropriate information and on-going care.
- Communication between primary care setting and care homes could be improved to provide a more seamless experience.

In summary, during this engagement process a total of 85 people were consulted and their experiences recorded. Of the 85 people engaged, 50% had positive experiences and were happy with the service they had received. .

However, 22% of participants (19 out of 85) shared their negative experiences of the discharge process. Overall, 50% of participants (43 out of 85) expressed negative remarks about the service they had received on being discharged from hospital. This figure brings into account not only the data collected regarding the discharge process itself, but also the communication aspect; this was identified as a major theme throughout the area and has therefore been taken into account.

7. Messages for the Better Health Programme

In summary, the 5 key messages that can be taken from this engagement with older people in a care setting about the discharge process are;

I. Discharge is taking too long due to missing paperwork and medication (17%) – patient perceptions are that they are being left waiting for too long after they have been told they are ready to be discharged. Of those who did have perceptions of long waiting times the average was 4-5 hours, this figure is from across the service and not limited to one or two CCG's. Examples given include the discharge letter not being signed by the doctor on time or medication taking hours to be dispensed.

II. Waiting for transportation - patient transport was noted as a one of the main cause of delays (5%). Two people that we spoke to suggested that patients are given a time window of 2-3 hours so they know roughly when they will be collected. Further to this, waiting time and pressure on the service could also be reduced if more patients were made aware that they can be collected by a family member and do not need to be taken by patient transport.

III. Lack of communication between staff and patients/families (13%) - patients feel staff need to be communicating more, not only with the families, but also with the patient if they have the capacity to understand. Many told us they are left confused and frightened because they don't understand what is happening to them. They feel staff often leave them 'in the dark' even when it is their own care that is being discussed. Finally it was also expressed that medical staff should be more understanding and attentive of additional patient needs so they are treated appropriately; such as those with Alzheimer's or physical disabilities.

IV. Lack of communication between hospitals, the primary care setting and other departments' e.g. social workers/other hospital departments (3.5%) - People expressed that the communication between the departments is too disjointed leading to miscommunications, delayed discharge and not all the necessary provisions being made for patients to ensure seamless care. Please see case study from an Anonymous Man in Darlington which demonstrates this point.

V. There is a lack of support being offered to some patients (8% - Many expressed the view that if they were given further support after being discharged, such as referrals to other services like Occupational Therapy or Physiotherapy, it would have greatly improved their speed of recovery and quality of life. An example of this can be seen in a case study from an anonymous man from the North Durham CCG.

8. Contact Details

If you would like any more information on this project / report please contact:

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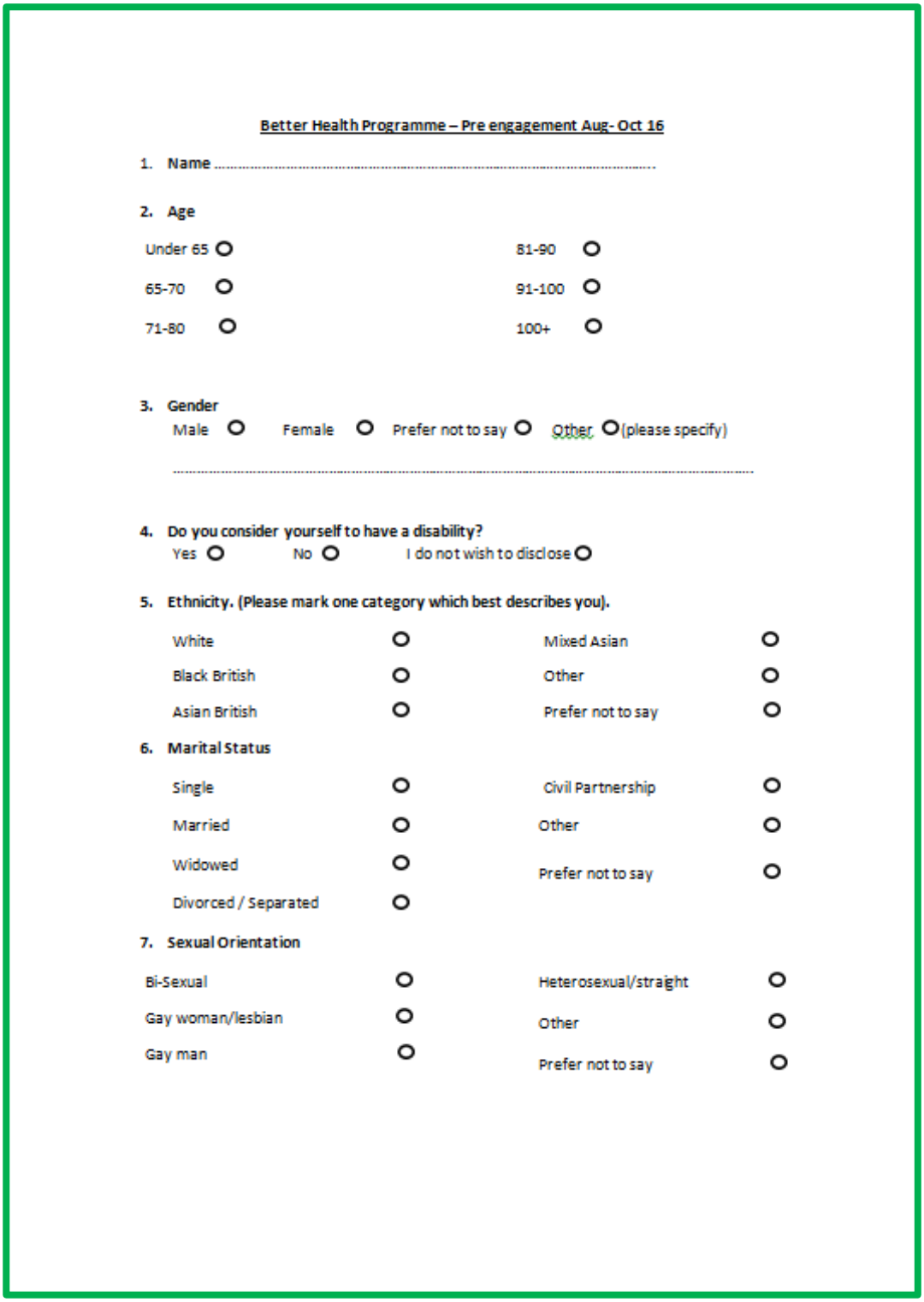
Please note; the points documented are the opinions of, and information given by, the participants of the engagement exercise and do not reflect the opinions of Groundwork North East & Cumbria. Some information provided by the participants may also not be factually accurate, but it reflects their understanding and experiences of the services received.

9. Appendix

9.1. Participant Registration Form



Better Health Programme – Pre engagement Aug- Oct 16

1. **Name** .....

2. **Age**

Under 65 ○	81-90 ○
65-70 ○	91-100 ○
71-80 ○	100+ ○

3. **Gender**

Male ○ Female ○ Prefer not to say ○ Other ○ (please specify)

.....

4. **Do you consider yourself to have a disability?**

Yes ○ No ○ I do not wish to disclose ○

5. **Ethnicity. (Please mark one category which best describes you).**

White	○	Mixed Asian	○
Black British	○	Other	○
Asian British	○	Prefer not to say	○

6. **Marital Status**

Single	○	Civil Partnership	○
Married	○	Other	○
Widowed	○	Prefer not to say	○
Divorced / Separated	○		

7. **Sexual Orientation**

Bi-Sexual	○	Heterosexual/straight	○
Gay woman/lesbian	○	Other	○
Gay man	○	Prefer not to say	○

8. Religion or belief

Muslim	O	Buddhist	O
Christian	O	Sikh	O
Hindu	O	No religion or belief	O
Jewish	O	Other religion or belief	O
		Prefer not to say	O

9.2. Prompt Questions for Interviewer

Prompt questions

- When was the event?
- Was the admission a planned or unplanned admission?
- Which hospital where they initially treated in?
- How long was the participant in hospital for? And do they think this was the right length of stay for them?
- Were they transferred to another hospital / service prior to discharge?
- Where were they discharged to? (i.e. home / care home)
- Who was their main carer upon discharge?
- Did they feel they had any unmet needs at this point?
- Where there any incidents of readmission for same or connected problem after discharge?
- What support / services where they provided with upon discharge?
- Was communication/ information given to participant and or carer adequate?
- How did they feel about the experience? How would they rate the quality of the discharge process / out of hospital care they received?
- Do they feel they received seamless care (joined up between hospital and discharge services)?
- How could the process / experience have been improved?

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Better Health Programme

North Durham

Agenda Day™ Report

Report written by Shaun Taylor supported by

Chris Affleck Project Worker

October 2016

Introduction

We are part of the County Durham Health Group for Investing in Children. Investing in Children is committed to ensuring that Children and Young People have a say in decisions that affected then. Investing in Children's young people's Health Group is a group funded by North Durham & Durham Dales Easington and Sedgefield Clinical Commissioning Groups (CCG). The group is a county wide group that meets second Thursday of the month in Durham. The meeting consist of around twelve young people and we gather to discuss different matters and have covered a range of topics.

We were asked by North East Commissioning Support (NECS) to involve young people in discussions through Agenda Days™ about the Better Health Programme. An Agenda Day™ is an adult free space, this means that adults don't take part in the debate, and the children and young people are free to discuss issues without adult influence. This was achieved by using young people as facilitators.

The 'Better Health Program' (BHP) is about how the NHS in Darlington, Durham, Tees and North Yorkshire can improve care for patients in hospital and in the community. Key points are listed below:

- More patient care could be provided outside of hospital, in the community or at home supported by GPs, NHS community services, social care and the voluntary sector.
- Your local hospital would still provide: outpatients clinics; scans and other tests; planned operations; midwife led maternity care, and urgent care for non life threatening illnesses and injuries.
- For life threatening emergencies patients should go by ambulance to a specialist emergency hospital with senior experienced staff 24/7
- This happens now for heart attacks, strokes and serious injuries. They believe this should also happen in other serious emergencies, like internal bleeding, and for women and babies at risk of complications during childbirth.
- We should centralise care for serious emergencies in fewer hospitals than at present so that experienced staff can be available 24/7

21 Young People age 13-17 attended Stanley Young People's Club on the 20th October - 9 Male, 10 Female, 2 chose not to say

The first question both groups of young people were asked was: What was good or bad about specialist hospitals?

The general reaction to specialist hospitals was very mixed among the young people, with the majority saying this is a both a good and bad idea in the fact that specialist care is available 24/7 in these hospitals, but it may take longer to get there in an emergency. There were also concerns regarding increased cost (both to the NHS and patients)

Quotes from young people:
Benefits:

- ***"Better health care due to specialists/experienced staff"***
- ***"Lots of help available in one place"***
- ***"Help seriously ill patients"***
- ***"More dedicated care"***

Drawbacks:

- ***"Transportation cost for patients"***
- ***"Could cost more for the NHS"***
- ***"Takes longer to get there in an emergency"***
- ***"Could be busy, so waiting times will increase"***
- ***"Specialist hospital could be too far away"***
- ***"Someone who needs help with (e.g.) lungs… may not know where that specific hospital is"***

The next question the groups were asked was: What type of health services would you like to be able to access in your local community?

In the group there was a majority for Mental Health and Sexual Health services in the local community, amongst other services which are highlighted below:

Quotes from young people:

- ***"Mental Health Services"***
- ***"Sexual Health Clinic (STI Testing)"***
- ***"Closer Hospitals"***
- ***"Cancer Clinics/Services"***

- ***"X-rays"***
- ***"CAMHS"***
- ***"Closer Hospitals"***
- ***"Same day appointments"***
- ***"Physiotherapy"***
- ***"Counselling"***
- ***"Checkup Centre's - for unknown illnesses, to decide best course of action"***

The next question the groups of young people were asked was: How can we get people to use the community services rather than go to a hospital?

The majority of the group favoured posters placed in popular places, such as community centres - as well as having displays in hospitals about local services

Quotes from young people

- ***"Put posters in a local/popular place"***
- ***"Door to door, posters, newspapers, TV"***
- ***"Billboards, radio broadcasts"***
- ***"Advertise in schools"***
- ***"Advertise on facebook, ensure people know its legit with professionals/specialists"***
- ***"Big, bright posters"***
- ***"Assemblies"***
- ***"Social Media"***
- ***"'Relaxed' advertising - so people aren't scared/intimidated"***
- ***"Tell people in the community what these services are and what they do, make sure they know they'll be easy to access/closer"***

The next question the groups were asked was: What is important when leaving the hospital?

The general view of the group of young people is that services should be provided either in the home or in the local community

Quotes from young people

- ***"In a 'front street' location"***
- ***"In a One Point Hub"***
- ***"Near or in GP surgery"***
- ***"Somewhere where everyone can have easy access"***
- ***"Aftercare in your home"***
- ***"Nurse visits you"***
- ***"Follow ups done in GPs"***
- ***"Somewhere within reasonable bus distance"***
- ***"Near my home"***
- ***"In serious incidents doctors come to your home"***
- ***"In your home, to make you feel safe"***

- ***"Local Area"***

The next question the groups were asked was: What is good about reducing Paediatric wards and what is bad about it?

This was responded to very negatively by the group of young people, with all young people saying children are more likely to require care and so there needs to be 24hr wards a short distance away from where they live.

Quotes from young people

- ***"The problem about lowering the opening hours is a child's immune system is very delicate and that means they may not be able to fight illnesses… and this can be very dangerous"***
- ***"More emergency appointments are made for children by parents due to paranoia"***
- ***"Good as more staff, however children may not get enough healthcare"***
- ***"Children may not be able to access medical care"***
- ***"Staff will be less stressed, however childcare may not be as good"***
- ***"Cheaper and save funds, however puts more stress on fewer wards"***
- ***"More injuries happen with children"***
- ***"Not all children will have access to care e.g. during the night"***
- ***"Children are vulnerable and need more help"***
- ***"Kids are the new generation and so need help when they get injured"***

The final questions was: Is it better to get the best possible care and have to travel further, or have services cover but not necessarily specialist services?

The general view on this question amongst the young people is that the answer depends on the situation - i.e. the severity of the injury or illness.

Quotes from young people

- ***"Better service - get the best treatment to make it better in long run"***
- ***"Closer care is better in an emergency"***
- ***"Not everyone has a car so they would not be able to travel - taxis and buses are expensive"***
- ***"It depends on how you define 'further'"***
- ***"Access to best possible care is worth the extra travel"***
- ***"Closer is easier to get to"***
- ***"An emergency patient could die on if they have to travel a long way"***

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We are a Community Interest Company (registered in England & Wales) No. 8428687

Better Health Programme

South Durham Agenda Day™ Report

Report written by Erin Talbot supported by

Chris Affleck Project Worker

October 2016

Introduction

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- For life threatening emergencies patients should go by ambulance to a specialist emergency hospital with senior experienced staff 24/7
- This happens now for heart attacks, strokes and serious injuries. They believe this should also happen in other serious emergencies, like internal bleeding, and for women and babies at risk of complications during childbirth.
- We should centralise care for serious emergencies in fewer hospitals than at present so that experienced staff can be available 24/7

15 Young People age 10-19 attended 2 sessions 1 in Bishop Auckland and 1 at Hope Wood Academy in Easington.

The first question both groups of young people were asked was: What was good or bad about specialist hospitals?

The group of young people at Hope Wood Academy said:

Good:
"You would get better transport and then you wouldn't have to get moved to another hospital"

"If there is a minibus or help for families to come and see you it would be fine"

Bad:

"You could die on the way there"

"My mum can't drive"

"Parking and travel are expensive"

The group from Bishop Auckland said:

Good:

"Put in perspective the idea is good but it has its problems"

Bad:

"Might die or get worse before you get there"

The next question the groups were asked was: What type of health services would you like to be able to access in your local community?

The group of young people at Hope Wood said they would like to be able to access services such as; x-ray, plaster cast, pharmacies/chemist, doctors and they also wanted more education about where to go if you have something wrong with you rather than going to the hospital for everything.

The group of young people from Bishop Auckland said they wanted to be able to access services such as; doctors in the hub, physiotherapists, improved ambulance systems and chemo therapy.

The next question the groups of young people were asked was: How can we get people to use the community services rather than go to a hospital?

The group at Hope Wood said that you could tell people where to go depending on what's wrong with them and not have to go to hospital for everything.

The group from Bishop Auckland said it could be advertised through social media sites such as Facebook.

The next question the groups were asked was: What is good about reducing Paediatric wards and what is bad about it?

The group from Hope Wood Academy did not answer this question but the group from Bishop Auckland said:

"Keep it open in Bishop Auckland"

"If a child is ill it's unfair. Should give children special care to make them feel safe and comfortable."

"Take longer and would be worse"

The next question the groups were asked was: What is important when leaving the hospital?

The group from Hope Wood said that it is important to go to the doctor for review rather than travel back to the hospital every two days. They also said that the doctors should come to you and there should be a medication delivery service to save you from having to keep going to get medicine.

The Bishop Auckland group said that it is important that the care after hospital is given at the patient's home to avoid any other illnesses or injuries.

The final question the groups were asked was: Is it better to get the best possible care and have to travel further or have services closer but not necessarily specialist services?

The Hope Wood Academy group decided that it was better to travel further for the specialist services in order to receive the best possible care.

The Bishop Auckland group decided that specialist care was more important but it would be better to get specialist care in every hospital.

The Bishop Auckland group came up with a few more points they wanted to add during the discussion:

"Instead of doctors it should be specialist nurses as many people prefer to talk to nurses"

"Shouldn't pay for dental care"

"Shouldn't have to pay for prescriptions"

"Want them to stop closing down hospitals"

"More entertainment in hospitals"

"More attention to young people/teenagers"

"Faster ambulance time"

"More specialist care in hospitals"

"Specialist doctors should make house calls"

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