

North Yorkshire County Council

Scrutiny of Health Committee

8 February 2013

Mental Health Services for Older People in the Harrogate Area

Purpose of Report

1. The purpose of this report is to provide an opportunity for the Scrutiny of Health Committee to agree its response on proposals for mental health services for older people in the Harrogate area, in particular on the future plans for in-patient services currently provided at Alexander House in Knaresborough for older people with dementia.

Background

2. Currently Alexander House in Knaresborough and the Rowan Ward at Harrogate District Hospital have 32 beds between them. The NHS locally has highlighted that fewer than half of the beds are in use at any one time and also that national guidance suggests a population the size of the Harrogate area needs around 15 – 16 assessment and treatment beds for older people.
3. Older people's mental health services in Harrogate are provided by Tees, Esk and Wear Valleys NHS Foundation Trust. The Trust is proposing to reduce the number of beds to the recommended number of 16. It is also being proposed that all beds will be provided at the Rowan Ward in Harrogate District Hospital. Alexander House would then be used as a community-focused mental health resource centre for older people with a memory clinic and other dementia services.
4. Under the Trust's plan resources freed up by reducing unnecessary beds at Alexander House will lead to a range of service improvements including essential early diagnosis and increased level of home care for those living with dementia. Information given to patients emphasises the importance of early diagnosis as it will give the person living with dementia and clinicians the best possible chance of managing the condition successfully. The Trust has indicated its commitment towards supporting people to remain in their own home by providing care in the community. The Trust also points to evidence which shows this approach helps to slow the onset of the most severe symptoms of dementia as well as minimising distress to the patient and their family.

Introduction

5. Members will recall that representatives from Harrogate and Rural District Clinical Commissioning Group (CCG) and Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) attended the Scrutiny of Health Committee on the 18 August 2012.

6. The purpose of this meeting was for the CCG to seek support to hold a comprehensive public engagement on the future of the inpatient beds in Alexander House, Knaresborough. There were no proposals to replace the inpatient services with an alternative service. A public engagement therefore seemed more appropriate than a full public consultation.
7. The Scrutiny of Health Committee conditionally supported the proposals for the public engagement. It was agreed that a public engagement would be appropriate providing the need for an alternative service did not arise during the consultation period. In the event a full public consultation would then be required. The CCG gave an undertaking to report back to the Scrutiny of Health Committee after the public engagement had closed.

Progress

8. The CCG completed its planned public engagement on the 21 January 2013. The CCG followed the consultation plan circulated to members on the 18 August. In addition to the planned engagements, the CCG and TEWV held an additional public engagement event in Knaresborough on the 16 January 2013. This was to provide members of the public and stakeholders with a further opportunity to comment on the proposals for older people's mental health services.
9. The CCG and TEWV also attended meetings with the Harrogate District Council Area Committee and the Overview and Scrutiny Committee, and also Knaresborough Town Council.
10. The needs of carers of people suffering with dementia were prominent issues throughout the consultation period. The CCG, TEWV and North Yorkshire County Council Social Services have agreed to work together in holding a focussed supplementary engagement event with carers.
11. This is due to be held outside the public engagement period on the 5 February 2013. The outcome of this meeting will be considered by the CCG Shadow Governing Body alongside those from the public engagement period.
12. The CCG is satisfied through the public engagement process that there remains no alternative service provision that should be considered through a full public consultation process. The issue remains one of an over provision of inpatient beds in the Harrogate and rural district area.
13. Subject to the Scrutiny of Health Committee's endorsement of the CCG public engagement process, the matter of the future of the inpatient beds in Alexander House will be considered by the CCG Shadow Governing Body in their board meeting due to be held in March 2013.
14. The "information for patients" document published as part of the engagement process is attached as Annex 1. The full summary of the outcome from the public engagement has been included in Annex 2.
15. George Lee (Senior Commissioning Manager, NHS North Yorkshire and York) and Adele Coulthard (Director of Operations - North Yorkshire Tees,

Esk & Wear Valleys NHS Foundation Trust (TEWV FT)) and Dr. Rick Sweeney (Clinical Lead for the CCG) will be attending the meeting to summarise the outcome of the engagement process.

Recommendations

16. Members are invited to:
- a) comment on whether they are satisfied that the public engagement has been provided in line with the plan shared with members on the 18 August 2012
 - b) agree the basis of a formal response to the proposals and agree that the Chairman be authorised to respond on behalf of the Committee taking into account views expressed as part of the discussions.

Bryon Hunter
Scrutiny Team Leader

County Hall
NORTHALLERTON

28 January 2012

Background Documents: None

Proposed changes to mental health services for older people in the Harrogate district



Information for patients and the public

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Introduction

Harrogate and Rural District Clinical Commissioning Group (CCG) is seeking the views of local people on proposed changes to the mental health services for older people in the Harrogate district.

Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) who provide the service have been in discussions with NHS North Yorkshire and York (PCT), the CCG, clinicians, patients, carers, relatives, staff and key support organisations in recent months and have developed the proposals put forward in this document.

Both the CCG and TEWV are totally committed to providing the best possible care for older people in the Harrogate area and making the best use of taxpayers' money by maximising the health benefits of every pound spent.

This means we need to look at changing how services are provided, working closely with our health, voluntary sector and social care partners so that we can continue to meet the needs of an increasingly ageing population. As the emerging local leaders of the NHS, the CCG wants to ensure a sustainable and fit for purpose local service for patients and the population we serve.

We are keen to hear your views on these proposals and to find out whether there are any additional issues that need to take into account when developing the service or making any changes.

Background

The publication of the National Dementia Strategy in 2009 heralded the beginning of a large and complex programme of change across health and social care.

As the population ages and we see an increasing number of people with dementia, it is important to make sure that older people in the Harrogate area receive the best possible care and support. This means working with our health and social care partners and the voluntary sector to ensure:

- individuals are assessed, diagnosed and start active treatment as quickly as possible
- people are able to remain independent and in their home environment for as long as possible
- patients' individual needs and those of their carers are recognised and acted upon quickly

As we strengthen our community services and change the way we work to support people at home, there is less reliance on inpatient beds. Bed occupancy has reduced significantly over the last year and TEWV is confident that we can now reduce the number of assessment and treatment beds in the Harrogate area to a level that is much more consistent with the national norm, whilst still maintaining a high quality service.

It is important that we make good use of taxpayers' money. By saving money on inpatient services we will be able to protect and invest further in our community services to bring them in line with the aims of the national dementia strategy.

This document provides more information on TEWV's proposal to develop mental health services in the Harrogate area that meet the changing needs of older people.

Changes in health and population

People are living longer and the need for specialist mental health services for older people is increasing. Harrogate and rural district has a total population of over 158,000 and 20% are over the age of 65 (compared to the national average of 16%). Figures estimate that this will increase further to 23% in 2020 and 28% in 2030.

The way we provide mental health services needs to continue to change to provide more tailored care that is based on the needs of the individual. More and more people are able to get the support they need at home and are spending less time in hospital. However, with an increasingly ageing population it will continue to be vital to ensure that we provide older people with appropriate health care, at the right time and in the right place.

Dementia, in particular, presents a huge challenge for those who live with the condition and their carers. It has become a high priority both nationally and locally with the launch of the national dementia strategy (Living well with dementia) in 2009. Since then, TEWV has been working with other NHS organisations, social services and the voluntary sector to improve services for people with dementia and their carers.

Towards the end of 2011, TEWV held an event in Harrogate which was attended by a wide range of local people including health and social care professionals, service users and carers. The aim was to discuss how best to continue to improve the quality of services whilst reducing costs and a key theme arising from the workshop was the need to provide

more care and treatment in the community and have more appropriate levels of inpatient beds.

Organic illnesses such as dementia

Although there are exceptions, people usually develop organic illnesses such as dementia in older age.

Evidence shows that early diagnosis and treatment is very important to improving the quality of life of someone with dementia, enabling independence for longer and preventing unnecessary admissions into hospital and care homes. A core aim of the national dementia strategy is to make sure that these services are available to everyone.

Although some people will need and benefit from admission to hospital, people with dementia generally want to stay in their own homes. Research shows that older people with dementia thrive best when they can be treated in their home environment. Moving someone with dementia from their home or nursing home very often increases their confusion and their levels of stress and anxiety. This has a direct negative effect on their wellbeing and their ability to do things for themselves.

In July 2011 an All-Party Parliamentary Group (APPG) on dementia reported that greater effort should be put into preventing inappropriate hospital admissions through investment in community services. They also said that better discharge planning and improvement to care pathways could reduce lengths of stay for people with dementia who did not clinically need to be in hospital.

In a survey for the Alzheimer's Society more than eight out of 10 carers or people with dementia said being able to stay in their own homes was very important.

This is available in the "Support. Stay. Save." report available from the Alzheimer's Society at www.alzheimers.org.uk/supportstaysave

Functional illnesses such as anxiety or depression

One in four people will experience a mental health problem at some point in their lives. Whilst dementia tends to affect people in older age, functional illnesses such as anxiety or depression can affect people at any time. Some older people will develop a serious mental health problem for the first time later in life whilst others may have experienced ongoing mental ill health.

As with dementia, most people prefer to be supported at home wherever possible. This helps them maintain their usual routines and independence as well as stay in contact with friends and family; all of which help improve their wellbeing and recovery.

Current services for older people in the Harrogate District

Provided by Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV)

1. Community services

TEWV currently provide a range of community based services including:

- **Rapid response intermediate care (RRICE) team**
The RRICE team provides a community based rapid response service to patients when they are experiencing a crisis or their clinical need or mental wellbeing suddenly changes. The service aims to support people in their own homes for as long as it is safe to do so. The team works from 8.00am to 6.00pm, seven days per week.
- **One community mental health team (CMHT)**
Harrogate and Rural CMHT. The team provides an assessment, treatment and monitoring service for older people (over 65s) with severe or acute functional and organic mental health problems. The team works from 8.00am to 5.00pm, Monday to Friday.
- **Day hospital services**
As we work towards providing individualised and tailored support for people with dementia, people are getting the support they need in a number of different ways. As a result of this the number of people attending our day hospitals has decreased. In consultation with patients and their families, we have combined three day hospitals previously provided in Harrogate, Knaresborough and Ripon. These are now run from a central base at Rowan Day Hospital in Harrogate District Hospital, the purpose of which is to support people with mental ill health to maintain an independent lifestyle in the community.
- **Memory clinic**
The memory clinic provides a diagnosis service, a specialist medication monitoring service and an education service to help people and their carers manage their own needs for as long as possible. This service is based in Alexander House in Knaresborough but can be provided in satellite clinics across the areas where these are required.
- **Acute liaison service**
This service works with colleagues in Harrogate and District NHS Foundation Trust to assess the mental health needs of patients with physical problems. The aim is to reduce lengths of stay, help facilitate appropriate discharge from hospital and ongoing care.
- **Nursing and residential care home liaison**
Only limited resources currently exist to assess and help patients in nursing and residential care homes and support the staff who work in the homes. Improving and developing this service is an important priority.

- **Young dementia team**

This team includes a qualified nurse, social worker and support worker and provides services for younger people with suspected dementia and their families, making sure they get the specific care and support they need.

2. Inpatient services

There are currently 32 NHS specialist beds for older people with organic and functional mental illness in the Harrogate area based in two units:

- **Alexander House** - a purpose built community unit situated in Knaresborough with 16 beds. Historically the unit has also provided long term care and planned respite care.
- **Rowan Ward** - a 16 bed ward in the Briary Unit, Harrogate District Hospital.

The need for change

It is important that we make the best use of our resources to meet the needs of an increasing and ageing population.

We want to provide services that offer the very best care for older people with mental health problems. For many people this will mean providing services which help them stay in their own home for longer, or which maximise independence. For others, this will mean meeting their needs by providing care in a more appropriate setting.

We want to make sure people with dementia are diagnosed early and that they get the support and treatment they need as quickly as possible.

In Harrogate we currently have twice as many beds as the national average for the size of our population. Bed numbers for people with dementia are also significantly higher than in other areas where TEWV provide services, as shown below.

Locality	Number of assessment and treatment beds per 100,000 of population - 2010/11
County Durham and Darlington	21.6
Tees	24.2
Scarborough, Whitby and Ryedale	30.4
Hambleton and Richmondshire	33.6
Harrogate	78

The number of admissions to hospital was also high compared to other areas serviced by TEWV:

Locality	Number of acute admissions (older people) per 100,000 of population – 2010/11
County Durham and Darlington	235
Tees	108
Scarborough, Whitby and Ryedale	108
Hambleton and Richmondshire	354
Harrogate	960

However, we are already starting to see changes in the use of inpatient services. Bed occupancy at Alexander House is reducing significantly - currently only 2-3 beds are in use at any one time. Because of the increasing complexity in the needs of people who are being admitted to hospital all admissions are being primarily directed to Rowan Ward at Harrogate District Hospital where the environment is more appropriate to both meet those complex needs and manage the associated clinical risk.

Occupied bed days (as a percentage)

Unit	July to September 2010	October to December 2010	January to March 2011	April to June 2011	July to September 2011	October to December 2011	January to March 2012	April to June 2012
Alexander House	68%	55%	58%	62%	67%	44%	40%	19%
Rowan Ward	64%	57%	70%	58%	62%	75%	71%	52%

Meeting your needs

If we are to meet the future needs of the people of Harrogate, we need to:

- continue to expand the memory assessment and treatment services
- strengthen community based care
- reduce inappropriate admissions to hospital
- ensure that where hospital admission is required, facilities are fit for purpose
- provide more support for people with dementia and the staff who care for them in nursing homes

By saving money on inpatient services we will be able to protect and invest in our community services.

Our proposals are in line with evidence-based practice and national policy (see details at the end of the document) and reflect the findings of the Independent Review of Health Services in North Yorkshire and York (August 2011).

Proposals

1. Reduce the number of inpatient beds

According to national guidance a population the size of the Harrogate area needs around 15 to 16 assessment and treatment beds for older people. TEWV are confident that 16 beds will give us sufficient capacity to continue to provide high quality services for local people.

We propose providing these services on a single site at Rowan Ward in Harrogate District Hospital for the following reasons:

- Reducing bed numbers on each of the present two sites would be potentially unsafe, inefficient and more costly per bed to run. There is clinical guidance about the numbers of qualified and unqualified staff required to run a unit safely, which makes two small units unviable.
- Adult and older people's inpatient assessment and treatment services would both be located at Harrogate District Hospital. With the increasingly complex needs of those being admitted to hospital, this would mean a greater pool of experienced staff to call on and provide support when required.
- Alexander House is isolated at night which is not ideal for safely managing the increasingly complex needs of those who are admitted to hospital.
- The close proximity of general hospital services to Rowan Ward would be an additional benefit.
- There is more scope to develop and improve the environment on Rowan Ward.
- It frees up space at Alexander House to develop a community-focused mental health resource centre for older people on that site. Staff would work from this site and provide outreach services for the local communities. This would mirror proposals that are being developed for adults of working age in the area and provide a real focus for community services.

Reducing the number of inpatient beds will enable us make the savings we need to protect and invest in our community services and to continue to improve services for the benefit of local people.

2. Strengthening community services

Improved care and experience for older people in care homes

We will invest to expand our liaison service for nursing and residential care homes by employing an additional three qualified nurses in this specialist field. We will work with staff, residents and families to develop detailed care plans to help maintain residents in their home and prevent admission to hospital.

The team will also support and educate staff in care homes to help improve their care of people with dementia and associated challenging behaviour. This will also ensure that local residents have the same access to these more specialist services as residents of other areas served by the Trust.

Improved care and experience for older people in acute hospitals

Significant numbers of older people who are admitted to acute hospitals have dementia. The liaison psychiatry service is a specialist mental health service which works in our major hospital in Harrogate, the community hospital in Ripon and the Lascelles Neuro-Rehabilitation Unit in Harrogate. It has a key role to play in helping to support staff treating patients with dementia and reducing lengths of stay in the acute hospital. It is already working well in the Harrogate and rural district.

We will continue to develop this service and, by working closely with on-call psychiatry, will extend the service to cover seven days a week. We expect to have this in place by the end of March 2013. Clinicians will also work with colleagues in the acute hospitals to support care for people at the end of their life.

Day hospital service

We have combined our three day hospitals at a central base at Rowan Day Hospital in Harrogate District Hospital. We plan to develop day hospital services to provide specialised mental health interventions such as medication monitoring and behavioural assessment.

We will continue to work closely with social care colleagues so that patients and their families get care and support that has been tailored to meet their individual needs using, where possible, direct payments and personal budgets.

Development of a dedicated memory service

In line with the National Dementia Strategy we are developing our memory service to provide early access to good quality diagnosis and treatment as well as education, support and advice.

Our aim is to reduce the time it takes to receive a diagnosis of dementia and to start active treatment. We have already reduced waiting times from ten weeks to seven weeks and our aim is to offer an appointment within four weeks of referral.

Management of anti-psychotic prescribing

Ninety per cent of people with dementia will at some point experience behavioural and psychological symptoms, such as restlessness and shouting. These distressing symptoms can often be prevented or managed without medication. However, people with dementia are frequently prescribed anti-psychotic drugs as a first resort. This increases the risk of other health problems and can reduce a person's quality of life.

Reducing the use of anti-psychotic drugs for people with dementia is a national priority. We will work with local services to monitor and reduce the level of anti-psychotic drug prescribing and initially focus this with nursing and residential care home services.

Improve the inpatient environment

For those people who need to spend time in hospital it is important that the quality of the environment supports the quality of care they receive. TEWV has an excellent track record in modernising its facilities and has some of the best inpatient accommodation in the country.

We recognise that the current quality of the inpatient environment in Harrogate is not as high as we would wish and we are looking at how we can improve the environment to bring it up to the standard of other TEWV properties i.e. providing single rooms with en-suite facilities.

The future use of Alexander House

Alexander House is a valuable part of the mental health infrastructure in the Harrogate area and we want to make sure that we make the best use of this excellent facility.

Historically, staff on the unit have provided planned respite care for patients with dementia. Respite is an essential component of the care available for people with dementia and their carers. However, it is really important that patients and their carers get the individualised care they need, at the right time and in the most appropriate environment.

A hospital bed is not the best environment for regular, planned respite care and there are other organisations that are better placed to provide this type of support.

Currently there are no more than four people who receive respite care at Alexander House at any one time. We will continue to provide respite care for those who need it until more appropriate support can be found and we will work closely with social services, families and the voluntary sector so that people continue to get the respite care they need.

If these proposals are approved Alexander House will be used for community teams and services.

In the meantime, however, we want to continue to make good use of the facility and will use it to accommodate a small number of patients from Malton while we build a specialist inpatient unit for the whole of North Yorkshire.

The new facility, which will be built on the site of the existing unit in Malton, will care for older people with dementia who have complex needs. Work on the development starts in October 2012 and will take a year to complete.

Some frequently asked questions

Q: You talk about services for older people – who do you mean exactly?

Generally speaking, we mean people aged 65 and over. However, people are very different and have very different needs; individuals will be cared for in a ward that best meets their needs.

If, for example, a person aged 55 with early onset dementia needed inpatient treatment and it was deemed that the older people's ward could best meet their care needs that is where they would be treated. Alternatively, a fit and active 75 year old with depression may be treated within the younger adult service.

Q: Is keeping things the way they are an option?

Evidence shows that the use of inpatient beds is declining as more people receive the support they need in their home environment and that Harrogate has too many beds.

Bed occupancy at Alexander House is less than 25% and this is not a good use of taxpayers' money. We need to focus our investment on the development of more community based services and reducing bed numbers will enable us to do that.

Q: You state your analysis of the population shows that we need more community services and fewer hospital beds. Does this take into consideration the ageing population and any growth in the overall population in Harrogate?

Our analysis does indeed take these factors into consideration. Using the latest public health information and data we have been able to plan for the future.

Regardless of how much the population grows, the model of more community services and fewer hospital beds is the model that will bring the best results for patients.

The population may be ageing but in general older people are more fit and healthy than they have ever been. We will, however, continue to monitor this to ensure we are able to provide inpatient care when this is appropriate.

Q: How can you be sure that these bed numbers will be right in the future as the population grows and people use services differently?

We are confident that 16 beds will be enough for the foreseeable future. There are a number of reasons for this.

We know that increased community support will mean more people can remain independent in their homes as they wish and are less likely to be admitted to hospital. We also know that by improving the quality of the environment, people will recover faster and spend less time in hospital.

We are committed to regularly reviewing how services are being used and considering how we can adapt what we provide to match demand. The way we are proposing to organise services means that we will be able to use the facilities flexibly.

Q: We can accept that community services provide better outcomes and that avoiding admission to hospital is a good thing. Instead of changing everything why don't you just take a few beds out of each of the current wards?

If we were to do this we would make each of the wards potentially unsafe, inefficient and more costly to run. If we took a few beds out of each ward we would not be able to make the investments we need in community-based services or in improving the environment of the existing facilities.

Q: Haven't you already stopped using some beds?

It is correct that in recent months there has been a reduction in bed usage, particularly at Alexander House as a result of changes to clinical practice. The wards are consistently under used and by bringing them together we will be able to consolidate the beds into one ward, enhancing staff levels and make best use of NHS resources.

Q: Haven't you already stopped providing respite care at Alexander house?

It is correct that in recent months we have reviewed the provision of short term admissions to Alexander House. The provision of short term care for people with dementia in a hospital inpatient environment can be both disorientating and distressing. As such an admission should be focused on providing assessment and review of treatment. Where it is clinically required, short term admissions are still taking place.

Q: I have always had respite care from Alexander House, what will happen now?

Ideally regular respite care should be provided in a suitable, safe environment in the community which meets the person's individual needs. We have been working closely with our colleagues in social care at North Yorkshire County Council to identify opportunities for regular respite care in more suitable environments.

We will continue to provide short term admission to hospital where care needs have been identified to include NHS respite care, or where safe appropriate alternatives to meet the individual need of the patient for this respite care are not currently available in the community setting.

Policy and evidence documents

Below is a list of policy documents or evidence we have referenced in this document or we are basing some of our service proposals upon. Also included are links to where they can be found on the internet.

- ***The National Service Framework for Older People (2001)*** – a Department of Health framework for services that are centred around the person regardless of their age.
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003066
- ***Inpatient care for older people within mental health services (2011)*** - a report by the Faculty of the Psychiatry of Old Age of the Royal College of Psychiatrists. Provides some recommendations around key issues surrounding inpatient provision**
http://www.rcpsych.ac.uk/pdf/FR_OA_1_forweb.pdf
- ***Our health, our care, our say (2005)*** – from the Department of Health sets a clear direction for services to make sure they are based in community settings, linked to primary care (GPs) and with pathways into specialist, secondary care services (such as our service). It highlights the need to promote early intervention and prevention*
<http://www.official-documents.gov.uk/document/cm67/6737/6737.pdf>
- ***Everybody's Business (2005)*** – from the National Mental Health Development Unit says that mental health services for older adults should be 'joined-up' supporting both the patient and carer*
<http://www.nmhd.org.uk/our-work/mhep/older-life/everybodys-business/download-documents/>
- ***The National Dementia Strategy (2009)*** – from the Department of Health contains guidance about dementia services and how these should be provided in the future. It talks about:
 - Providing better information
 - Earlier diagnosis and services to keep people out of hospital
 - Improved support for carershttp://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058
- In July 2011 an **All-Party Parliamentary Group (APPG) on dementia** reported that greater effort should be put into preventing inappropriate hospital admissions through investment into community services. They also said that better discharge planning and improvements to care pathways could reduce length of stay for people with dementia who did not clinically need to be in hospital. www.dh.gov.uk

The Government's Dementia Challenge and supporting documents can be found at <http://dementiachallenge.dh.gov.uk/strategy/>

Giving us your views

It is vital to involve local people in making decisions about future services.

Harrogate and Rural District Clinical Commissioning Group (CCG) working with TEWV are totally committed to providing the best possible care for older people in the Harrogate area and making the best use of taxpayers' money by maximising the health benefits of every pound spent.

This means changing how we provide services and working closely with our health, voluntary sector and social care partners so that we can continue to meet the needs of an increasingly ageing population.

The CCG and TEWV will be seeking people's views on these proposals between 15 October 2012 and 21 January 2013.

We are keen to hear your views on these proposals and whether there are any additional issues that we need to take into account when developing services or making changes.

There are a number of ways you can share your views.

1. By attending a Public Event

During November we are holding four public events.

Date	Venue	Time
Monday 12 November 2012	Knareborough Town Hall Knareborough House High Street Knareborough HG5 0HW	Evening meeting Doors open: 6.15pm Presentation: 6.30pm Close: 8.30pm
Tuesday 13 November	Ripon Town Hall Market Place Ripon HG4 1BZ	Evening meeting Doors open: 6.15pm Presentation: 6.30pm Close: 8.30pm
Tuesday 20 November	St Marks Church Leeds Road Harrogate HG2 8AY	Afternoon meeting Doors open: 2.00pm Presentation: 2.15pm Close: 4.00pm
Thursday 22 November	St Robert's Centre 1 – 3 Robert Street Harrogate HG1 1HP	Evening meeting Doors open: 6.15pm Presentation: 6.30pm Close: 8.30pm

The format of the meetings will be a presentation on the proposals followed by discussions. This will give those attending the opportunity to meet with clinicians, NHS and North Yorkshire County Council representatives and staff to hear more details, ask questions and express your views.

2. By sending us your views in writing:

By email to the CCG at: nyy-pct.HaRD@nhs.net

By free post (no stamp needed) to: Harrogate and Rural District CCG
FREEPOST RSHB-UTRR-LZUA
The Hamlet, Hornbeam Park
HARROGATE HG2 8RE

3. By inviting us to attend one of your meetings

If you would like a representative to come along to one of your meetings please let us know as soon as possible by telephoning the CCG on 01423 859623, or by emailing us at: nyy-pct.HaRD@nhs.net

4. By completing a survey

We have designed a survey for people to feed back their views about our proposals.

This is available via the CCG website until 21 January 2013. Visit:
www.harrogateandruraldistrictccg.nhs.uk

If you would prefer a paper copy of the survey you can request one by contacting the CCG on 01423 859623 or by emailing us at: nyy-pct.HaRD@nhs.net

Remember: This engagement period will end on 21 January 2013.

We look forward to hearing your views on these proposals

Report from Public Engagement process on the proposed changes to mental health services for older people in the Harrogate area

1. Summary

During the engagement period which ran from 15 October 2012 through to 21 January 2013:

- 5 open public events have been held. Four of these were in November 2012 and the last in January 2013. A total of 64 carers, patients, voluntary sector representatives and members of the public attended the events
- 3 invitations were received during the engagement period for representation at Local Council meetings to discuss the proposals and answer questions
- 43 valid survey responses have been received
- 2 letters and 1 email detailing concerns from members of the public have been received
- 1 more targeted event has been arranged outside the 'official' engagement period specifically with carers via Carers' Resource. This is due to take place on 5 February 2013. The responses and comments received at this meeting will be added to this report for consideration by the Governing Board of the Harrogate and Rural District Clinical Commissioning Group, and will be verbally reported to the North Yorkshire County Council Overview and Scrutiny Committee on 8 February 2013.

The majority of feedback received throughout the engagement period has been largely in support of most of TEWV's proposals; namely to improve the memory services, to improve both liaison services (hospital and for nursing/residential care homes), and the development of day hospital services.

The main area of concern has consistently remained around the proposals to reduce the number of in-patient beds for older people with mental health problems and to concentrate all in-patient services in Harrogate Hospital's Rowan Ward.

In addition, the importance of respite care and the need for clarity over the provision of respite has arisen as a major theme throughout the engagement process.

2. Background

NHS Harrogate and Rural District Clinical Commissioning Group (CCG), in partnership with Tees Esk and Wear Valleys NHS Foundation Trust (TEWV), held four public engagement events during November 2012 in order to inform the public of the changes proposed and obtain people's views. It was decided to hold an additional open public event on 16 January 2013 before the end of the engagement period.

Alongside the open public events, the CCG and TEWV have spoken at Local Council meetings, and the CCG has also undertaken a survey seeking people's views on each of the specific proposals put forward in the consultation document.

Invitations to comment, complete the survey, and attend a meeting, were sent out with the consultation paper to a wide range of key organisations and individuals including patients, carers, the voluntary sector, local representatives, advocacy organisations, key committees and groups (e.g. Overview and Scrutiny Committee), local and County Council, NHS staff, Foundation Trust members, etc. (see Appendix 1)

Groups were asked to contact the CCG if they wanted to invite representatives from TEWV and the CCG to one of their own meetings.

The following report provides a summary of the engagement process and feedback received.

3. Public Engagement Events

Date	Venue	Time
12 November	Knaresborough Town Hall	6.30 to 8.30pm
13 November	Ripon Town Hall	6.30 to 8.30pm
20 November	St Mark's Church Harrogate	2.00 to 4.00pm
23 November	St Robert's Centre, Harrogate	6.30 to 8.30pm
16 January	Knaresborough Town Hall	2.00 to 4.00pm

In total 64 members of the public, patients, carers, voluntary sector representatives, advocates, Parish, Local and County Council representatives, and representatives from local care homes and charities attended the five events. Two members from the local press also attended meetings in their respective areas.

Alongside the above, managers, operational staff and clinicians from the CCG, TEWV and the PCT (NHS North Yorkshire and York) attended each meeting to help with the discussions.

Amongst the local voluntary sector organisations attending the meetings and contributing to the discussions were representatives from the following: Age UK North Yorkshire, the Alzheimer's Society, Carers' Resource, Dementia Forward, Harrogate Mind, York Mind, Harrogate and Area CVS, Ripon and District CAB, Supporting Older People, and North Yorkshire Forum for Older People.

Four of the meetings were chaired by Cllr Clark, Chair of North Yorkshire County Council Overview and Scrutiny Committee, and one by Kevin McAleese, Chair of NHS North Yorkshire and York.

Following presentations on the proposals, facilitated discussions took place at each table where attendees were invited to ask questions and put forward their views. Notes were taken by support staff from the North Yorkshire and Humber Commissioning Support Unit.

3.1 Summary of discussions – Main themes

The main themes arising from the discussions can be summarised as follows:

- Generally the participants showed cautious approval of the proposals to improve memory services, both liaison services (hospital and for nursing/residential care homes), and some agreement around the development of day hospital services.
- Concerns were mainly raised around the proposals to reduce the number of in-patient beds. Some comments were made specifically about Rowan Ward and its fitness for purpose.

The vast majority of comments received revolve around the needs of carers of older people with mental health problems and particularly dementia.

- The importance of respite care both for the cared for and the carer – comments that this has not been addressed in the proposals
- Meeting the needs of carers is vital – they are the key to support patients in their own homes and the proposals were seen as increasing the pressure on carers because of the reduction of inpatient services and lack of clarity around respite.
- Information needs of carers, and training support.

Other themes

- Concerns about patients who live alone/ have no carer support
- Working with voluntary sector
- Need for joint working/ shared services/ more integration/ seamless
- Rural communities and access to services
- Early diagnosis and role of the GP and primary care
- Out of hours – what happens then?

The main comments from each individual event are detailed in Appendix 2.

4. Meetings attended during the engagement period

The CCG and TEWV were invited to attend three external meetings to outline the proposals and take questions and comments from Council members. In advance of each meeting members were sent a copy of the engagement letter and proposals.

A summary from each meeting follows below.

4.1 North Yorkshire County Area Committee for the Harrogate District – 1 November 2012

The meeting was attended by George Lee, Senior Commissioning Manager from the CCG, Dr Nirodi, Consultant Psychiatrist from TEWV, and Paul Hyde, Head of Service for Older People's Mental Health Services, TEWV.

George Lee provided a verbal overview of the reasons why the CCG wished to hold a public engagement on the future of inpatient care beds in Alexander House, Knaresborough, and outline details of the preceding work that had been done with TEWV and also the North Yorkshire County Council Scrutiny of Health Committee.

The questions and thematic comments that the attendees responded to were:

- Details on how and where the engagement had been publicised.
- Assurance that the costs of providing respite care would not be transferred from TEWV to the Local Authority.
- Why the additional highly specialised dementia care unit was to be sited in Malton, North Yorkshire.
- Members also expressed concern and sought reassurance that proposals would not adversely affect the support to carers of people with dementia and in particular access to respite care and breaks.
- There was concern about the quality of the Briary wing and a view that Alexander House was more homely environment.

Following the discussion, Members and Co-opted Members of the Area Committee resolved to encourage as many people as possible to comment on these proposals.

4.2 Knaresborough Town Council - 5 November 2012

The meeting was attended by George Lee, Senior Commissioning Manager from the CCG, and Adele Coulthard, Director of Operations, TEWV.

Following a verbal overview and presentation the questions and thematic comments that the attendees responded to were:

- Details on how and where the engagement had been publicised and why the ward level Councillor had not been made aware.
- There were comments that Alexander House had been commissioned against a business case that argued it had been required to meet local needs? Some members expressed surprise at proposals to cease providing inpatient care and wanted to understand why it was thought that fewer beds would be required given the increasing numbers of older people in Harrogate and Rural District.
- There were concerns that local people would have to travel further, and what assistance would be given to relatives.
- Why the additional highly specialised dementia care unit was to be sited in Malton, North Yorkshire, and why more local solutions could not be sought, for example in Leeds.
- Members also expressed concern and sought reassurance that proposals would not adversely affect the support to carers of people with dementia and in particular access to respite care and breaks.

4.3 Harrogate Borough Council Overview and Scrutiny Commission – 8 January 2013

The meeting was attended by:

Amanda Bloor, Chief Officer (Designate) Harrogate and Rural District CCG
Adele Coulthard, Director of Operations, TEWV NHS Foundation Trust
Dr Rick Sweeney, GP Clinical Lead, Harrogate and Rural District CCG
John Pattinson, Director of Quality, Harrogate and Rural District CCG
George Lee, Senior Commissioning Manager, Harrogate and Rural District CCG

Amada Bloor provided a verbal overview of the reasons for the public engagement on the future of inpatient care beds in Alexander House, Knaresborough.

Adele Coulthard gave members a presentation on the proposals.

The questions and thematic comments that the attendees responded to were:

- There were comments about the quality of the inpatient environment in the Briary suite and the impact of this on patients.

- Given the expected increase in the numbers of older people who will suffer dementia, there were concerns that there would not be sufficient beds in the Harrogate and Rural District area if the beds at Alexander House were to be closed.
- Members also expressed concern and sought reassurance that proposals would not adversely affect the support to carers of people with dementia and in particular access to respite care and breaks.
- Members welcomed the proposals to improve services, to include memory clinics, support to residential care, nursing homes, and Harrogate Hospital.

Members closed the meeting following a show of hands for support for the proposals. The TEWV proposals were supported by a majority of members.

5. Survey Results

5.1 Survey Process

The survey could be completed on-line via a link from the Harrogate and Rural District CCG website, it could also be downloaded, and hard copies were included in the packs handed out to all attendees at each of the 5 public events. Any hard copies could be returned via a Freepost address to the CCG.

A **total of 43 surveys** were completed during the engagement period. The majority (33) were filled in by respondents via the on-line survey, with the other 10 questionnaires either completed on hard copies and returned to the CCG Freepost address, or downloaded and sent back to the CCG via email.

Unfortunately not all respondents completed every section.

One respondent made an additional survey entry to demonstrate their concerns over the potential for survey respondent bias. They had already completed their questionnaire and then opened an additional survey with the comments below:

“Please note: when compiling survey responses i.e. number who agree/disagree, survey results may not be completely accurate as “survey monkey” enables surveys to be completed a multiple number of times simply by using different computers and web browsers. This particular response should be classed as nil and void, as I have already completed a survey and merely wanted to raise my concern that the survey process is not reliable!”

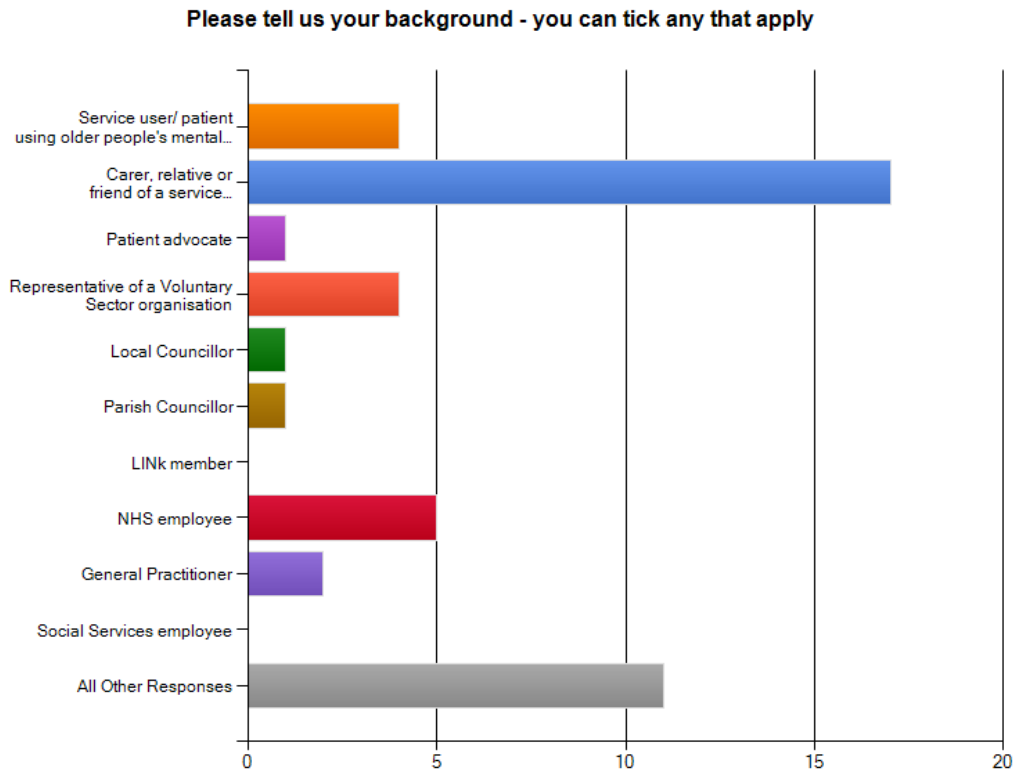
The above response has been removed from the analysis and is not included in the figure below.

In answer to the concern raised by the respondent, they are right in that any survey which is not carried out face to face can be open to the potential of respondent bias. This is not limited to on-line surveys such as this. Postal surveys could easily be completed many times by the same person and sent in separately to the return address. Any on-line survey package could be manipulated in the way suggested by the respondent – not just Survey Monkey – although it does retain IP addresses so that suspiciously large numbers of responses from the same IP addresses can be checked for repetition etc.

This particular survey was designed so that people could give their views in detail to each of the proposals. In data-checking there has been no repetition within the qualitative responses. Also, in designing the engagement process, we have used different approaches to gather local people’s views, and have not relied on only one method.

5.2 Background of Respondents

We asked respondents about their background in order to gauge who we were reaching with the survey. The majority of respondents who answered the question were a carer, relative or friend of a service user/patient (17 people), 4 service users and 4 voluntary sector representatives also completed the survey.



In the 'All Other Responses' category, the respondents included 2 Public Members and 1 Public Governor of TEWV, a member of the local clergy, a member of the public, a local resident, a volunteer, a GP Practice Manager and a "Relative of a now deceased service user (Alexander House, Harrogate District Hospital and a Care Home)".

We then asked respondents about each of the proposals put forward by TEVV which were summarised above each question.

5.3 Proposal to expand the specialist liaison service for nursing and residential care homes

Do you agree with the proposal above to expand the specialist liaison service for nursing and residential care homes?		
Answer Options	Response Percent	Response Count
Yes, completely	56.8%	21
No, I have some concerns	43.2%	16
Please tell us what your concerns are		17
Answered Question		37
Skipped Question		6

A number of respondents used this space to comment in general on caring for people with dementia in their own homes, rather than expressing concerns about this specific proposal. Their comments are included in the analysis of later questions.

The main points raised about the proposed expanded specialist liaison service are below:

- Need for investment in the training of staff in nursing and residential homes
- Need to ensure that the training provided is put into practice
- How many specialist staff are there currently providing such liaison services?
- Will 3 extra staff be enough?

One respondent commented: *“Three extra specialists in this field hardly seem enough for this area, especially taking into consideration the large rural communities it covers. It is not only staff in care homes that need extra training, the staff in the various community care teams (both private & social carers) need better training & much more time to spend with clients & their carers.”*

Another said: *“Staff in care homes definitely need to be supported and educated to help provide their care of people with dementia – too many horror stories.”*

“Three qualified specialist nurses will be a help. However the growing number of dementia, Alzheimer’s sufferers and those with later age mental health problems will need a central place where people can seek support, help and guidance in a future where many more carers will be based in their own homes. It’s a growing problem worthy of a much more comprehensive response coupled to highly a visible, easily accessible, locally based service.”

5.4 Proposal to extend the liaison psychiatry services in hospital

Do you agree with the above proposal to extend the liaison psychiatry service which works with staff and patients in hospital?		
Answer Options	Response Percent	Response Count
Yes, completely	80.0%	28
No, I have some concerns	20.0%	7
Please tell us what your concerns are with this proposal		6
Answered Question		35
Skipped Question		8

The majority of respondents, who answered this question (80%), agree with the proposal. The concerns raised were:

- Whether there were to be additional clinicians to provide the extended service, if not how would they cover the extra workload?
- How would patients access these services once back in their own homes?
- A comment from a carer saying that it is the carer who needs the extra psychiatric support – and that a stay for the patient in hospital provides the carer with a break.

5.5 Proposal to develop the Day Hospital Service

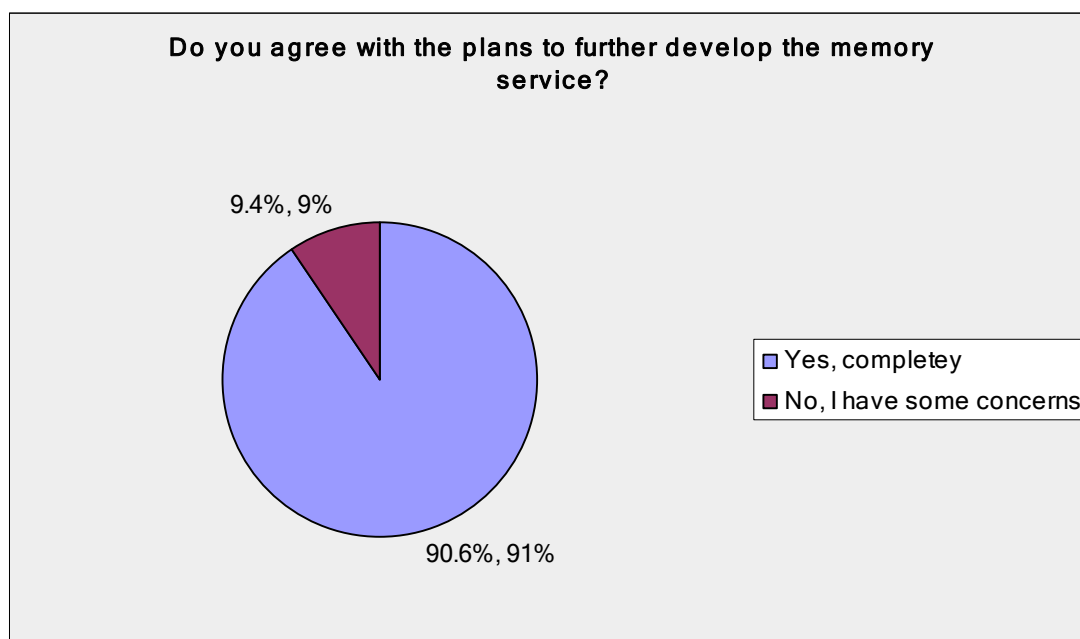
Do you agree with the proposal to develop the Day Hospital Service?		
Answer Options	Response Percent	Response Count
Yes, completely	59.4%	19
No, I have some concerns	40.6%	13
Please tell us your concerns about the plans to develop the Day Hospital Service		13
Answered Question		32
Skipped Question		11

Again, the majority of those who answered the question agree with this proposal. However, more people expressed concerns with this aspect of TEWW's plans.

Concerns that were raised included:

- Centralisation:
 - Issues around accessibility of Day Hospital services – particularly for those in the more rural areas – e.g. with the closure of the Orchards in Ripon
 - Loss of local services in favour of city-based
- What services will more a developed Day Hospital Service provide? E.g. group sessions based around activities?

5.6 Proposal to develop the memory service



The vast majority of those who answered this question agree with the proposal (29 respondents or 91%). Three people said they had concerns and 7 people commented on the proposal.

One respondent who had been a carer said they had some concerns and commented, *“It is excellent to hear that the 4 weeks target has already been achieved. However, increased efficiency will create increased demand on resources, as currently nationally only 33% nationally (45% in Harrogate) of patients are diagnosed. Also there is a recorded reluctance by primary care to refer to specialist MH services (DH 2009).”*

Another view from a carer/relative: *“I think that such a service is vital and should be available as soon as possible to those with a diagnosis of dementia. I would, however, query whether the four session course initially proposed would be adequate. The course we attended was run by Alzheimer's Society over a twelve week period, giving time for those taking part to get to know one another and feel comfortable with the sessions. It gave time to tackle many aspects of living with dementia in an unhurried and relaxed way, something which could not be achieved so effectively over a shorter time.”*

A carer who is in favour of proposal added that, *“It is very hard to get a diagnosis of dementia for people under the age of 70”.*

Another carer/relative in favour of the memory service plans said: *“It is not just the actual diagnosis of dementia, the follow-up procedure needs improving drastically. Saying you will get an appointment in six months does not happen. The service is not fit for purpose.”*

5.7 Proposal to reduce the number of inpatient beds

Do you agree with the proposal to reduce the number of inpatient beds for older people with mental health problems?		
Answer Options	Response Percent	Response Count
Yes	46.7%	14
No, I have some concerns	53.3%	16
Please outline any concerns you have about this part of the proposals		18
Answered Question		30
Skipped Question		13

Just over a half of the survey respondents who answered this question do not agree with this proposal. This was the main issue that attendees at the meetings were concerned with. Unfortunately 13 respondents did not actually answer this question.

A summary of the concerns raised is as follows:

- National guidance/guidelines does not take account of local needs
- Concern that this will not address the projected increase in the number of patients with dementia in the future. Particular concern for an area like Harrogate with an increasingly elderly population.
- Concern that this will limit the number of patients who can be assessed and treated at any one time.
- Concern that some patients will be missed, or left in the community when they should really be in in-patient care.
- Concern that this will mean “*even less respite care*” will be provided leading to a greater pressure and knock-on effect for [unpaid] carers
- One respondent had concerns about current provision on Rowan Ward, and that it would have to be enlarged in order to provide the right environment. They stated that at present Rowan Ward “*is quite crowded, and dementia patients greatly annoy patients with mental illnesses such as depression...found Rowan very claustrophobic.*”

Some of the comments received from carers/relatives are as follows:

“Together with the concerns expressed in section 4, I feel that this siting of a single unit at Harrogate Hospital is far from ideal. An assessment process requires observation over a continuous period of time but in an environment that is as much like a home environment as it can be, so as to get a true picture of what treatment and care needs really are. A separate unit, away from a hospital environment, which provides day care facilities where a patient can become familiar with staff and surroundings before being admitted to an inpatient bed on the same site for fuller assessment seems to me by far the best option. Sadly, finance seems to be an important part of this decision...”

Another asks for more information and clarification

“(a) Harrogate has a x3 rate of in-patient admissions in the region for 2010/2011. (b) Current assessment beds = 78, but there is no supporting evidence provided for this figure as of January 2013 provided for this estimate. (c) Harrogate has a higher rate of 65 year olds than the national average (National Press 2012). (d) What are the current rates of admission for anxiety/depression? These are not stated. However, it would be essential for Rowan Ward to convert to single rooms to avoid inappropriate close proximity with dementia patients (DH 2009 p54). (e) There is no mention of facilities for continuing/intermediate care, particularly for those patients with concomitant physical problems.”

A local clergyman comments:

“This would clearly result in the private sector Nursing Homes taking on a greater burden for providing this service. As a regular visitor to nursing homes, my experience is that those that are registered to care for residents with dementia are covering up for the NHS low usage of the facilities they have at their disposal. In other words, this is privatization by stealth of the care of people with dementia needing residential care.”

Another comment from a local Councillor reflects a point raised by a number of people attending the open public meetings:

*“I am concerned about lack of appropriate in-patient facilities for patients with a **functional mental illness**. The focus is on dementia but the needs of those with other mental health problems must not be overlooked. And a "dementia" ward is not the place to care for those with a severe depression or anxiety disorder.”*

5.8 How do you think the Trust can make best use of Alexander House in the future?

Respondents were able to give their views on the potential use for Alexander House should the proposals go ahead. 19 people put forward their suggestions.

Some of those who commented would like to see Alexander House used for providing services to help support [unpaid] carers. This included:

- respite day care
- carers' meetings
- information events for carers
- social care and health care coming together to talk to carers
- for talks and demonstrations for carers and relatives

- somewhere *“where not only staff will be able to provide first class services for clients and carers, but that carers will feel more in touch with all services provided and not feel left out.”*

A comment from a carer/ relative which reflects the views expressed at two of the open public meetings is that:

“Alexander House needs above all to be a true community resource for older people with mental health issues and their carers, with many of the characteristics of a drop-in centre - welcoming and readily accessible as a centre for information, support and practical help.”

Other main themes were:

- A base for community mental health services/ centralise community teams/ recovery focussed mental health resource centre (primary and secondary care together in the one building)
- More day activities for the cared for
- Day centre providing the existing memory clinic, occupational therapy, and other therapies as appropriate to local people with dementia and other mental health problems
- A possible centre for activities for older people to help reduce isolation and loneliness
- Physical therapy area should be included; falls and depression in elderly people with mental health problems need to be acknowledged as a priority.

And a plea for more respite [emphasis in capitals by respondent themselves]:

“PLEASE TRY TO OFFER SOME FORM OF REGULAR RESPITE CARE IN THE FORM OF FLATS THAT COULD BE “LET” OUT TO FAMILIES SO THAT THEY CAN PROPERLY PLAN RESPITE CARE AND ENABLE THEIR RELATIVES TO STAY IN THEIR OWN HOME!”

5.9 Other suggestions/ comments / issues

- 16 beds is not enough
- Respite care and the needs of carers are vital
- Respite care future arrangements are not covered in the proposals
- Need to take account of the other carers [not only the primary carer based in the house with the patient] - family

Comments about the respite care

1. *“The information regarding future arrangements for the respite care traditionally provided at Alexander House seems rather vague. The “more suitable environments” referred to need to be clearly identified and secured so as to ensure this service does not fall by the wayside.”*

2. View from a carer/ relative: *“A major concern in all of this is the lack of respite care, particularly residential care; often the straw that breaks the camel's back for exhausted carers, however committed they are to their carer's role. I greatly regret the loss of inpatient beds both at Alexander House and The Orchards in Ripon. The sheer relentlessness of caring for someone with dementia twenty-four hours a day, day in day out, with no prospect of any real break is exhausting and demoralising. All too often, it can lead to a very stressful life which causes real distress to both cared for and carer.”*
3. *“Dementia needs come in twos – THE CARER – a very important part of your proposals to keep patients in their homes. They also have needs!”*
4. Another felt that the proposals are a *“cost-cutting exercise that is continuing to put pressure on carers to provide full time support 24 hours a day... the carers in Harrogate District need more respite care not less in order to take a break from the arduous work they do! Offering carers support one hour a fortnight if they are lucky is a joke”*

One respondent commenting on the first question raised their concerns about caring for someone with dementia at home:

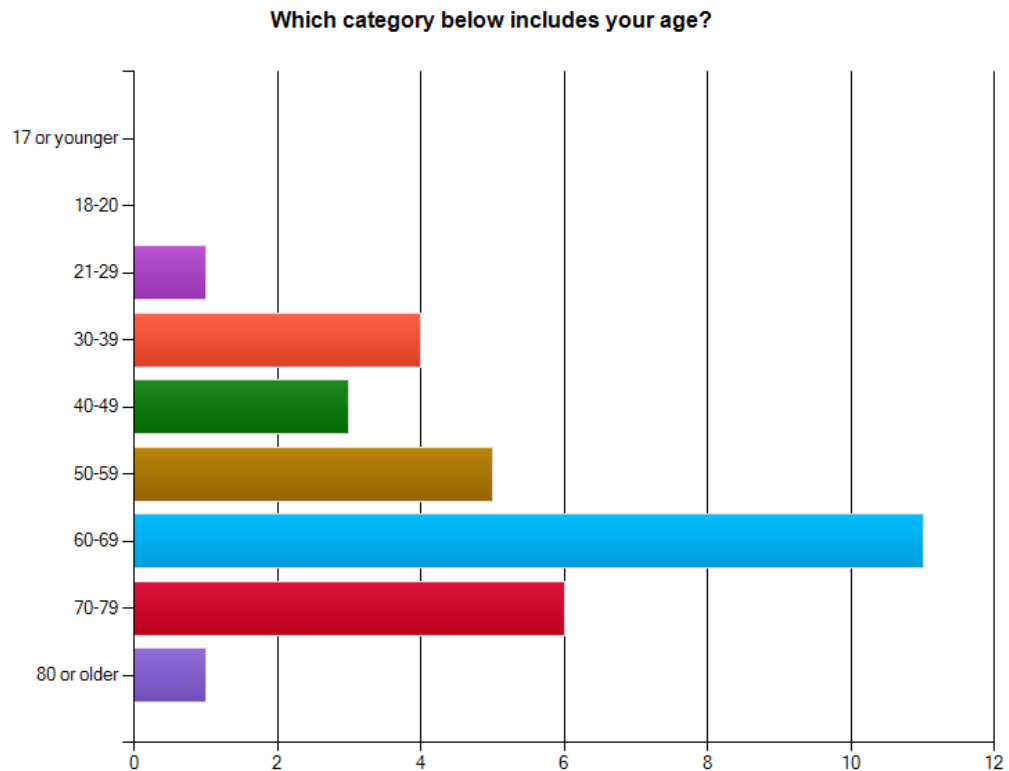
“I have no concern with the establishment of these 'teams' to develop care plans. But a plan is no use if it cannot be followed through. My experience - based on my late father's situation - is that care in their own home is difficult to service. This especially applies to dementia people who are faced with irregular hours, short visits and big turnover of staff in any given period. This adds to their distress and confusion.”

A former carer commented:

“2 main issues are inadequately addressed: 1. The success of this whole strategy depends on intra-agency support which, from personal experience, I would suggest does not currently exist. In the community it is easy for individuals to get 'lost' in the system. 2. A major issue, not addressed adequately in these proposals, is the support of carers and the need and provision of appropriate respite care for both patients and carers. Also: Personal budgets are suggested as a solution for optimising care in the community, but do overburdened and possibly frail and elderly carers have the expertise/confidence to make use of these? Recent Government changes in the retirement age and state pension will also impact on the availability of lay-carers.”

5.10 Demographic information about our respondents

- **Age Group** – the majority of respondents (11 people or 35%) are in the 60-69 age group and the breakdown of age range can be seen in the table below. 12 people did not answer this question.



- **Gender** – 63% of those who completed the survey are female, and 37% male.
- **Ethnic background** – a total of 29 people answered this question. 89% (or 26 people) ticked the White British category, 1 person said they were White – Other, and 2 ticked the 'I'd prefer not to answer' box. In the 'Other – please state' box, 1 respondent replied that they are Sinhalese from Sri Lanka and another American.
- **Closest town** – the majority of those who completed the survey live closest to Harrogate.

Please tell us which of the following towns is closest to where you live.		
Answer Options	Response Percent	Response Count
Harrogate	60.0%	18
Knaresborough	16.7%	5
Ripon	20.0%	6
Other - please state	3.3%	1
Answered Question		30
Skipped Question		13

6. Letters and emails received

Two letters were received by the CCG and one email. All three reflect very much the issues raised in the survey responses and during the discussions at the open public events.

Comments were around:

- Early diagnosis and treatment of dementia – the need to have information available very widely (citing the recent TV campaign about memory loss) being a good example. This should be followed up locally.
- Helping people to stay at home longer – use of Telecare, occupational health and key members of multi-disciplinary teams to help people with dementia and their carers with the right equipment, support and advice.
- Carers and relatives – concerns that this is where the current system breaks down. The current level of services do not adequately sign-post people who are at ‘breaking point’ to the support that is out there. Current services do not work closely enough with the voluntary sector support services.
- A service user commented that the service they had received at home from the Community Mental Health Team and a physiotherapist, having pushed for a year with different GPs and trying different medications, has now helped the patient feel well and *“normal....It made a big difference being seen at home”*.
- A respondent who had attended one of the meetings had written in to comment on what they felt was a ‘missed opportunity’ that the issue of respite had not been addressed in TEWV’s document – whilst recognising that respite comes from different providers. It should not be so difficult to access.
- They emphasised the stressful role that any carer has to endure – and that often carers can become ill and/or depressed themselves because of their caring responsibilities. The need for full respite care in such circumstances is vital – both for the carer and patient and to *“significantly extend the length of time a dementia patient can remain in their own home”*.
- The respondent also highlighted the financial case for properly supporting carers to continue providing help for patients for as long as possible at home. *“A carer saves the NHS/social services about £800 very week they can prolong the length of time a patient can remain in their own home.”*
- This person says that in their experience, a *“week’s respite every 8 weeks can extend care at home by three years or more. If respite and permanent care in a private dementia unit costs £800 per week, a saving of £36,400 for each year the patient can remain at home would result...”*
- *“I am aware that cost saving can accrues to the NHS because a cost is transferred to the social services budget but both these services must cooperate to bring about the best possible outcome for the taxpayer.”*

The respondent urges TEWV and the CCG to ensure that there is no reduction in the provision of respite care.

- *“I recognise that luncheon clubs, days out and a visit from a carer support worker such as those provided by the Alzheimer’s Society can improve a patient’s quality of life but they do not extend the length of time a dementia patient can remain at home.”*

Appendix 1

Stakeholder list for Letter and Consultation Document

Letters of invitation to the open public events and information on other ways to comment on the proposals were sent along with the consultation document outlining the proposals, to the list below via Harrogate and Rural District CCG and TEWV Foundation Trust. A second letter was sent prior to the extra public event in January 2013.

Patients via TEWV
Carers and families of patients via TEWV
Alzheimer's Society
Age Concern – (North Yorkshire, Knaresborough, Harrogate, Ripon)
Ripon Council for Voluntary Services (CVS)
Harrogate and Area CVS
Carers' Resource
Dementia Forward
Harrogate and Ripon MIND
Supporting Older People – Ripon
Crossroads
Citizens Advice Bureau
Harrogate District Local Involvement Network (LINK)
North Yorkshire LINK
Independent Care Group
Care Homes – public and private

Harrogate and Rural District CCG
GPs and practice managers
TEWV Foundation Trust Staff
Trade Union Representatives
TEWV Foundation Trust Governors and Members

North Yorkshire County Council (NYCC)
NYCC Overview & Scrutiny Committee
Harrogate Borough Council
Ripon City Council
Knaresborough Town Council
Parish Councils

Harrogate and District NHS Foundation Trust (HDFT)
HDFT Foundation Trust Governors and members
Yorkshire Ambulance Service
Strategic Health Authority (NHS Yorkshire and the Humber)
Commissioners (NHS North Yorkshire and York, other CCGs)
Social Services
Local MPs
Media
Professional bodies

Appendix 2

Feedback from the open public events held during November 2012 and January 2013

Event 1: Knaresborough Town Hall, Monday 12 November

Questions and points raised by members of the public

- Respite care can provide a relief for the carers.
- The need for services which get patients out of the house and doing things, this helps the carer with respect to respite and stimulates the patients.
- Hospital environment versus smaller bespoke setting such as Alexander House.
- Having people in familiar surroundings may be best but keeping people in their own home can be challenging for the family and it also needs to be to be acknowledged that some people do not have families or families who are willing/ able to help.
- In the past when services have been transferred into the community they have failed. This is too important to fail in that way.
- Concerns that Alexander House may be sold off in the future.
- What will happen at the Orchards in Ripon (Answer – this will be used as a centre for young people with dementia).
- Comments that it “all sounds good in theory”, but concern that they need commitment to follow through.
- Concern that patients may “go under the radar”.
- The vital importance of carers’ needs. Questions about who is supporting the carers? Concerns that the burden is falling heavily on the carers and respite is only a small part of this. The point was also made to not always presume that respite is the answer, as carers need support on a day to day basis. Assessment for the carer as well as the ‘cared for’ is essential. How are you going to identify if the carer needs help? GPs need to identify problems a lot earlier.
- Early diagnosis - We need to put more services into GP surgeries in order to catch dementia earlier. We need to get more information to the general public, in rural areas in particular. We suggest a mobile dementia service.
- Concern about what will happen to Alexander House. Worry that the building will be sold privately.
- Liaison Services - getting support to staff in care homes is imperative. This support needs to reach staff before admissions to hospitals.
- How will you go about making Rowan Ward fit for purpose? Comment that at present Rowan Ward would be an “extremely distressing place for someone who is in the very early stages” of Dementia.
- The trend is for NHS beds to decrease, to enable NHS staff to support its population it may need to reverse the decrease in beds or increase the number of patients supported at home.

- Sufficient capacity for frontline staff.
- Carers need to be trained.
- Respite care is important
- 16 beds for 10,000 people seems frighteningly small.
- Support at night time is much more problematic for carers.
- Dementia is not the only thing we need to consider, depression can also be an issue.
- The care plan is key to what is needed.

Event 2: Ripon Town Hall, Tuesday 13 November

- Who decides on whether this goes ahead, CCG or TEWV? PCT never managed the money well.
- GPs can't see someone unless the patient refers themselves. However, the family may know that the patient may have issues that the doctor can't pick up on.
- What will happen with out of hours?
- Rural communities can be difficult for the voluntary sector to serve. This is a question of access rather than money.
- It was expressed by one member of the public that they felt this was privatisation by the back door and a move towards patients paying for care.
- Concern that there was no representative from social services and that more people from the voluntary sector should be present at the meeting.
- Carers will be very frightened about the changes as they may feel they may not be able to cope without respite services.
- What will happen to those who live alone or don't have families or support?

Event 3: St Mark's Church, Harrogate, Monday 20 November

- It is an excellent idea to help people in their homes and to have all the beds concentrated at one site.
- Who will take care of people at home? Families can't be expected to do it all.
- Only having 16 beds is ridiculous.
- Once comment suggesting that the 32 beds are not all currently in use because the NHS is not admitting people to them because it wants to run the service down.
- If people are to be cared for in the home, you will need someone in that home all the time, how do you propose to do that?
- There are very few residential care homes which take dementia or EMI patients, how do you propose to get round that?
- To implement these things you will need lots more staff, will you be putting more staff in place?
- What will happen if extra beds are needed, where will they be?

- Will different agencies become more integrated? One carer commented that they had an experience where they were sent to a number of different agencies, given the same information over and over again, everything took too long, and their mother died before she got the care she needed.
- Rowan ward is not a pleasant place to be - what will happen to change this?
- Social Services need to be here. Why are they not here?
- Supportive of proposals to help maintain independence and living at home for as long as possible. However support within the home for the carer is required to look after the patient.
- Respite and support for carers is required as it is very lonely and isolating – e.g. lack of conversation/motivation/social activities/time to yourself
- Additional support required for carer if patient has to go into hospital.
- Greater communication from “The Memory Service” to enable the carer to understand the patient’s assessments/scoring system.
- Education/training/advice required for clinicians and carers.
- Advice to carers in what to expect/ how condition in patient will manifest itself.
- The pathway/journey the patient will travel – e.g. where will they go next, what will happen after that, what to expect?
- Who can provide further support/guidance and further information to carers as carers often have to find this out for themselves?
- Identified that the level of support/financial aid given to patients/carers is very much dependent upon the carer finding this information out for themselves. This can vary depending on each individual carer and their ability to access this information. Solution would be better joined up working between services such as LA/Social Services/GPs etc to provide information to carers when the patient presents to the GP.

Event 4: St Roberts Centre, Harrogate, Thursday 29th November

- Caring for people in the community is the way things need to go. All of this mirrors work ...as someone who works with carers in Harrogate.
- People do not want to be connected to the health service, dementia sufferers do not want to be seen as patients.
- Resources and training need to be looked at for carers, is this being looked at?
- It is important that we match the right patient to the right carer, in order to get the best results?
- Could some work be done with the private sector to look at the way they work, they seem to be investing a lot into care homes when they could be providing at home care?
- Need to be confident that services in the community will work
- Concern that it is in the detail – how will it actually work at the individual level
- Need to work closely with the voluntary sector

- Services have failed in the pas because they haven't been shared – including sharing with voluntary sector providers
- Cross-sector working is key to success
- Discussion around integrated care teams, single assessment processes and stream-lining assessment so patients aren't passed from one service to another
- Need to share records and information between services
- Recognition that patients' needs can change considerably at different times and this needs to be built into the system so these changes are not missed
- Concern about patients who do not have carers at home or nearby
- Need to think about what happens out of hours after 5pm
- Seems like a very small number of beds for the area
- Voluntary sector can help – but need to have high standards of training, consistency of support, etc
- **Useful suggestion from a member of the public** = to establish a unit in care homes specifically for patients who need to be segregated (e.g. for assessment or because they have had an episode). The CCG could fund a small unit for such a critical time, bringing in experienced staff on-call. They gave an example of a lady sent by ambulance to A&E from a care home. A&E sent the patient back to the home and asked for extra care there at night, and to look at her medication. Having more support like this in care homes could be greatly beneficial.
- Points raised about the needs of younger patients with dementia – are there plans to develop services for these patients?
- Need to improve domiciliary care as well – important to help support carers; identify patients with mental health needs, etc. The focus needs to be taken away from buildings and into actual services.

Event 5 – Knaresborough House, 16 January 2013

- Personal experience and discussion around the inappropriateness of A&E departments for people suffering with dementia.
- Comments on the ambulance service were raised - including that "friends and relatives are being discouraged from accompanying patients in the ambulance on the journey to A&E. This is just not suitable for people suffering with dementia."
- It was suggested by members of the group that a pathway could be developed similar to that of the children's pathway which is already in place. Patients could be taken to a different area to limit the amount of chaos they are exposed to in a busy A&E waiting room which could be quite distressing for a person suffering with dementia.
- Some work within the Dementia Collaborative is taking place around A&E which will go to the Overview and Scrutiny Committee on 8th Feb 2013.
- Concerns raised about hospital admissions and lack of nurses trained in mental health – again in relation to a personal carer's story.

- Lack of nurses' awareness of the needs of a patient with dementia on a medical ward. The patient sadly died 4 days into his stay. *"My husband said he didn't want anything to eat, so they didn't feed him. He said he didn't want anything to drink, so they didn't give him a drink. They made him sleep on a mattress on the floor because they were scared he would fall out of bed. I was appalled. Every ward should have someone thoroughly trained."*
- Lack of access to respite for carers. The group suggested that we need to look more closely at what people want from respite care – Friends of the Elderly were offered as an example of an organisation currently doing a good job.
- A comment from a carer = "At the moment, Social Services offer a package and that's it. There is no offer of respite."
- Concerns were raised about the care provided at home for people with dementia – again a lack of training and skills in dealing with patients with specific mental health problems such as dementia was highlighted. E.g. a carer had employed someone from an agency to help with bathing, etc. Unfortunately, as her husband suffered with dementia and the carer was not adequately trained, the carer was unable to carry out the care as her husband wouldn't let the carer touch him.
- There is a need to be much more focussed on carers' respite, whether it is a package or individual plan, sitting service, overnight stay or longer stay. At the heart of that are individual assessments and unfortunately there appears to be a national issue with the number of carers assessments which are low. Once carers respite is granted, people would have more influence over the services offered.
- Another carer's experience was where a carer and her father, a dementia sufferer, were offered respite. However, the place on offer wasn't suitable as her father was bedbound and there was no alarm system, etc. The carer had to pay privately in the end but could not do this often as it would have been too costly.
- Adele Coulthard urged the group to be vocal. If there is a demand for high quality respite care she said that providers will respond. Carers who were at the meeting were encouraged to express their needs in order to stimulate the market place and let the demand be known. Adele agreed that respite care is "vitally important" and medical respite is available. If there is a medical need which is diagnosed through a consultant then medical respite will be offered. Unfortunately, Adele said she did not have the luxury of influencing non-medical respite care but is working with the Local Authority to raise this issue.

Other comments at the meeting were around the huge importance of the statutory sector working closely with the voluntary sector who provide vital support services to carers and to patients with mental health needs

- One group felt that it is about being creative and not just looking at the clinical side but at the whole continuum. The social, voluntary sector and health service need to join together in order to provide a brilliant service - there needs to be much more collaboration.

- It was felt that Alexander House could become a real Community Resource Centre – i.e. there for the needs of the community, including support right THROUGHOUT the illness. This was emphasised – that there needs to be strong support towards the end of life for the patient and their family.
- Carers' Resource and other voluntary organisations want to be involved in changing Alexander house. The group felt that it is essential there is a support system for the family and so such a community service is essential; it provides stability through the ups and downs. If there is a central point that people are aware of where they can deal with crisis it will help enormously.
- Carers see the new 'community resource centre' as an extension of the hospital and the public see it as just office space. It needs to be somewhere where they can drop in for a cup of coffee. An example the group thought was excellent is at Easingwold. However, it looks as though this would not be the model for Alexander house. Therefore, it was suggested that the voluntary sector organisations get involved in the re-design of Alexander House if TEWV's proposals go through.
- There was concern that after this public engagement period everything will go quiet and no alternative will be given.
- Some comments about the process of engagement were that the public see the proposals as TEWV removing a service without providing a substitute. The consultation process should be to allow people to suggest alternatives and it is important they are given the reassurance that there will be one.
- The best thing that can come out of this is if the voluntary organisations such as Carer's Resource and Dementia Forward that are involved in people's care and carer support can continue to have a say in how the changes take place and have a 'seat at the table'.

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