Patient and service user engagement and evaluation around integrated care in Wakefield District

A summary of the key findings

January 2017

Contents

Connecting Care Summative report – patient element

Connecting Care Carers report

Care Homes Vanguard resident evaluation phase one

MCP engagement focus groups report

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Background

Since 2014 in Wakefield District, local health, social care and voluntary sector organisations have been working together to provide an integrated community health and care service called Connecting Care. In 2015, Wakefield was also successful in receiving funding from NHS England under the New Models of Care programme to support two Vanguards; a care homes Vanguard and a multi-speciality community provider (MCP) Vanguard.

The successful elements of all these local initiatives are now being aligned and consolidated under the next phase of development, informed by the emerging MCP framework from NHS England. This describes a Multi-speciality Community Provider as a 'new type of integrated provider. An MCP combines the delivery for primary care and community-based health and care services – not just planning and budgets. It also incorporates a much wider range of services and specialists wherever that is the best thing to do[1].

There are three emerging levels of contracting for this MCP:

- Virtual MCP – providers enter into alliance arrangements with a shared vision, clear governance/risk sharing arrangements and a commitment to managing resources together.
- Partially-integrated MCP – commissioners procure, under a single contract, all services in scope of an MCP with the exception of primary medical services.
- Fully integrated MCP – single provider holds a single whole population budget for the full range of primary medical and community based services.

Wakefield is one of six areas being supported to develop this new model of care, and has chosen to work towards the virtual MCP arrangement in 2017/18, supporting existing providers to work together more closely under an alliance contract.

Patient and service user engagement and evaluation

Throughout this process, the opinions and experiences of local people have been captured through a range of methods, both by the CCG and providers individually and through commissioning external independent organisations to conduct robust evaluation and engagement work.

Over 1,100 people have been interviewed or have taken part in a focus group

This document describes the patient and service user work that has been commissioned by NHS Wakefield CCG and West Wakefield MCP Vanguard from Healthwatch Wakefield and Niche Health and Social Care Consulting. The specific pieces of work are as follows:

1. From April 2014 to December 2016 – with a survey developed in partnership with Niche Health and Social Care Consulting and Public Health, Healthwatch Wakefield conducted 680 interviews with people who had experienced the Connecting Care service. These interviews were conducted in people's own homes and had a participatory appraisal approach with local lay interviewers using a quantitative survey with qualitative techniques.

2. Niche Health and Social Care Consulting and Healthwatch Wakefield conducted 53 qualitative, semi-structured interviews with unpaid carers of people who were receiving Connecting Care services between July 2015 and April 2016.

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[1] NHS England New Care Models 'The multispecialty community provider (MCP) emerging care model and contract framework', July 2016, p5

3. Under the Care Homes Vanguard initiative, Healthwatch Wakefield interviewed 70 residents of 5 care homes about their experiences of health and care services in April to June 2016. A second phase of this work will take place January to March 2017 when a further 5 care homes will be visited.

4. In December 2016 Healthwatch Wakefield facilitated eight focus groups with 83 local people about the move from Connecting Care to the new MCP contract for an accountable care system.

5. From November 2016 Healthwatch Wakefield have been interviewing patients who have received services from the West Wakefield MCP Vanguard; specifically their experiences of:
    a. Care navigation
    b. Physio First
    c. Pharmacy in General Practice
    d. Extended operating hours
    e. Healthpod
    f. Fusion cell of Connecting Care at Waterton hub – patients and carers
    g. Assistive technology

    This work will continue until June 2017.

All finished reports have been appended to this document.

Key findings overall

Integrated care in the community – patient / service user perspective

People are generally positive about integrated care services being delivered through Connecting Care.

- 85% of people interviewed felt that the health and care services provided through Connecting Care are very good or quite good.

- 86% of people interviewed felt they were definitely or to some extent as involved as they wanted to be in making decisions about their care and support

Good health and care co-ordination *as a specific function*, both within Connecting Care and in the integration of Connecting Care with wider health and care services, was seen as vital in improving people's experience of the service.

- When people felt that they had a Connecting Care health professional as a named person to co-ordinate their care and support, they reported higher levels of satisfaction in relation to how involved they felt in decisions about their care (92% as opposed to 57% of those people who said they didn't have a clue if anyone coordinated their care).

- 66% of people interviewed reported that people mostly or always worked well together. When people felt that this hadn't happened it was often in relation to system communication issues, often not the fault of individual staff. It was noted that problems were also related to the fact that although Connecting Care is itself an integrated service, it still has to interact with other health and care systems around it, for example domiciliary care and hospitals. We saw a definite need for a solution to support people to co-ordinate their health and care provision, to be aware of what is out there for them and how to access it.

We found that people who reported a lack of social contact also had poorer self-reported outcomes

- 37% of people (249 individuals) interviewed didn't feel as though they have enough social contact.
- 32% of this cohort feels they are less able to cope with their situation than a month ago compared with 14% of those people who say they definitely have enough social contact.
- 40% feel worse in themselves compared with 13% of people who definitely have enough social contact.

Integrated care in the community – unpaid carer perspective

Unpaid carers reported very mixed experiences within their role as carer, but all described significant impacts on their own health and wellbeing.

- One of the biggest impacts of being a carer is on people's mental and emotional health. Many carers said they were exhausted, shattered and tired all the time and a number were in tears during the interviews. 20% of carers told us they were on anti-depressant medication 'to cope' (although we didn't specifically ask this question). They reported being frequently irritable, one was self-medicating with alcohol and one was self harming.
- Many carers reported feeling lonely and socially isolated, with very little opportunity to leave the person they are caring for – sometimes having only an hour a week to themselves. They frequently had additional difficulties in getting out even when they had the opportunity, e.g. lack of transport or their own health and mobility issues.
- Only eight of the fifty three carers said their caring role had not had an impact on their physical health; most reported issues such as bad backs, torn muscles, worsening eczema and joint pain. One lady aged 84 told us that helping her 94 year old husband to the toilet or off the floor when he fell had made her bad hip a lot worse.

Our interviewers identified a clear need for better support, more information and clearer communication and liaison with carers.

- Around a quarter of carers interviewed described a frustrating and exhausting process of trying to find out about and get help for the person they cared for and for themselves when the need for more assistance first arose.
- Carers reported difficulty in getting information and advice about their loved one's care, support and treatment, or in being included or consulted in decisions about their care. This left them feeling marginalised and frustrated and in some cases feeling that this had compromised the safety of the person they cared for.
- Most carers we talked to were also being supported by other family members, both for practical assistance with the person being cared for and providing respite. They said their ability to care was very dependent on this support.

In almost all cases, without the support and input of the unpaid carer, it was patently clear that the patient/ service user would be unable to live in their own homes and would need much more intensive support from health or care services.

Care home residents (benchmarking from care homes not yet in the Vanguard programme)

Care home residents interviewed reported generally favourable experiences of health and care services, although the selection sample was biased towards those who had the cognitive and physical ability to engage.

- 88% felt they could see their GP when they wanted to.

- 84% said they know who to contact with questions about their health and care needs (this was mostly care home staff) and 74% felt that that person understood them and their condition.

- 83% felt that the health and care provided met their needs.

Potential areas for improvement included care planning and liaison between care homes and other health settings.

- 57% said that when they went to hospital their medication and other needs were known.

- 47% of the people interviewed said they felt that health and care services worked well together.

- Only 30% had discussed their health care plan with someone.

- More people told us that they would like to be fully involved in decisions about their care than those who felt that they actually were fully involved.

Most residents reported fairly high levels of personal wellbeing. We asked three of the four questions from ONS-4 the Office of National Statistics subjective personal wellbeing questionnaire. This measures people’s self-reported wellbeing on a scale of 0 to 10 where, for example, 0 = not at all satisfied and 10 = very satisfied. Again, these statistics should be treated with caution as we interviewed only the residents who were most well and we recognise that there is a strong likelihood of participant bias.

- 73% said they were satisfied with their life nowadays (gave a score of 7-10 out of 10)
- 71% said they had felt happy that day
- 65% said they had not felt depressed that day

Quality of life of those people who were able to engage (only 30% on average of the population of the care homes) seemed to be relatively good.

- People mostly said that being comfortable, cared for and safe was a key element of having a good life. After that, they mentioned activities, visits, trips out and contact with other people as being things that allow them to feel socially included and part of a community. Choice and freedom were also mentioned quite frequently.

- Specific activities that were talked about included singing, reading, dancing, games, writing, films, gambling / cards, memory classes, watching sports on TV. Singing was mentioned specifically five times. An attractive environment, including gardens and flowers was important, as was good food and drink (particularly the odd glass of wine, whisky or beer).

General public engagement around MCP contract and accountable care system approach

People mostly thought that the direction of travel towards shared delivery of health and care services was the right one.

- 85% of people agreed that organisations should work together more closely and 78% agreed that they thought this would make their care more effective.

- 93% of respondents said they understood what was being planned in the new model of care and 63% said they thought it was probably the right thing to do.

- 83% of people agreed that the outcomes for the new model of care are the right ones.

There was a more mixed picture around whether or not proceeding to full merging and contracting out of an integrated service was a good idea.

- People were generally unsure whether fewer organisations delivering care *under one contract* would make our care more effective, with significant concerns about what this step might lead to in the future and the fear of large scale privatisation.

There was general agreement around the question of whether self-help in relation to health and wellbeing was a good thing, but there was less conviction when we asked how likely people would be themselves to take advantage of health support provision, e.g. exercise, healthy eating or low level mental health initiatives.

- 78% of people agreed that people should take more responsibility for their own health and wellbeing.

- 45% said they were likely to take advantage of support to improve their own health, but the majority were unsure or said it was unlikely that they would.

There was an almost unanimous agreement that unpaid carers should be supported through the new model of care.

- 95% of people think that the new model of care should include support for those caring for family or friends, 5% said they were unsure.

- Nearly 70% of people said they themselves would be willing to help support friends and neighbours, but indicated some concerns about how that might work in practice.

Overall, most people said that they were willing to share their health and care information more widely in order to improve the effectiveness of care provision, although there were concerns about the level of and extent to which information is shared.

- 74% of people agreed that giving health and/or care professionals access to their relevant health and care records is likely to make their care more effective.

- 73% of people agreed they would be happy for their own health and/or care records to be shared.

- Concerns about sharing health and/or care records included the risk that decisions detrimental to us might be made based on what people see in our records and that opening up records to a wider audience might make information more open to misuse.

- 80% of people agreed that a single, joint assessment shared by health and care professionals is a good idea.

Patients receiving services from MCP Vanguard (early stages of evaluation)

At this point in the evaluation it is not possible to give any robust information about most of the interventions as numbers are still too low. However, we have a relatively good number of surveys about care navigation within GP practices and people's experiences of the Healthpod.

Care navigation in West Wakefield is the use of reception/admin staff with GP practices to signpost patients to alternative professional than a GP, should this be appropriate. To date Healthwatch has made 23 visits of approximately 3 hrs duration each to 12 GP practices to interview patients in the waiting rooms. Of the 330 people we have spoken to so far:

- 39 individuals were offered an alternative to a GP appointment
- 32 individuals identified themselves as being explicitly care navigated. That is, 32 individuals accepted an alternative to a GP appointment

For the individuals who were care navigated:

- 100% were OK to see a different healthcare professional

For the individuals who were offered an alternative appointment, and those who accepted an alternative appointment:

- 75% felt OK about being offered an alternative appointment by practice staff
- 68% felt that enough effort had been made to find out what was important to them
- 70% thought it was helpful for practice staff to signpost patients to other healthcare professionals

For the remaining individuals who had not been care navigated**:

- 65% would feel OK about being offered an alternative to a GP appointment
- 77% thought it was helpful for practice staff to signpost patients to alternative appointments

Within these surveys, Healthwatch Wakefield has recorded further comments surrounding the implementation of care navigation. From these comments the following preliminary 'themes' have emerged:

'Dependant on the presenting problem'

Many individuals interviewed have highlighted that the suitability of care navigation is dependent on the presenting health issue, concern or complaint.

'Role of the practice staff'

Many individuals interviewed have expressed concerns regarding the role of the practice staff in care navigation. Many do not believe practice staff to be 'qualified' to make the decision of signposting patients to other healthcare professionals.

***It is important to note that although not explicitly identified as 'care navigated' – many individuals may be care navigated. A majority of surgeries visited operate using an appointment system which requires the patient to contact the surgery on the day to make an appointment. The patient will inform the practice staff of their health question, issue, concern and/or complaint to which the practice staff will 'ring back' with the* *appointment options. Therefore, it is plausible to suggest that the patients who go through this process are care navigated.*

HealthPod

Since November 2016, Healthwatch has visited the HealthPod 6 times for 2 to 3 hours at a time. During our visits the HealthPod has provided general health and wellbeing checks only. Healthwatch has interviewed a total of 32 individuals who have used the HealthPod.

- 65% of those interviewed heard about the HealthPod in passing.
- 100% of those interviewed found the information and advice received helpful.
- 94% of those interviewed felt they had sufficient privacy when in the HealthPod.
- 71% of those interviewed gave a rating of 5/5 for satisfaction level with the HealthPod (5 denotes very satisfied). The remaining 29% of individuals interviewed gave a rating of 4/5 for satisfaction level with the HealthPod.

Unfortunately nobody we spoke to gave us permission to contact them again to see if they had followed up the advice that they were given.

Next steps

1. Connecting Care / MCP Contract – Healthwatch Wakefield will be interviewing 250 people in 2017/18 to monitor their experience of integrated care and other MCP interventions as partners move towards a closer partnership working through the new contract arrangements.

2. Phase one of the Care Home Vanguard evaluation interviewed residents in five care homes that were not in the Vanguard but were planned to be. Three of those homes were supported by the Vanguard in 2016/17 and the residents in those three homes will be interviewed again using the same survey questions to ascertain any difference in their experience.

3. Further engagement work will continue around the development of the new MCP contract.

4. Until June 2017 Healthwatch Wakefield will continue to interview patients who have received services from the West Wakefield MCP Vanguard; specifically their experiences of:
    a. Care navigation
    b. Physio First
    c. Pharmacy in General Practice
    d. Extended operating hours
    e. Healthpod
    f. Fusion cell of Connecting Care at Waterton hub – patients and carers
    g. Assistive technology

Further evaluation of the strands of work that are continuing into year 3 of the West Wakefield MCP Vanguard is not yet decided.

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Appendices

Connecting Care Summative Report – Patient Element
Connecting Care Carers Report
Care Homes Vanguard Resident Evaluation Phase One
MCP Engagement Focus Groups Report

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Connecting Care in Wakefield

Evaluation report
January 2017

CONTENTS

NB. Only the patient / service user interviews section is reproduced here.

3. PATIENT / SERVICE USER INTERVIEWS

3.1 Background

Healthwatch Wakefield was commissioned in 2014 to provide an independent evaluation of the Connecting Care service from the point of view of the person receiving the care. The evaluation was conducted alongside the development of the Connecting Care service itself.

The evaluation survey was designed to capture people's experience of integrated services (rather than their care in general) based on the National Voices "I" statements. The results from the survey were captured and fed back to form part of the formal evaluation. They were also used to create the patient metric for the Better Care Fund and form part of the high level integration "Assurance Framework "on a quarterly basis. Patient experience metrics have been displayed beside more conventional quantitative metrics such as those measuring reductions in hospital attendances and admissions.

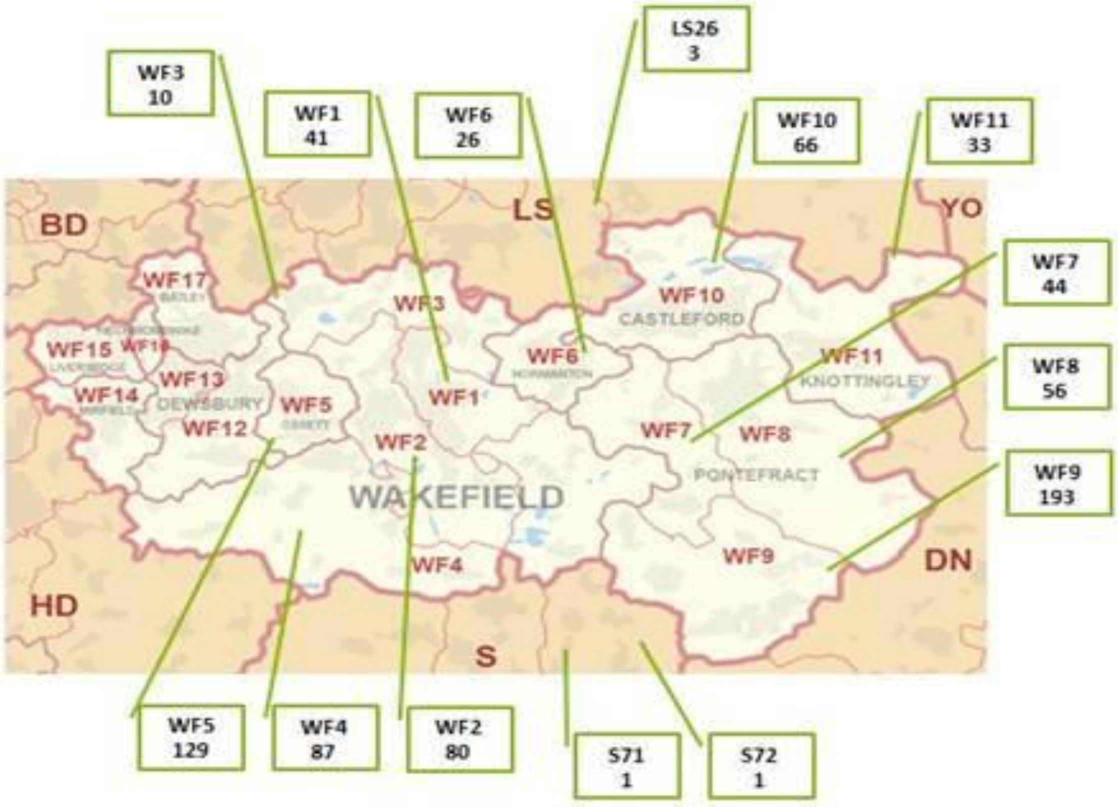
The approach was one of participatory appraisal, using local lay people as volunteers to conduct the interviews, which combine qualitative interviewing techniques with a quantitative scoring system. The interviews took place in people's own homes, with consent being obtained by frontline Connecting Care staff to enable Healthwatch Wakefield to telephone to arrange for a visit. The three hubs referred people from all over the district for interviews.

A combination of staff, sessional workers and volunteers were used to complete the surveys. They conducted interviews in pairs as this helped with more accurate recording of the findings, and offered some mutual support and safety. It was also felt to be good practice in relation to safeguarding, not just for the interviewers but for the person also. Full training was provided, which included a detailed briefing on Connecting Care, the interview method, safeguarding, personal safety and dementia awareness.

There were a number of challenges during this process. The referral process was difficult to maintain as frontline Connecting Care staff had to obtain consent from individuals then pass that consent and contact details through hub administrative staff to Healthwatch Wakefield. The administration function within the hubs struggled with capacity and their ability to pass referrals to us was variable. The provider of the administration function also changed hands during the evaluation which caused delays. As a result, there were a number of times when months went by without sufficient referrals being obtained.

The target for the number of interviews was 1000 and we reached 680. We noticed that, as numbers rose, the variation of responses overall became less marked. In addition, with the target being so high, there was a need to maintain constant awareness of the quality of interviews as opposed to the quantity. We chose to abort interviews on several occasions when realising that people had only received one service from the Connecting Care team as this would not be a true integrated care experience.

By the time the evaluation came to an end, we had interviewed 680 service users and 53 carers about their experiences of receiving Connecting Care. The distribution of service user interviews across the district was as shown on the map below:



The interviews with carers were depth interviews, and a separate much fuller report is available on their findings. In brief summary, these interviews with carers found that the Connecting Care services which were most frequently mentioned as helping and supporting them were Age UK and Carers Wakefield. It is clear that having these two services within the Connecting Care teams is enabling a greater and more comprehensive service to be offered to carers. The fact that Carers Wakefield could develop an ongoing relationship with carers was something which carers who had experienced this, particularly valued and found helpful.

We met other carers where the picture was mixed. Maybe the services delivered to the service user/patient were good, but the carer felt isolated and unsupported personally. Or the carer had found it difficult to access services, which were good once accessed, but the process of trying to organise things had taken their toll. Around half of the carers we spoke to, fell into this middle group.

There was an additional group of carers (around 25%) who had received very poor support and services. In some cases, this was around difficulties in accessing the services in the first instance - both finding out about and locating services and waiting (e.g. on a waiting list) for access. For other people it was really not clear why, despite very clear needs (both for service user and carer), they had not been offered the support which they obviously required. Several of these stories related to end of life care. The carer was not always clear why they had not been able to get the help that they needed.

The remainder of this section relates to the interviews with patients / service users.

3.2 Findings from the full sample

The data presented here are based on 680 interviews, of which 43% were conducted with the carer present, either supporting the person through the interview or answering questions on behalf of the person who had been receiving Connecting Care services. If the person being interviewed had a significant lack of cognitive understanding then the interviews were generally conducted with the carer, although being inclusive of the person involved as far as possible. In these cases the focus was on the experience of the person from the carer's perspective, rather than the carer's experience of the service.

97% of people interviewed were white British and 62% were female**.** The majority (79%) were over 65, with and 69 people were over the age of 90. 42% of people interviewed live alone.

There were 22 questions in the survey which have been grouped under four main themes:

1. Overall experience of health and care services
2. Co-ordination of care and services
3. Understanding and wellbeing
4. Carers, friends and family

3.2.1 Overall experience of health and care services

What care or help have you received in your own home in the last few months?

		Response Percent	Response Total
1	Nursing	45.95%	312
2	Physiotherapy	54.05%	367
3	Occupational Therapy	63.33%	430
4	Seen GP	50.66%	344
5	Help with shopping/cleaning/food preparation etc	20.91%	142
6	Assistance at home with personal care (eg washing self, continence care, getting dressed etc)	23.12%	157
7	Help from Mental Health services	8.10%	55
8	Social worker	22.83%	155
9	Housing staff	26.07%	177
10	Age UK staff	25.18%	171
11	Carers Wakefield	10.75%	73
12	Going to day care centre	8.98%	61
13	Help from family, friends or neighbour	40.06%	272
14	Pharmacist	2.21%	15
15	Other (please specify):	43.30%	294

From the beginning of the evaluation, referrals to the Healthwatch team came predominantly from the Connecting Care staff employed by Mid Yorkshire Hospitals Trust, including the MyTherapy team. It was only in the last year or so that referrals from social services and the voluntary sector started to increase. This might have some implication on the number and type of services that people have reported receiving.

When people ticked the 'other' box this mainly included care and help from family, friends or neighbours. Other responses included private home care, community matrons, health and wellbeing worker, privately paid cleaner and gardener, vicar, Macmillan. Later months showed an increase in help from housing/Occupational Therapy (OT) services although we noted that OT is provided through more than one organisation in Connecting Care.

We noticed that the options relating to help with shopping, cleaning and assistance in the home were often answered in relation to the care and help provided by friends and family, rather than by Connecting Care services.

> **“Age UK transport service is great. So glad for what we have - all these people help us live better and we are not alone.”**

How have these services helped you? (Tick as many as you want)

			Response Percent	Response Total
1	It helped me to come home from hospital more quickly		25.00%	162
2	It helped me to stay in my own home rather than go into a nursing home/hospital/elsewhere		56.79%	368
3	It helped my family/carers		50.00%	324
4	It helped me to recover more quickly (from ill health)		36.88%	239
5	It helped me to stay more independent		62.81%	407
6	It helped me to cope better		66.67%	432
7	They have not really helped me		13.27%	86

The majority of people reported some positive outcomes in relation to their experience of Connecting Care. The highest positive responses were that Connecting Care had helped them stay more independent and cope better in their own home.

> **“GP wanted her to go into hospital but by having the nurses round to care for her at home she was able to stay at home which is what she wanted.”**

Did you get the help and care when you needed it, or did you have to wait?

			Response Percent	Response Total
1	I had to wait too long		14.75%	99
2	I had to wait, but not too long		23.40%	157
3	I didn’t have to wait at all		56.63%	380
4	Not sure or can’t remember		2.83%	19
5	Not applicable		2.38%	16

Most people felt that the waiting period for Connecting Care services was acceptable, with 57% of people saying that they didn’t have to wait at all. 15% of people felt that they had to wait too long, but their responses to the other questions in the survey were generally positive, with 74% rating the service overall as quite good or very good. Some of the comments about waiting times were in relation to specific services. Although not captured in the data, it is likely that sometimes the waiting times were affected by the fact that all three hubs were not fully operational from the beginning of the evaluation, with two hubs starting much later than the first and teams being relocated from elsewhere.

> **“I have been waiting for mental health services for over 6 months which I feel is far too long, the services need to be available sooner.”**
> **“Would be helpful having physiotherapists earlier - it was 5 or 6 weeks after I came out of hospital. Also someone to explain what would happen to my rehabilitation and how I would progress etc. after I left hospital.”**

If you had to rate the health and care services you have received overall (in your home) in the last month, would you say it was;

			Response Percent	Response Total
1	Very Good	🟥	54.92%	363
2	Quite Good	🟨	29.65%	196
3	Neither Good nor Poor	🟦	6.05%	40
4	Quite Poor	🟩	2.27%	15
5	Very Poor	🟧	2.72%	18
6	Don't Know	🟪	4.39%	29

85% of people interviewed felt that the health and care services provided through Connecting Care are very good or quite good. From our conversations with people we feel that this reflects a strong endorsement of the proactive and committed frontline staff in the Connecting Care teams. We often heard praise in relation to individual staff who had gone out of their way to ensure that people were looked after well and referred to services that they needed.

From what we have observed, integrated care works well not only when the organisations involved are committed to work together, but when the frontline staff are empowered and supported to be flexible and person-centred in their approach.

> **“Daughter reports that dad has had good care, has been offered services which he hasn't accepted, the staff are brilliant and flexible and she says she cannot praise them enough, they have been lovely.”**

People rating the service overall as quite poor or very poor

Of those people (5%) who reported the service as quite poor or very poor, 60% felt that people did not work together well and 10% felt they hadn’t been treated with kindness and compassion. 38% said they felt they had to wait too long before services were offered to them. 60% said their family or friends who care for them had received little or no support from Connecting Care services.

57% of this cohort reported that they had not enough social contact or none at all. They felt that they would benefit from help to get out and about (42%), more help from therapists such as physiotherapist / occupational therapist / speech therapist (42%) and better aids and adaptations for their home (32%).

> **“Patient said if he wanted support from social services he would have had to stay in hospital longer because they had not done a care package for him quickly enough – he wanted to be at home. All his care he has paid for privately.”**

There did not appear to be any linking factor between the people who rated the Connecting Care service poorly; they came from a wide geographic spread and generally followed the same demographic picture as the average.

Occasionally there was disagreement between the person being interviewed and their carer/ family about the rating of the service.

> **"The interviewee rated the service as quite good but the family did not agree – they felt there were gaps in the service. The interviewee felt everyone worked well as a team and shared information but the family did not. Generally it was felt that the services were not joined up and the communication was inconsistent between the service providers."**

Thinking about your care over the last few months, are there other services that would have been of benefit to help you regain your independence more quickly and/or feel better able to cope at home? (Select all that apply)

			Response Percent	Response Total
1	Help/more help from nursing staff		6.46%	42
2	Help/more help from my doctor		7.85%	51
3	More help from therapists such as physiotherapist / occupational therapist / speech therapist		14.31%	93
4	Better access to aids and adaptation for my home		8.15%	53
5	Help from mental health staff		2.62%	17
6	Help with eating/drinking/diet		2.46%	16
7	Help with continence needs		3.69%	24
8	More information about my medication or condition		5.23%	34
9	More information about financial support or benefits		7.69%	50
10	Help to get out and about		15.54%	101
11	More help for my family or carers		6.77%	44
12	No		49.08%	319
13	Don't know		3.69%	24
14	Other (please specify):		17.23%	112

For this question, the people interviewed were talked through the list so that they were given the option to think about whether these extra services might be helpful. Nearly half the people interviewed didn't think there were other services that would help them. The highest answer was 16% of people who said they'd like more help to get out and about.

Answers to 'other' include help with housework, cooking and shopping etc, getting medication from pharmacy, support with transport, help to get to church, counselling, memory clinic, Macmillan support and more social contact. People also suggested that more information on 'what's out there' would be useful.

Have all the staff who care for and support you at home treated you with kindness and compassion?

			Response Percent	Response Total
1	Yes definitely		85.78%	567
2	Yes most of the time		11.04%	73
3	Not really		1.21%	8
4	No definitely not		0.30%	2
5	I am not sure / can't remember		1.66%	11

The vast majority of people interviewed (97%) felt that they had been treated with kindness and compassion by the Connecting Care staff.

> **"They have been brilliant, nothing but praise."**

From an analysis of the open-ended comments from those few people who said they had not been treated with kindness and compassion, or were not sure, we heard stories related to poor discharge practices and not enough support being put in place on their return home from hospital. Some of the stories were in relation to poor experiences in hospital or with paid home care support (it was often difficult to keep people focused just on Connecting Care services). Many people also mentioned long waits for aids and adaptations in their homes. This appears to suggest system failings rather than individuals not being kind and compassionate.

3.2.2 Co-ordination of care and services

One of the main Connecting Care aims is to provide a more joined up service to people receiving health and social care support, whether it is from the NHS, council or voluntary sector. The co-location of professionals within three integrated care teams, or hubs, is part of the way that this joined up approach is being delivered. The following questions were designed to find out whether people who are receiving these services have benefited from the new ways of working.

If several different people were involved in your care and looking after you, did you find that everyone worked well together?

			Response Percent	Response Total
1	Yes always		43.18%	288
2	Yes mostly		22.64%	151
3	Neither well nor poorly		2.85%	19
4	Not really		9.30%	62
5	Not at all		4.50%	30
6	Myself or my family had to co-ordinate everything		2.70%	18
7	Not sure or not applicable		14.84%	99

66% of interviewees reported that people mostly or always worked well together. When people felt that this hadn't happened it was often in relation to communication issues, often not the fault of individual staff.

> **"The people are brilliant but the systems are at fault."**
>
> **"One bit of the hospital system does not talk to another so that the patient is left in the middle and messed about. So sort out the communication."**
>
> **"Be more open and communicate better with each other. We had to repeat ourselves every time someone came. They should know the history."**

It was noted that problems were also related to the fact that although Connecting Care is itself an integrated service, it still has to interact with other health and care systems around it, for example domiciliary care and hospitals. We saw a definite need for a solution to support people to co-ordinate their health and care provision, to be aware of what is out there for them and how to access it.

An important element of Connecting Care was to ensure that if people need other services staff were able to refer them internally, for example a district nurse recognising that help with shopping from Age UK might be useful for someone, or that a carer could do with some support from Carers Wakefield. We found that just over half of people we interviewed did feel that they had been given information about other support that they might need.

Have the staff who are supporting you given you information about other services that are available to you, including support organisations?

			Response Percent	Response Total
1	Yes, definitely		33.63%	225
2	I have had some information		19.88%	133
3	I have not had any information		35.28%	236
4	I am not sure/I can't remember		11.21%	75

From our more detailed interviews with carers we found that support was often not felt necessary at the time of first contact with the Connecting Care service, but that if leaflets or information had been left that they were able to follow up later if necessary. As Healthwatch Wakefield interviewers were going into people's homes after Connecting Care services had finished, they sometimes picked up situations where people were getting worse and were able to refer back into Connecting Care for further support.

We felt that a more consistent way of providing information about the services available under Connecting Care might help people feel better supported. We also felt it would be useful for people to know if and how they could refer themselves back in to the service if they needed help later on.

> **"Instead of waiting to be asked can we have help, they should be offering help not try to find out what people can get. People don't know about services. People need to be made aware."**

If you need to ask questions about your condition or treatment or support, who would you contact/ask? NB: don't prompt an answer here.

			Response Percent	Response Total
1	Community Matron		1.93%	13
2	Another health/social care professional		13.20%	89
3	My GP		50.45%	340
4	Don't know/can't remember		5.64%	38
5	Family or Friend		11.87%	80
6	Other (please specify):		16.91%	114

Despite the efforts of Connecting Care and other primary care interventions aimed at diverting people to other sources of support than primary care, most people told us that they would still contact their GP to ask questions about their condition, treatment or support. For those who ticked the 'other' box, answers included social worker, Stonham, health and wellbeing worker, carers, 111, internet, Carelink, Social Care Direct and Age UK.

If you needed advice or help out of normal working hours who would you contact?

			Response Percent	Response Total
1	My GP		6.52%	32
2	111 Service		17.11%	84
3	I would go to A&E		3.46%	17
4	I have another number to ring out of hours		3.67%	18
5	Community Matron		1.43%	7
6	Care Link		13.24%	65
7	Family member		19.55%	96
8	Not sure/Don't know		11.20%	55
9	Other (please state):		23.83%	117

Fewer people would contact their GP out of hours, most choosing a family member or 111. Care Link was also a high answer although not all people we interviewed had access to this service. Answers to 'other' include neighbours, 999, social workers, health and wellbeing workers, Stonham, palliative care contact, the warden at sheltered housing, friends and family.

Do you have a named health or care professional, or other support person, who co-ordinates your care and support?

			Response Percent	Response Total
1	Yes, definitely		23.27%	155
2	Not really sure		9.91%	66
3	No, not a clue		66.82%	445

Having a named professional to co-ordinate your care was one of the key aims of the Connecting Care service in 2014, but proved to be one of the most difficult to achieve. Just under a quarter of all people interviewed felt that they had a named health or care professional. The majority of people however said that this person was their GP. Although general practice is an essential element of care in the community, GPs do not form part of the integrated Connecting Care hubs so this statistic is somewhat misleading.

When people did feel that they had a Connecting Care health professional as a named person to co-ordinate their care and support, they reported higher levels of satisfaction in relation to how involved they felt in decisions about their care (92% as opposed to 57% of those people who said they didn't have a clue if anyone co-ordinated their care). When asked who these named professionals were, people mentioned occupational therapists, social workers, Age UK, district nurses, mental health workers, consultants and matrons as some examples. Some people didn't know the person's occupation only their name.

Of those people who thought they had a named professional, 84% felt that person definitely understood them and their condition.

When it comes to making decisions about your care and support - are you as involved as you want to be?

			Response Percent	Response Total
1	Yes, definitely		64.06%	426
2	Yes, to some extent		22.26%	148
3	Not really		6.02%	40
4	No, definitely not		3.91%	26
5	I am not sure		3.76%	25

86% of people interviewed felt they were definitely or to some extent as involved as they wanted to be in making decisions about their care and support, but 10% said not really or they definitely weren't and 4% said they weren't sure.

3.2.3 Understanding and wellbeing

Do you understand your medication (medicines and tablets) – why you need them and the side effects you might have?

			Response Percent	Response Total
1	Yes, definitely		60.03%	392
2	Yes, to some extent		21.44%	140
3	Not really		8.12%	53
4	No, definitely not		8.58%	56
5	I am not sure		1.84%	12

Most people felt that they understood their medication and its possible side effects, although 56 people saying they definitely do not understand is a thought-provoking number of people, even though they are in the minority in this survey.

Would you say that you feel safe living at home?

			Response Percent	Response Total
1	Yes, definitely		82.23%	546
2	Yes, to some extent		10.99%	73
3	Not really		3.92%	26
4	No, definitely not - I would rather be looked after somewhere else		1.36%	9
5	I am not sure		1.51%	10

The majority of people said that they felt safe living at home. The negative responses were often not necessarily connected with health and social care services but more about people's vulnerability in relation to the local environment, neighbours or other issues. Where appropriate, Healthwatch Wakefield alerted relevant support agencies for those people who said they did not feel safe, for example raising the issue with Wakefield District Housing who then made a visit to the property. However, it is also very possible that people might have told us they felt safe when they didn't because they don't want to leave their homes and go into a care home setting.

Do you have as much social contact as you would like?

			Response Percent	Response Total
1	Yes, definitely		32.59%	218
2	I have some, it's OK		28.40%	190
3	Not really		20.33%	136
4	No, definitely not		16.89%	113
5	I am not sure		1.79%	12

This question shows that 37% of people (249 individuals) interviewed don't feel as though they have enough social contact. An analysis of their other responses shows that 32% of this cohort feel they are less able to cope with their situation than a month ago compared with 14% of those people who say they definitely have enough social contact. 40% feel worse in themselves compared with 13% of people who definitely have enough social contact.

Not really or definitely not enough social contact	**Definitely enough social contact**
40% feel worse in themselves	13% feel worse in themselves
32% feel less able to cope	14% feel less able to cope

Compared to a month ago how do you feel you are coping?

			Response Percent	Response Total
1	Much more able to cope with my condition/situation	🟥	18.61%	123
2	A bit more able to cope with my condition situation	🟨	19.36%	128
3	About the same	🟦	37.67%	249
4	A bit less able to cope with my condition/situation	🟩	14.67%	97
5	A lot less able to cope with my condition/situation	🟧	9.68%	64

The reasons that people give for how they are coping and how they feel in themselves can vary according to their specific circumstances. Many people supported through Connecting Care are elderly with multiple long term conditions and they do not expect to feel significantly better or more able to cope within a month. This is reflected in the fact that the majority of people report that they are about the same.

Compared to a month ago how do you feel in yourself?

			Response Percent	Response Total
1	Much better in myself	🟥	19.82%	131
2	A bit better in myself	🟨	17.70%	117
3	About the same	🟦	35.70%	236
4	A bit worse in myself	🟩	18.61%	123
5	A lot worse in myself	🟧	8.17%	54

3.2.4 Carers, family and friends

There were two questions in this survey that related to the carers, family and friends of people receiving Connecting Care services. There is acknowledgment that unpaid carers provide a significant amount of support and care to people, enabling them to stay in their own home for longer rather than go into hospital or into care home settings. Often those people wouldn't describe themselves as carers and therefore don't access much needed support. As our more detailed report about their experience shows[2], this can result in a detrimental impact on their own physical and mental health. The questions in this survey were designed to elicit information about the level of involvement of carers, and also how much support they were offered in their caring role.

Most people we interviewed (79%) said that they felt that friends and family who cared for them had been as involved as they wanted them to be in decisions about their care and support, even when they disagreed about what was the best for them.

> **"I don't like putting on my family - they don't want me in a home but it is for the best. They agreed with me eventually."**

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[2] *'Evaluation of Connecting Care in Wakefield – Carers' Experiences of Connecting Care', August 2016, Niche Health and Social Care Consulting and Healthwatch Wakefield*

When it comes to making decisions about your care and support are your family and friends as involved as you want them to be?

			Response Percent	Response Total
1	Yes, definitely		63.64%	154
2	Yes, to some extent		14.88%	36
3	Not really		9.09%	22
4	I am not sure		2.07%	5
5	Not relevant - no involved family/friends		6.61%	16
6	I didn't want them involved in those decisions		3.72%	9

Only a very few people said that they did not want their family and friends who cared for them to be involved in decisions about their care.

Thinking about your family and friends who care for you, do you feel that they have had as much support from health and social services as they needed?

			Response Percent	Response Total
1	Yes they have had as much support as they needed		17.23%	41
2	They have had some support but not as much as they needed		10.08%	24
3	No they have had little or no support		34.87%	83
4	They did not want/need support		17.65%	42
5	There are no family members or carers to support		6.30%	15
6	I am not sure		13.87%	33

Only a small percentage of people interviewed (17%) felt that their family and friends have had as much support as they needed. The highest responses (45%) said that they had had little or no support, or not as much as they needed. This indicates a significant level of unmet need within this group.

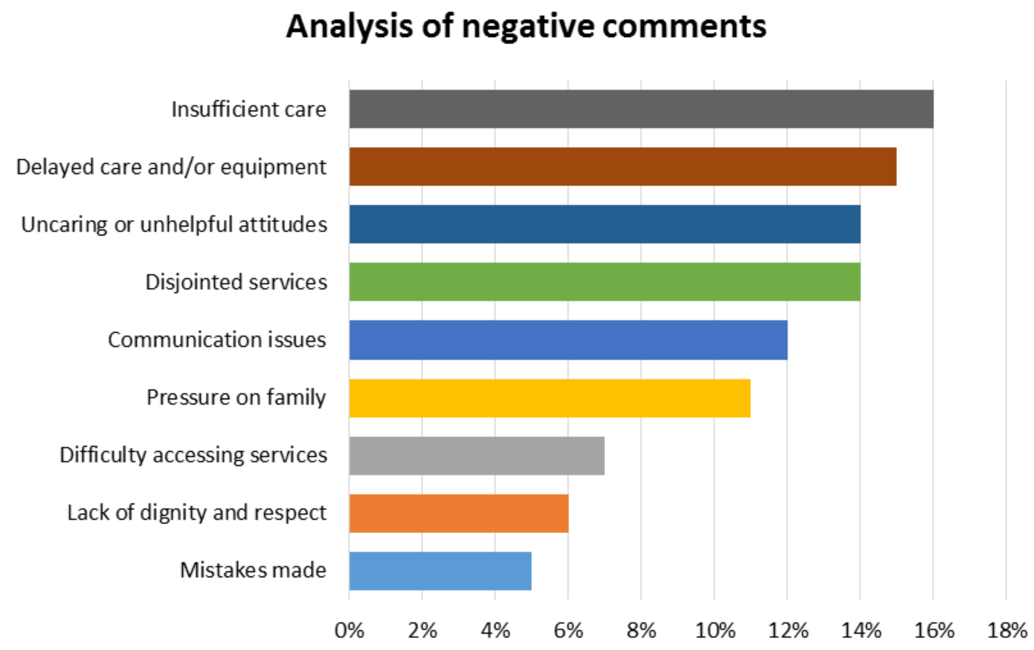
"I don't cope, I struggle. Don't know what to say."

3.2.5 Qualitative comments

The final question of the survey asked people to share any additional comments about the care/services which they had received which could help to improve them in the future. 613 comments were recorded, including many very detailed histories, some spanning decades. A significant proportion of the stories we heard were not directly in relation to Connecting Care, but to discharge issues, previous hospital visits, mental health interventions, domiciliary care support etc. We found that lots of people enjoyed the opportunity to chat to our interviewers, particularly those who were not able to leave their homes very often.

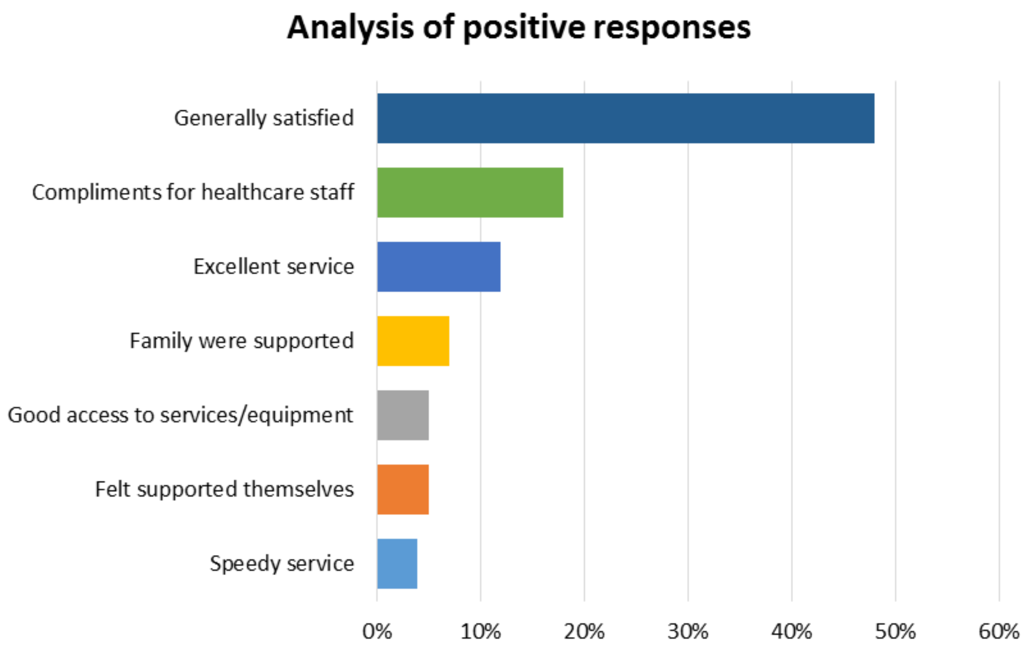
Of those comments that were relevant to the Connecting Care service, we found there was a fairly even mix of positive and negative comments. The negative comments, as one would expect, exemplify the instances when Connecting Care has failed to deliver a joined up service.

Her daughter reported during the interview that the family were confused about who does what - they felt the service was disjointed.



Those people who had some negative experiences primarily felt that their care had been insufficient. Some of the people who felt services were inaccessible were those who were expected to finance care themselves, one person with very little notice and experiencing great financial loss due to delays in the system. Delayed care and disjointed services were also seen as negative issues.

Those who had mixed views often involved comments by or regarding family. One family member had felt that care had been better previously but since more serious illness has occurred, this was no longer the case for their loved one. There were also comments that the system seems to rely perhaps too heavily on family members - for time and finances.
The themes from the positive responses are as follows:



It seems evident from our interviews with people receiving Connecting Care, that when staff are able to turn the aims of the integrated service into a reality on the ground, the outcomes for people are better and they are very satisfied with their care.

We conclude this section with case study examples from our conversations with people who have used the Connecting Care services. All are provided with permission of the patients/service users involved, and all names have been changed.

"..When Dad was ill the Community Matron AB organised short term carers so we could keep Dad at home rather than go into hospital… CD from Social Care helped too … the services work very well together … AB is amazing … if she is not there I contact her colleague who is really good, they are both very helpful … there is no better care, the team are fabulous.

Dad was very reluctant to have help and AB helped me coax him … AB put me on the right track … I can contact her anytime and if I ring they are out to him within the hour! … My aunt was having health problems and like dad she was very reluctant to have any help but AB got her on the list and now she says it is the best thing she has ever done and wished she would have done it years ago… AB really gets in touch with the patients and chats to him about sports etc … his face lights up when she comes in … 11/10"

Additional comments "it is a shame more people cannot access this service. Before we had to ring 999 when he became ill and he was in hospital getting anxious and it was an unnecessary burden for the staff at the hospital as we were there nearly every week but now we have the Community more staff, we need more Community Matrons"

Alf was referred to Age UK Connecting Care from the Age UK hospital to home scheme. He is 83 years old and has diabetes, arthritis and poor mobility. He wanted help to get a walking aid. He was seen and assessed by an Age UK using the LEAF assessment. His assessment identified that, in addition to his mobility problems, he was feeling quite socially isolated.

He was referred to MyTherapy for further help with his mobility and Age UK addressed his need for more social contact. Alf is now attending a local reading group every Monday and is using the access bus to do this, he has better walking aids now and feels a lot happier that he can now access the community and is back doing what he loves which is reading in large groups.

Alf said that he is very happy with the service that he has received from Age UK and that he didn't think it was possible for him to improve his life at his age and he couldn't have done it without the help from Age UK.

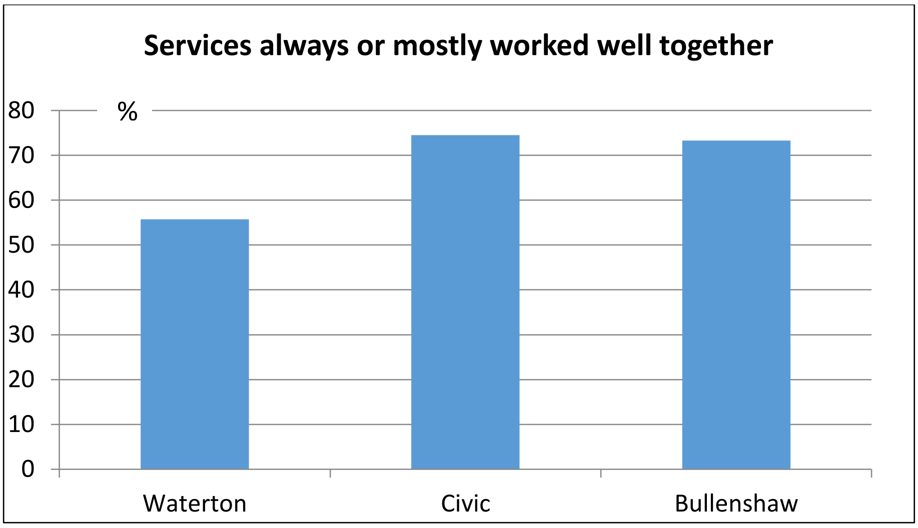
Elsie is 75 and lives alone. She has recently had a second heart attack and becomes short of breath when walking. Her family referred her to Age UK as they felt she was struggling to manage at home and was now living downstairs due to being too weak to manage the stairs. Following assessment Age UK give information and advice as well as making a successful referral to DWP for attendance allowance. Additional referral was made to MyTherapy for a kitchen and bathroom assessment which resulted in a stair lift being fitted and bathroom adaptations. MyTherapy also provided physiotherapy services to assist with the client's mobility.

Betty is in her late seventies and has COPD. She was referred from the district nursing service as her husband was struggling to cope looking after her, as he too was elderly. At that time they had no other services involved.

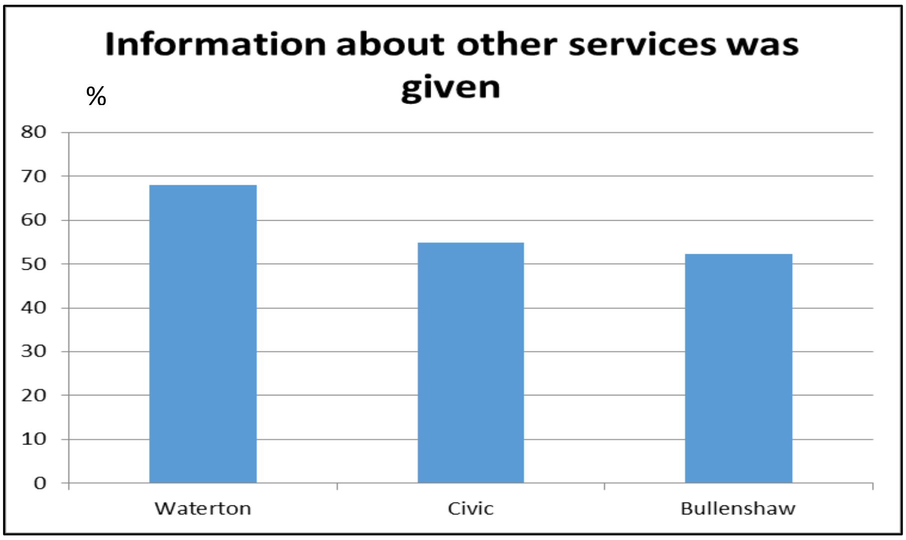
Betty's niece had originally rung district nursing in desperation as she knew someone who worked there. The Community Matron saw and assessed Betty and started working to improve her management of COPD. It was clear that Betty's mobility was also poor, and so the matron referred her to MyTherapy. She also identified that Betty and her husband were not receiving any benefits. Betty was also taking 2 to 3 hours to get herself dressed in the morning and was then so exhausted she could not do anything for the rest of the day, so she was also referred to Social Care to assess and provide carers to help in the morning and look at benefits. As the lady was elderly the matron also asked Age UK to assess her and her husband was referred to Carers Wakefield. "And all on one referral form!"

3.3 Tracing differences between hubs

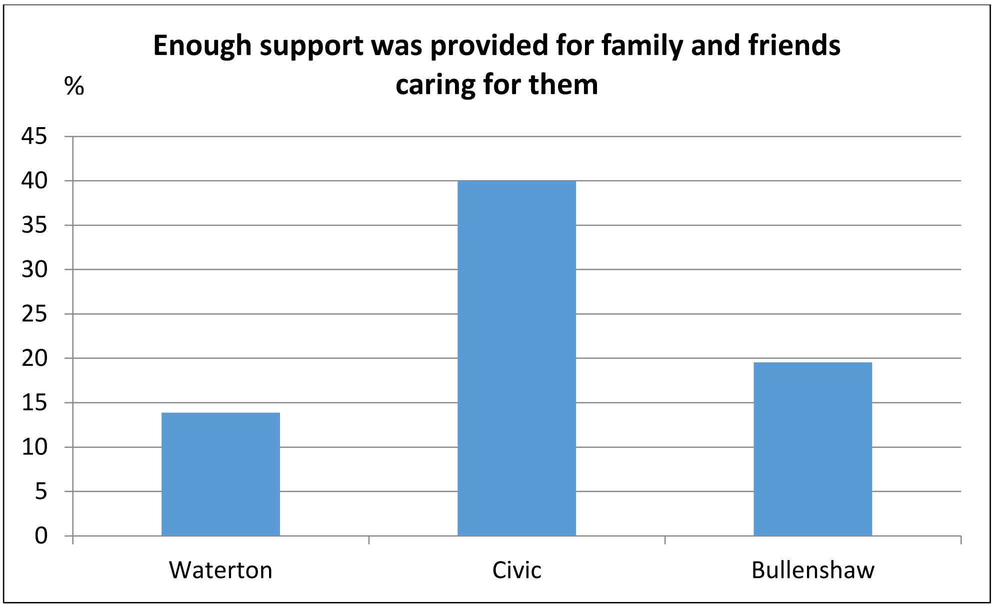
Analysis of the data from the three hubs shows that, on most of the indicators, there is not a significant amount of difference between the three. There are, however, also some interesting variations. Fewer people said that services from Waterton hub worked well together than the other two, which might suggest that the staff, although co-located in one building, are not working in a truly integrated way because of the layout of the environment.



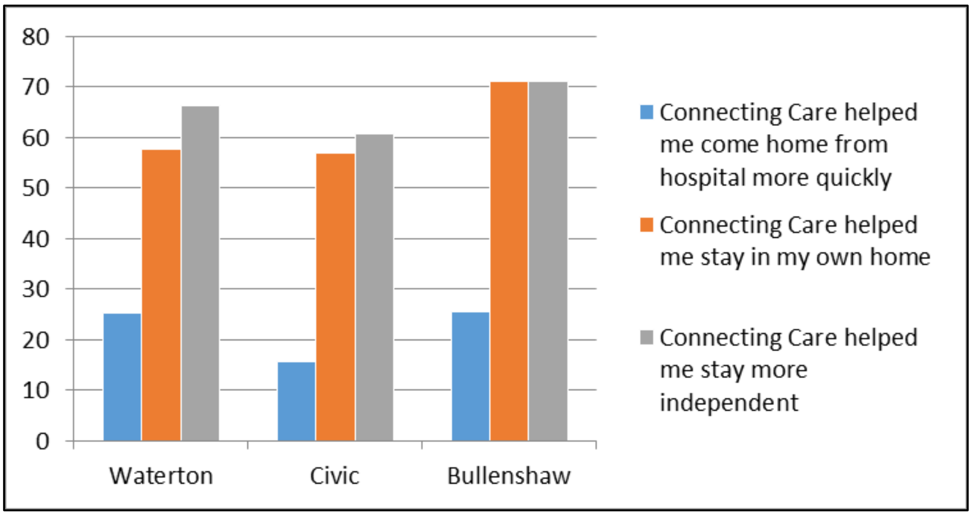
Interestingly however, more people said that Waterton hub staff had given them information about other services. This is a key indicator of whether or not Connecting Care staff are identifying additional needs that could be met through other colleagues within the integrated teams.



The most significant variation between answers in the hub was in relation to support offered to family and friends. As seen below, people being supported through the Civic hub were far more inclined to say that their family and friends caring for them had received enough support.



Most of the reported outcomes from the Connecting Care service were roughly similar across the three hubs. The chart below shows the three outcomes that had some variation in response. On these measures, the Bullenshaw Hub appears to have been more effective.



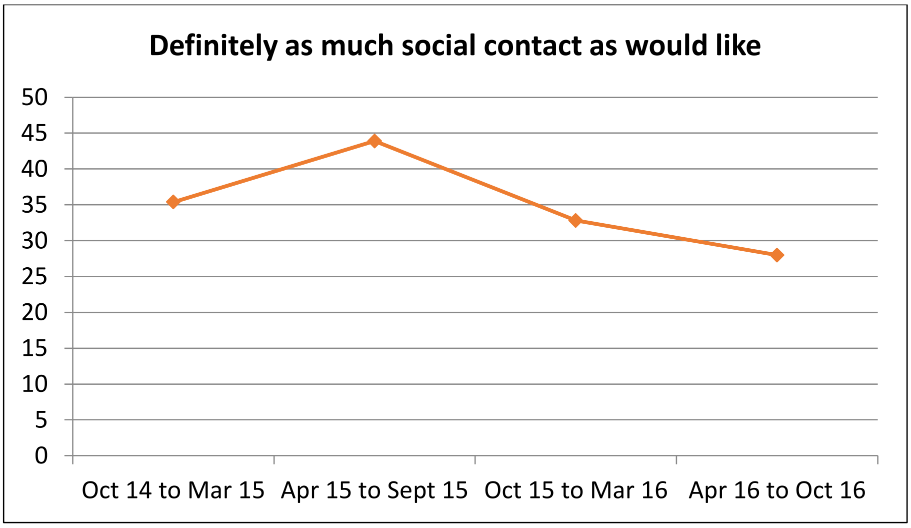
3.4 Tracing differences over time

The data collected over the two years has not been collected in a regular fashion due to issues such as the intermittent nature of the referrals to the evaluation team, the phased start-ups of the hubs and the occasional setback in relation to administration of Connecting Care. However, for the purposes of determining if any differences over time can be traced, the 25 months of data were divided into roughly six month sections, as follows:

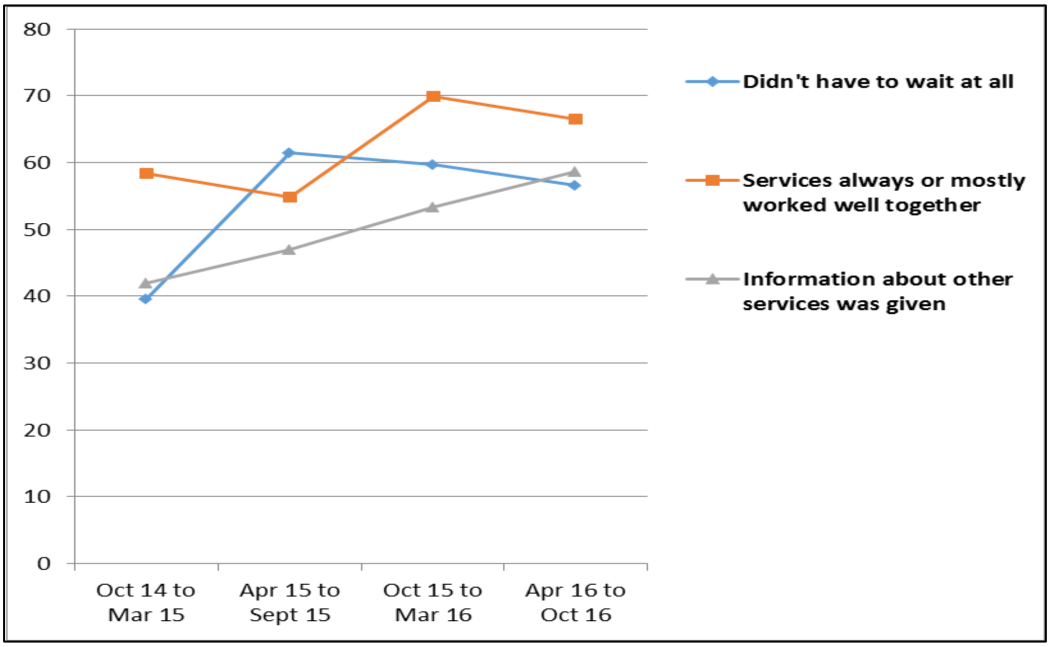
Timescale	Number of interviews
October 2014 to March 1015	66
April to September 2015	84
October 2015 to March 2016	252
April to October 2016	274

Some questions showed very little difference over time, but there were a few questions that did demonstrate a change in people's experience of Connecting Care from October 2014 when the service started, to 31 October 2016 when the evaluation came to an end. The majority of the change was positive.

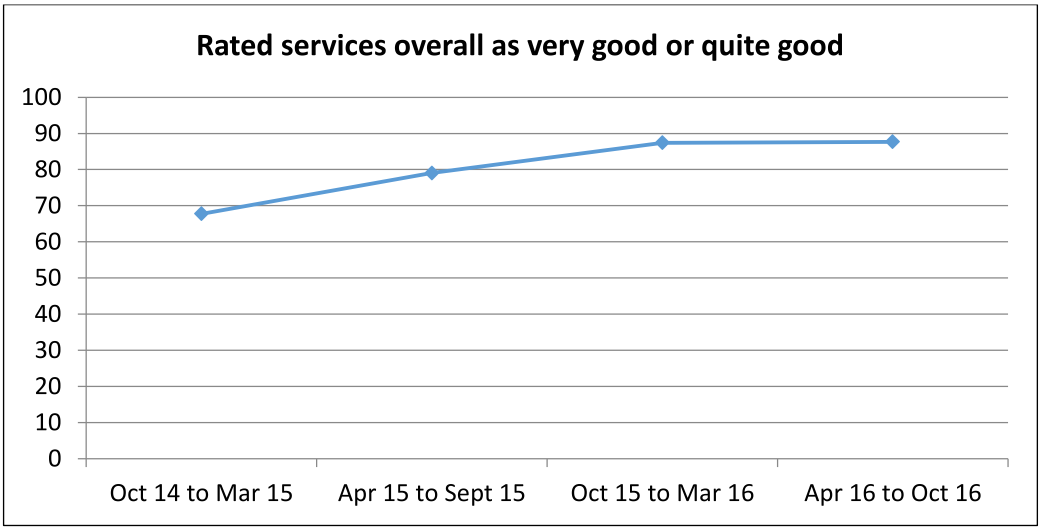
There was one question that showed a negative trend and this was not really related to the Connecting Care service; this was the question about whether or not people felt they had as much social contact as they would like. From our observations during the 680 interviews, this often related to the fact that many people were either very poorly or unable to leave the house as often as they would like for various reasons. From another question in the survey, 'Help to get out and about' was the most often identified service that people said would have been of benefit to them to help them regain their independence more quickly and/or feel more able to cope at home. This appears to be an unmet need for many people.



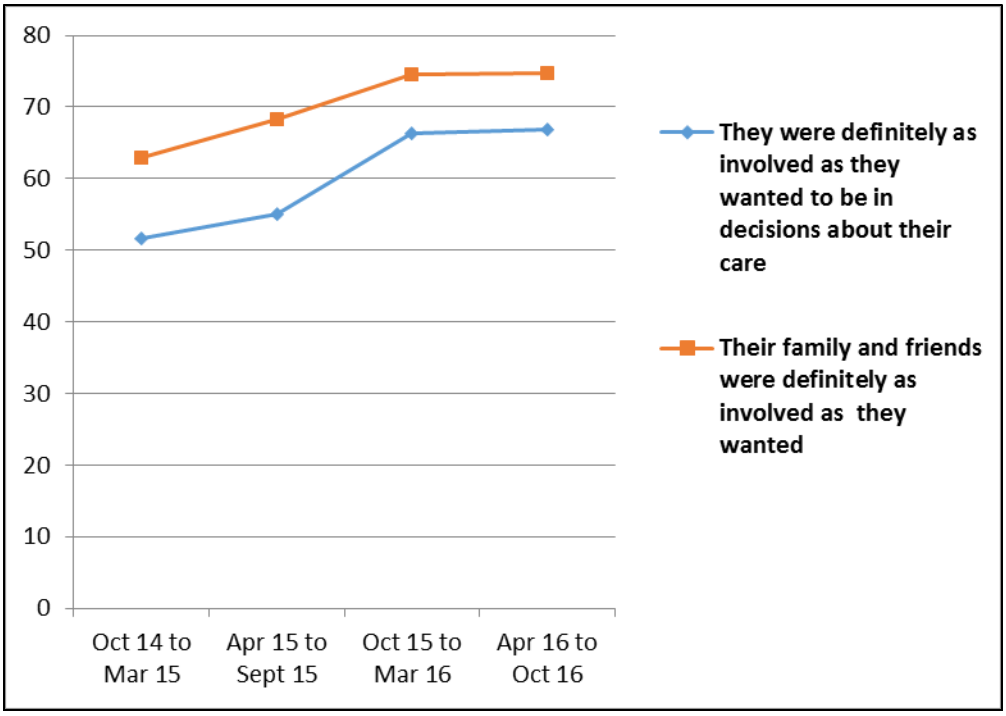
The questions that measured the integration of the service have shown improvements over time, albeit with a few peaks and troughs along the way. Overall, by the end of the evaluation period more people were reporting that they haven't had to wait for the service, that services always or mostly worked well together and that where appropriate, information has been given to them about other services that might be helpful.



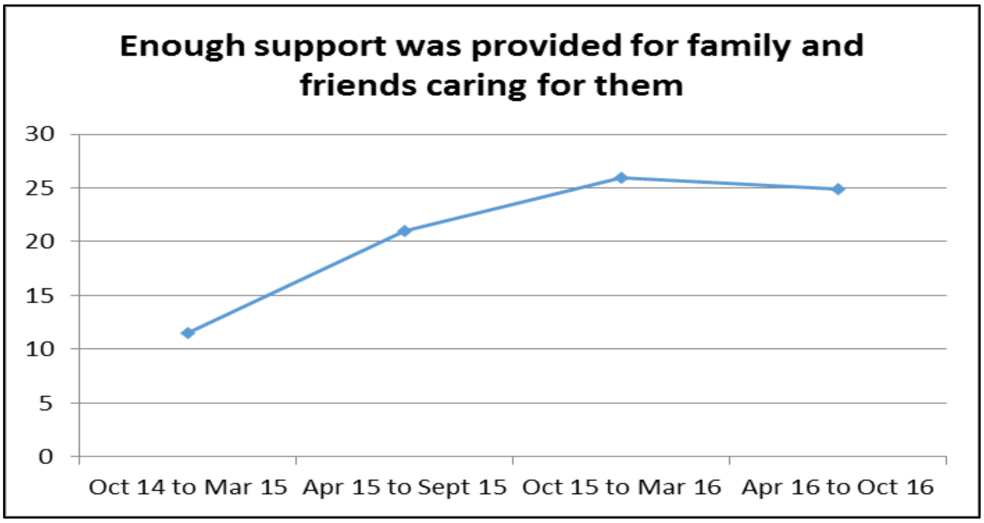
In addition, from 2014 to 2016 a gradual improvement in people's rating of the service can be traced, from 68% to 88% saying Connecting Care was very good or quite good overall.



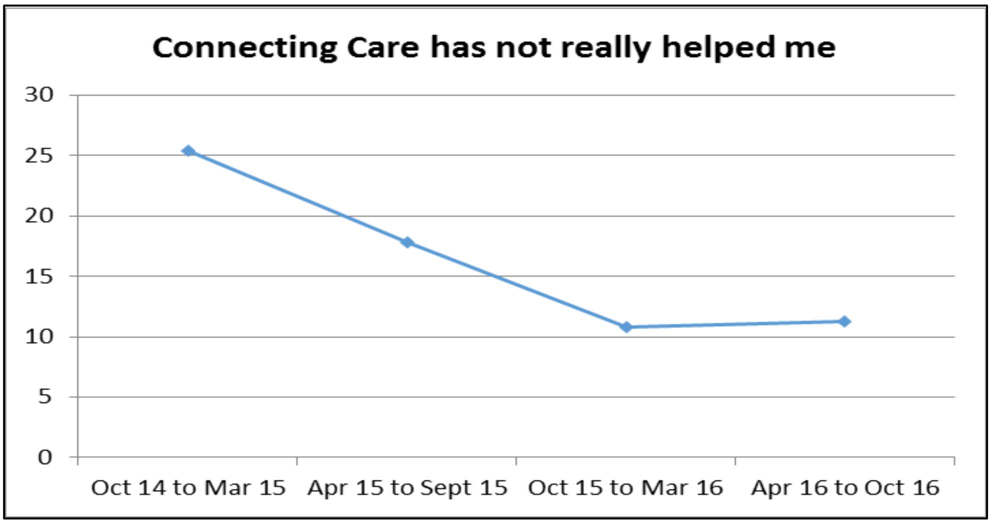
People also reported more as time went on, that they definitely felt involved in decisions about their care and that their family and friends who were caring for them were involved as much as they wanted them to be. This is a positive trend both in the experience of the service, but also in the move towards supporting people to take more control over their own health and wellbeing.



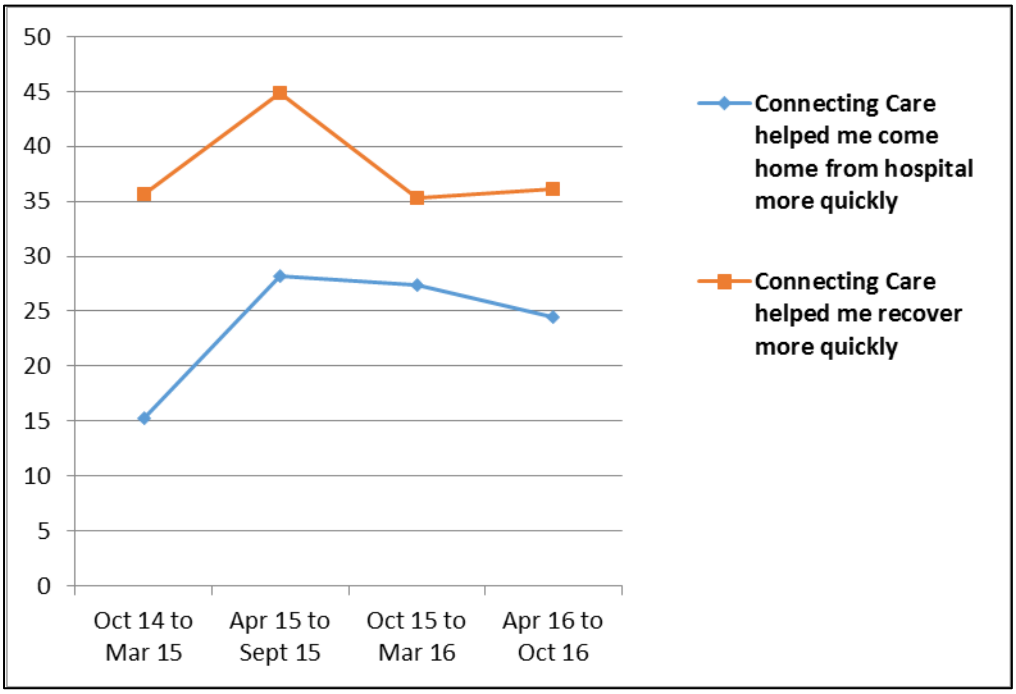
In relation to family or friends in caring roles, there was a positive trajectory over time, with 11% of people in 2014 saying that enough support had been provided increasing to 25% in 2016.



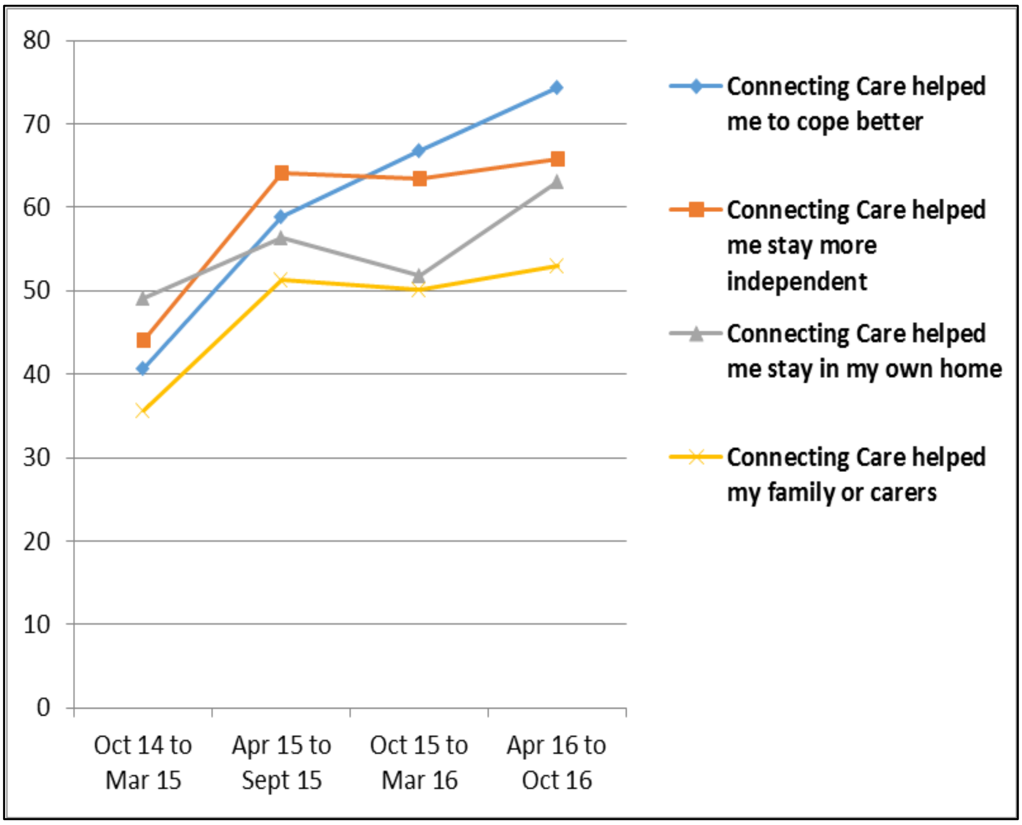
One could argue that the most important question of the evaluation was whether or not people felt the Connecting Care service had achieved the right outcomes for them. We measured seven outcomes that the service aimed to achieve, six positive and one that stated the Connecting Care services 'had not really helped me'. The graph below shows the downward trend of the answers to this final outcome.



The outcome 'Connecting Care helped me to come home from hospital more quickly' showed an initial increase from the first period, but then began to dip towards the end of the evaluation. 'Connecting Care helped me recover more quickly' has reverted to the same average response at the beginning, albeit with a large peak in the second period.



Four of the indicators, again with some peaks and troughs, show an improvement in reported outcomes from the beginning of the Connecting Care service in 2014 to the end of the evaluation in October 2016. In particular, the outcome 'Connecting Care helped me to cope better' increased from 41% to 74% over the two years.



On the following pages, we present an analysis of the movements over time, with 95% confidence intervals. This suggests that there has been statistically significant change from the first to the last survey period on 15 of the 26 indicators in this survey. Of these changes, fourteen are in a positive direction; only one has been in a negative direction.

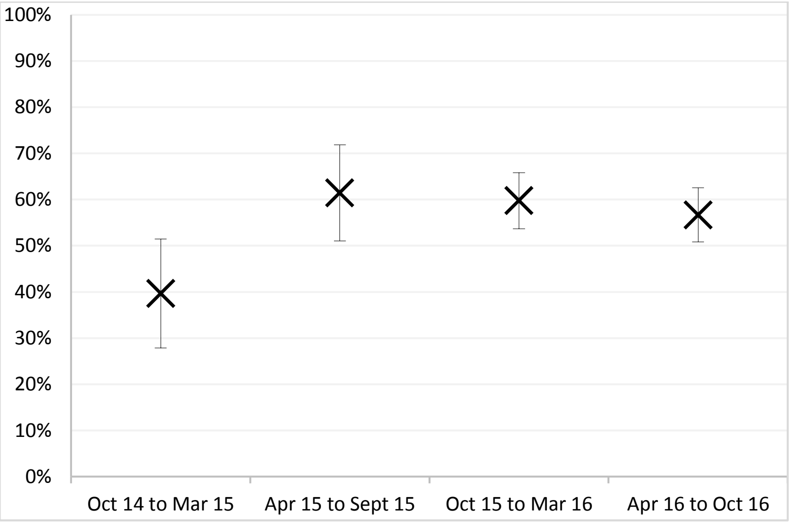
	Survey Question ****Results have been omitted where no improvement has been found.***	**Oct 14 to Mar 15 Result**	**Apr 16 to Oct 16 Result**	**Improvement Trend**
1.	Didn't have to wait at all	40%	57%	↑
2.	Services always or mostly worked well together	*	67%	—
3.	Definitely or mostly treated with kindness and compassion	*	98%	—
4.	Info about other services was given	42%	59%	↑
5.	Would ask GP about condition/treatment/support		50%	—
6.	Definitely has named health or care professional co-ordinating their care and support	14%	26%	↑
7.	This person definitely understands me and my condition	86%	78%	↓
8.	Definitely or to some extent understands medication		78%	—
9.	Definitely as involved as they want to be in decisions about their care	52%	67%	↑
10.	Family and friends definitely as involved as you want	63%	75%	↑
11.	Enough support was provided for family and friends caring for them	11%	25%	↑
12.	Definitely feels safe living at home	*	83%	—
13.	Definitely as much social contact as would like	*	28%	—
14.	Definitely not as much social contact as would like	*	18%	—
15.	Much more able to cope compared to a month ago	*	18%	—
16.	A lot less able to cope compared to a month ago	17%	10%	↑
17.	Feel much better in themselves compared to a month ago	*	18%	—
18.	Feel a lot worse in themselves compared to a month ago	*	10%	—
19.	Rated services overall as very or quite good	68%	88%	↑
20.	Connecting Care helped me come home from hospital more quickly	15%	24%	↑
21.	Connecting Care helped me stay in my own home	49%	63%	↑
22.	Connecting Care helped my family or carers	36%	53%	↑
23.	Connecting Care helped me recover more quickly	*	36%	—
24.	Connecting Care helped me stay more independent	44%	66%	↑
25.	Connecting Care helped me to cope better	41%	74%	↑
26.	Connecting Care has not really helped me	25%	11%	↑

Improvement Trend Key	
↑	Improvement
—	No movement
↓	Negative movement

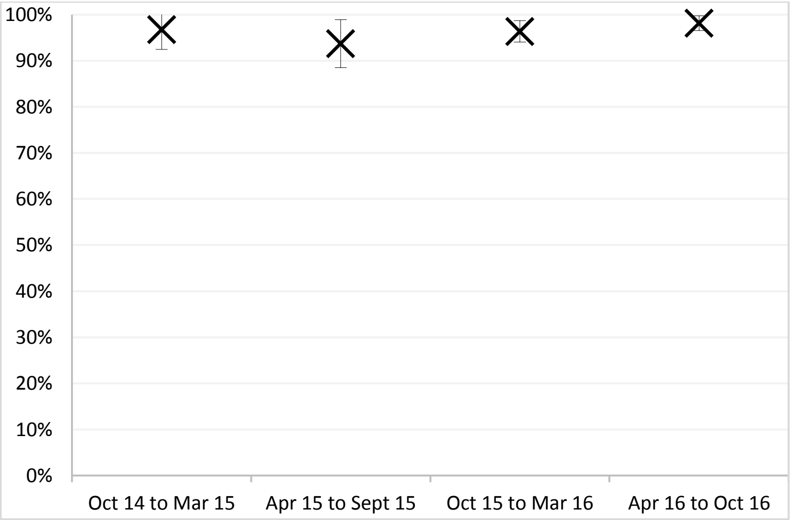
1. Proportion of respondents who agreed with “Didn't have to wait at all”,

2. Proportion of respondents who agreed with “Services always or mostly

with 95% confidence intervals.

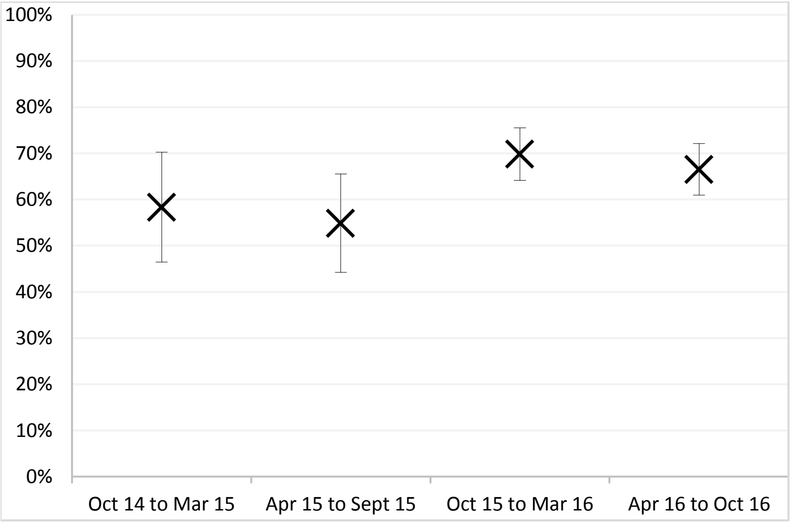


3. Proportion of respondents who agreed with “Definitely or mostly treated with kindness and compassion”, with 95% confidence intervals

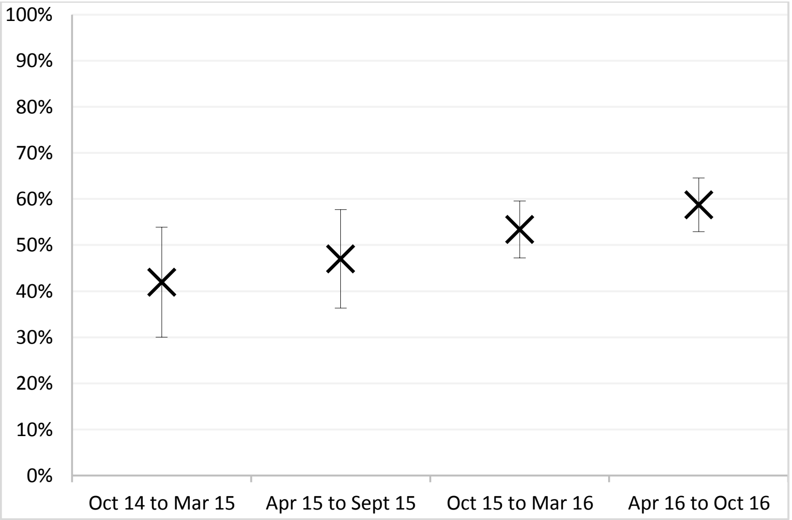


5. Proportion of respondents who agreed with “Would ask GP about condition/treatment/support”, with 95% confidence intervals.

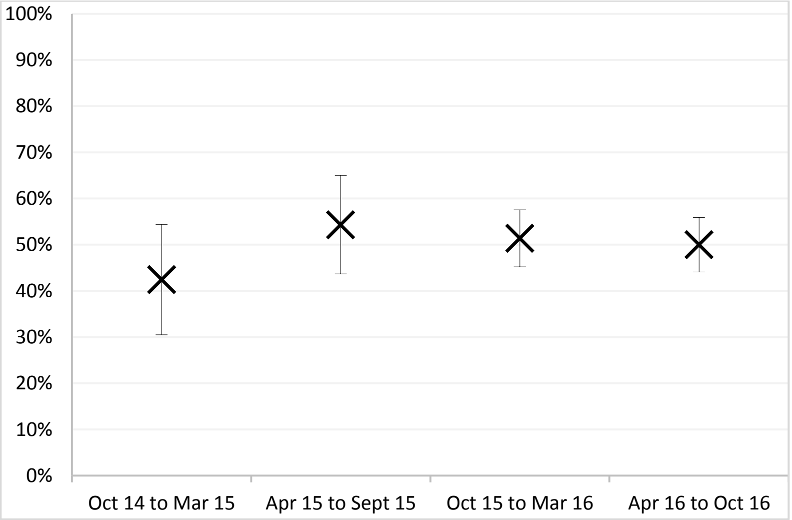
worked well together”, with 95% confidence intervals.



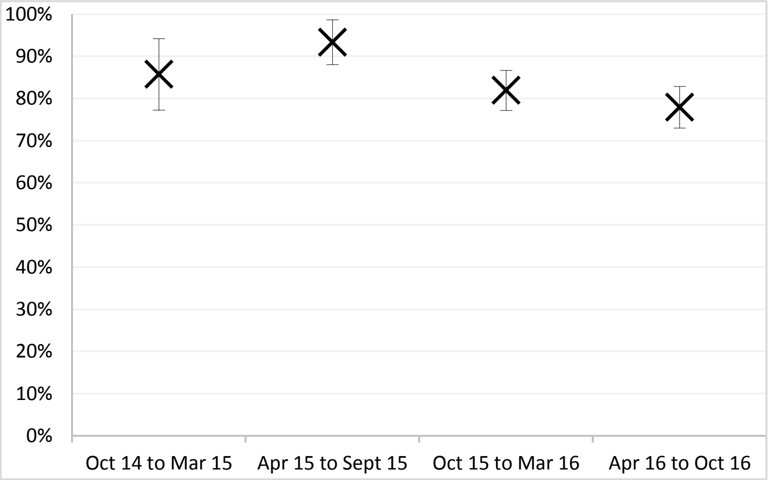
4. Proportion of respondents who agreed with “Info about other services was given”, with 95% confidence intervals.



6. Proportion of respondents who agreed with “Definitely has named health or care professional co-ordinating their care and support”, with 95%

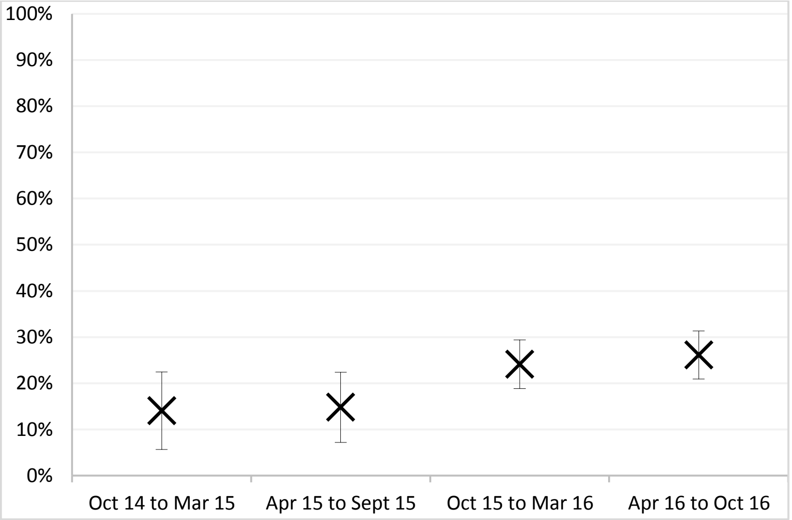


7. Proportion of respondents who agreed with “This person definitely understands me and my condition”, with 95% confidence intervals.

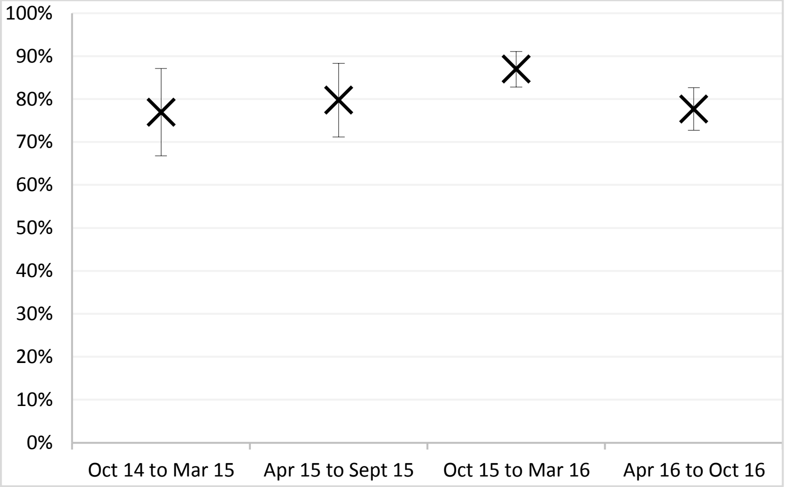


9. Proportion of respondents who agreed with “Definitely as involved as they want to be in decisions about their care”, with 95% confidence intervals.

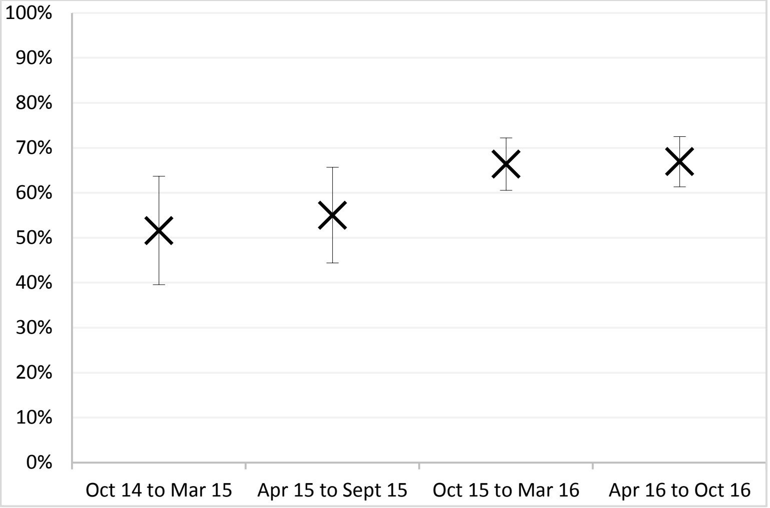
confidence intervals.



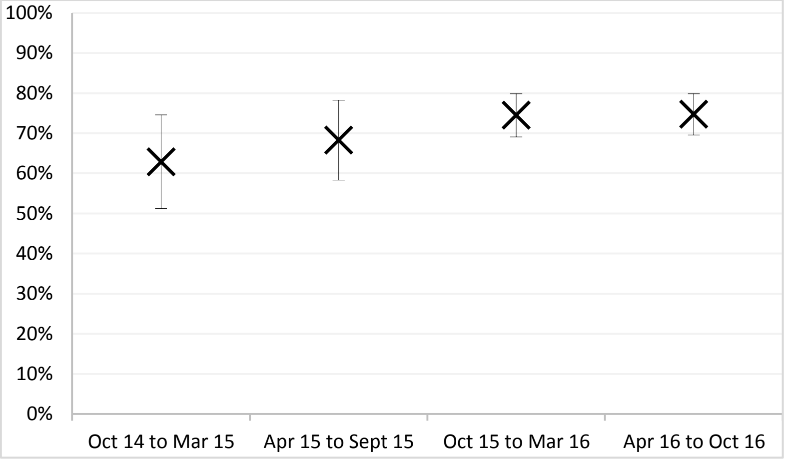
8. Proportion of respondents who agreed with “Definitely or to some extent understands medication”, with 95% confidence intervals.



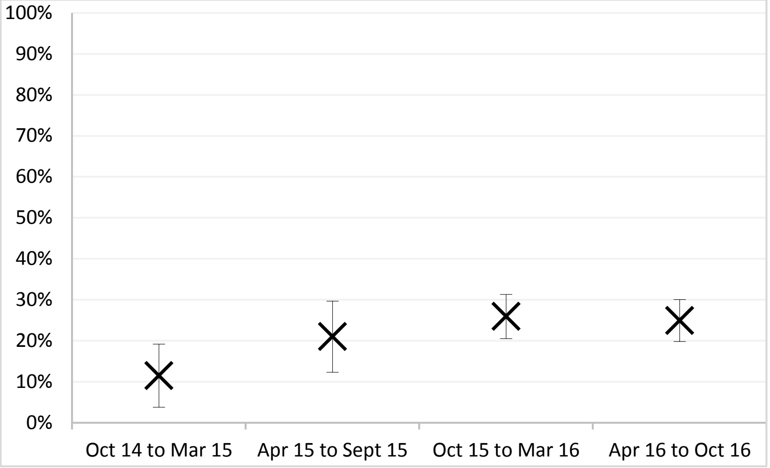
10. Proportion of respondents who agreed with “Family and friends definitely as involved as you want”, with 95% confidence intervals.



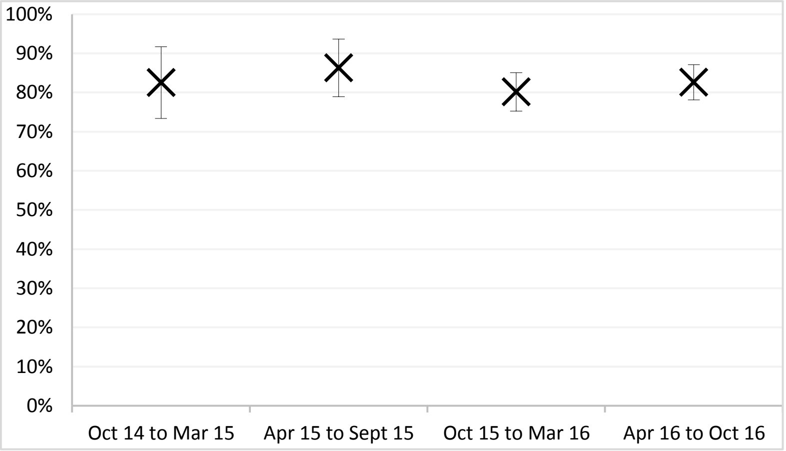
11. Proportion of respondents who agreed with "Enough support was provided for family and friends caring for them", with 95% confidence intervals.



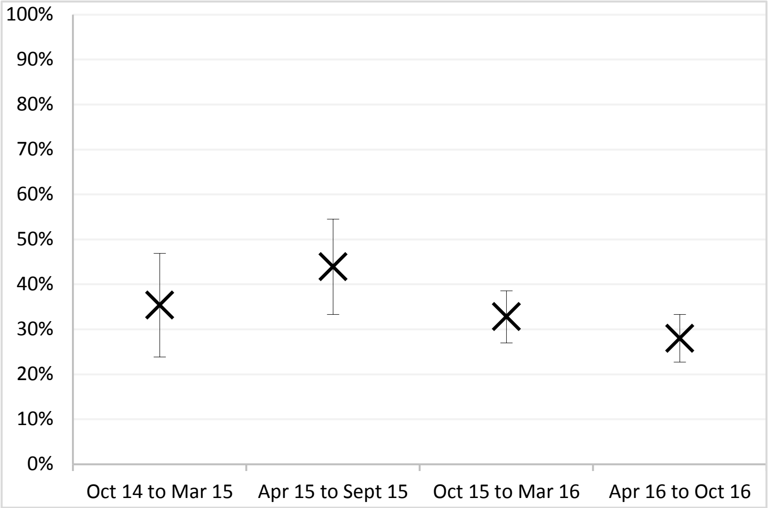
12. Proportion of respondents who agreed with "Definitely feels safe living at home", with 95% confidence intervals.



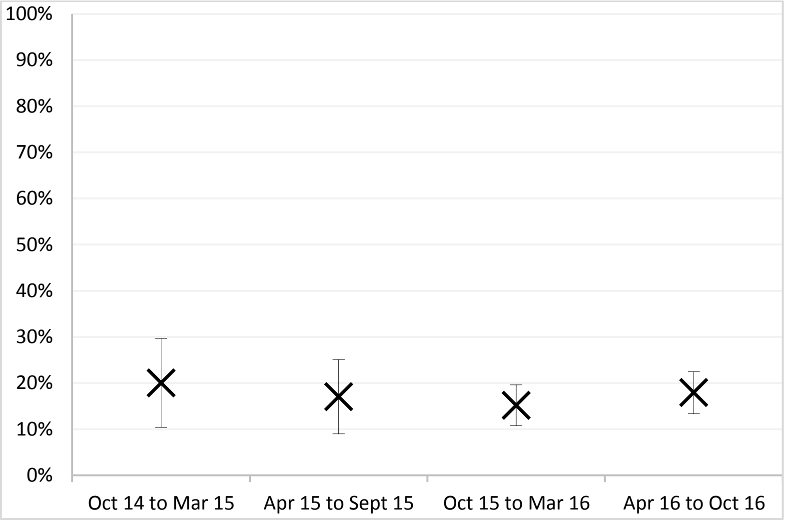
13. Proportion of respondents who agreed with "Definitely as much social contact as would like", with 95% confidence intervals.



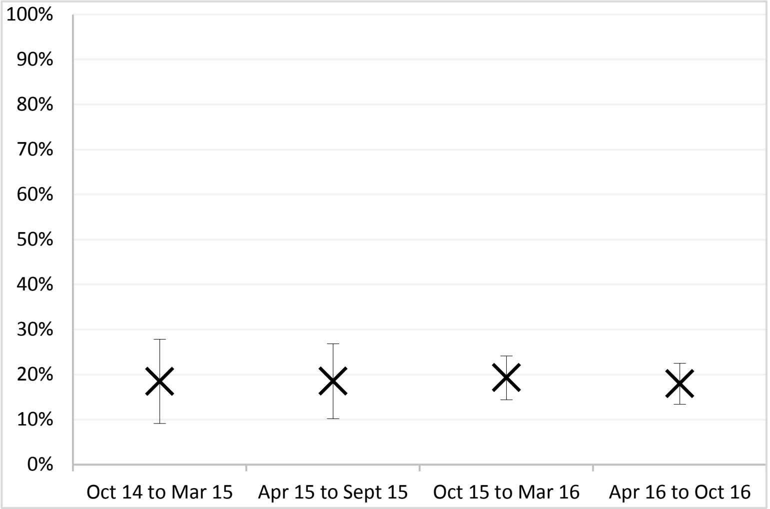
14. Proportion of respondents who agreed with "Definitely not as much social contact as would like", with 95% confidence intervals.



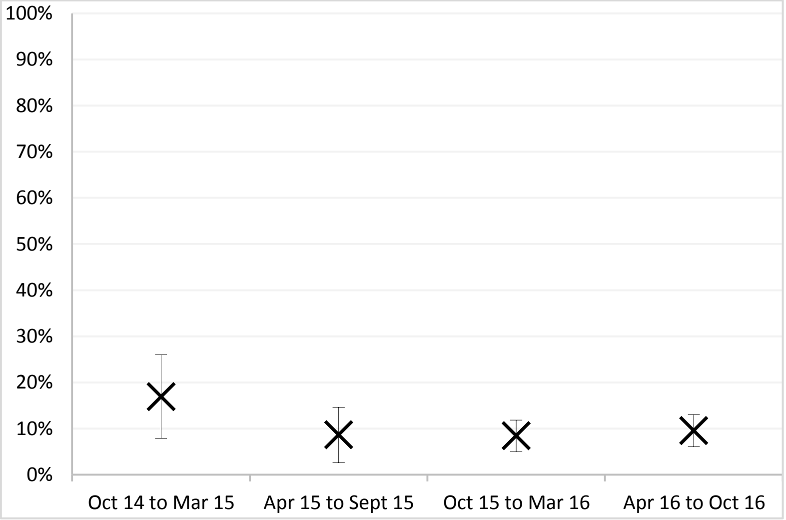
15. Proportion of respondents who agreed with “Much more able to cope compared to a month ago”, with 95% confidence intervals.



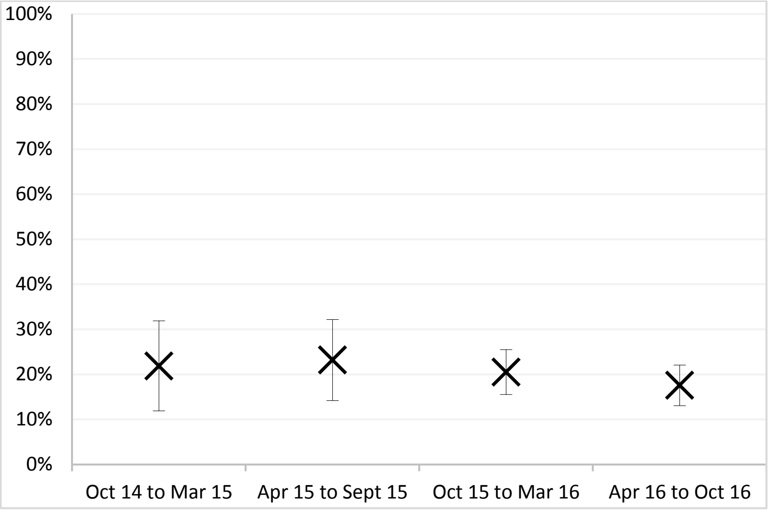
16. Proportion of respondents who agreed with “A lot less able to cope compared to a month ago”, with 95% confidence intervals.



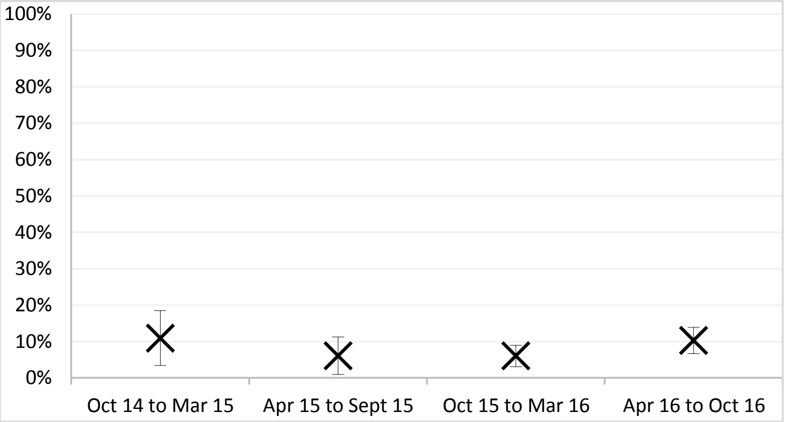
17. Proportion of respondents who agreed with “Feel much better in themselves compared to a month ago”, with 95% confidence intervals.



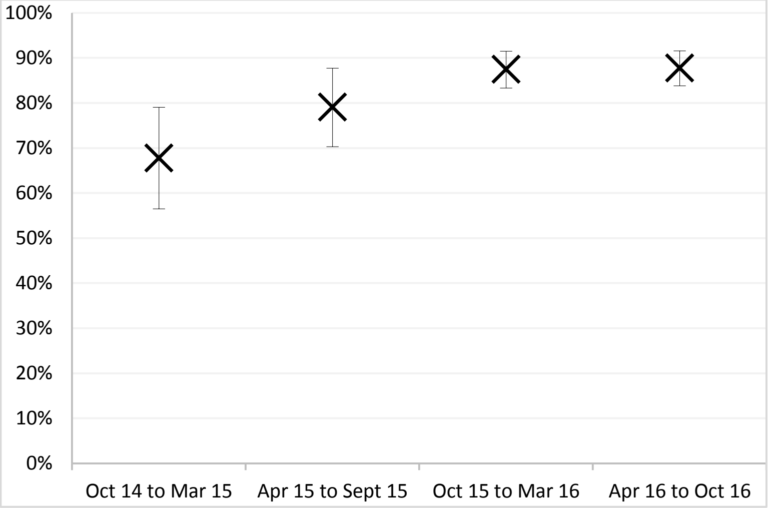
18. Proportion of respondents who agreed with “Feel a lot worse in themselves compared to a month ago”, with 95% confidence intervals.



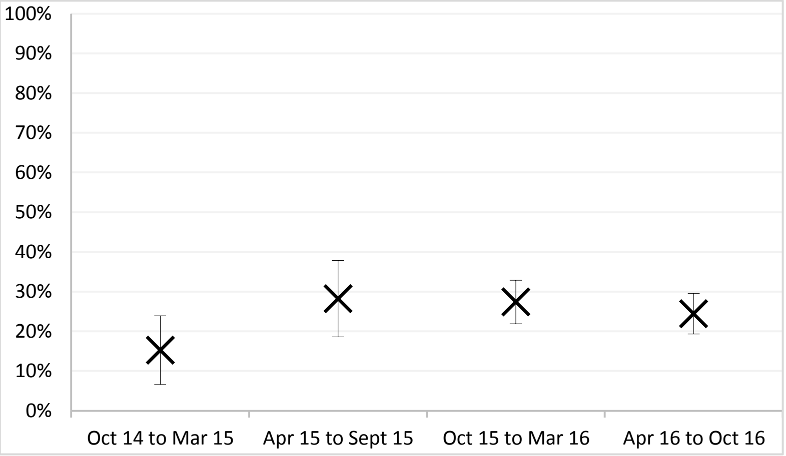
19. Proportion of respondents who agreed with "Rated services overall as very or quite good", by 6 month period, with 95% confidence intervals.



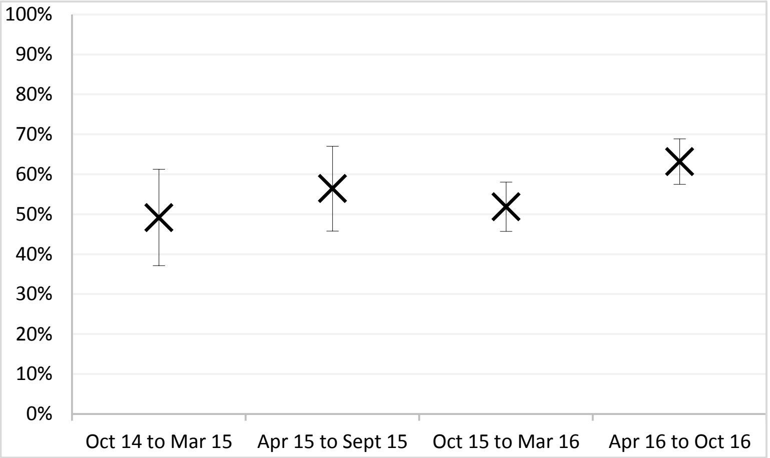
20. Proportion of respondents who agreed with "Connecting Care helped me come home from hospital more quickly", with 95% confidence intervals.



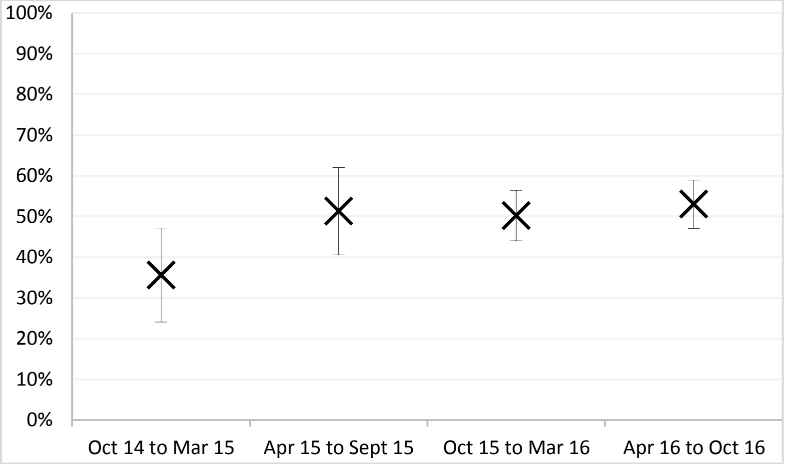
21. Proportion of respondents who agreed with "Connecting Care helped me stay in my own home", by 6 month period, with 95% confidence intervals.



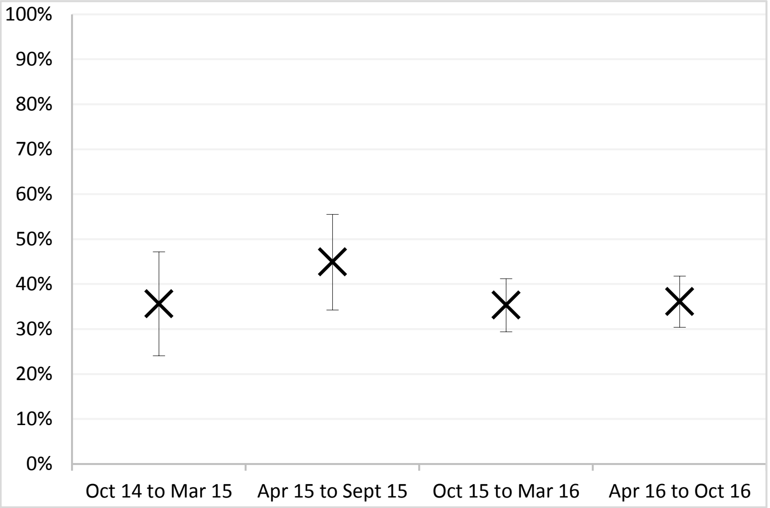
22. Proportion of respondents who agreed with "Connecting Care helped my family or carers", by 6 month period, with 95% confidence intervals.



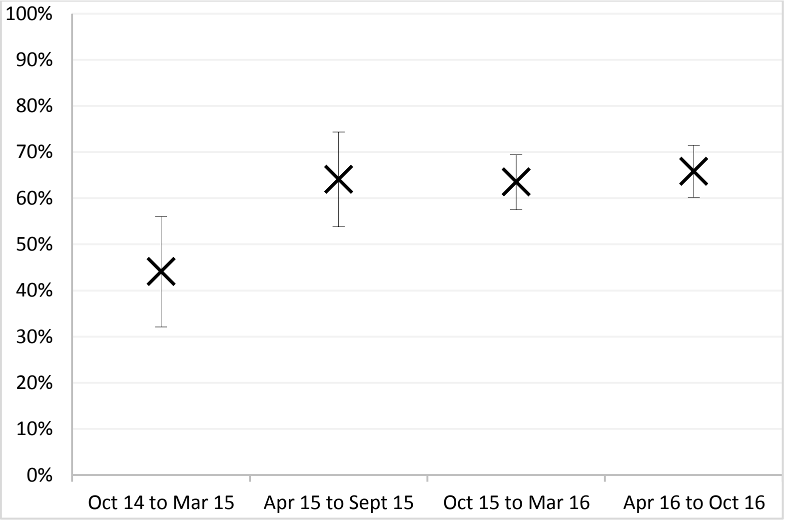
23. Proportion of respondents who agreed with "Connecting Care helped me recover more quickly", by 6 month period, with 95% confidence intervals.



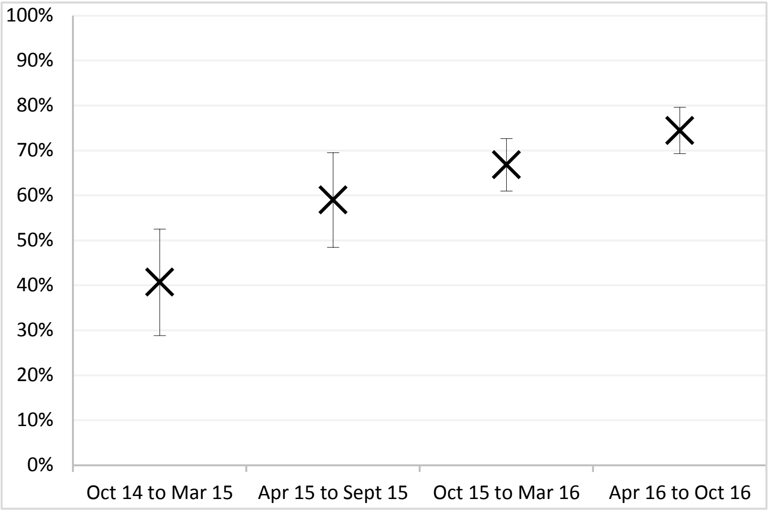
24. Proportion of respondents who agreed with "Connecting Care helped me stay more independent", by 6 month period, with 95% confidence intervals.



25. Proportion of respondents who agreed with "Connecting Care helped me to cope better", by 6 month period, with 95% confidence intervals.



26. Proportion of respondents who agreed with "Connecting Care has not really helped me", by 6 month period, with 95% confidence intervals.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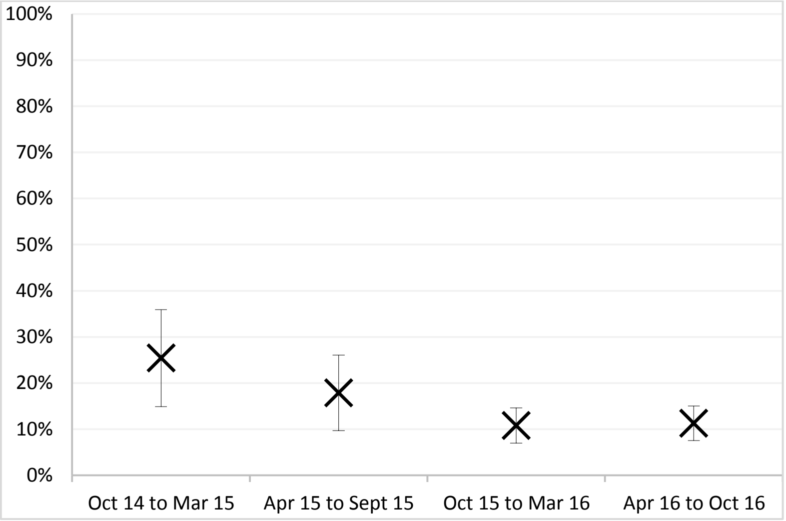
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1.1

Evaluation of

Connecting Care in Wakefield

CARERS' EXPERIENCES OF CONNECTING CARE

June 2016

CONTENTS

1. INTRODUCTION

This report details the findings from an independent evaluation of carers' experience of the impact of Connecting Care (CC) in Wakefield; based on 53 one to one interviews with unpaid carers.

The evaluation forms part of a wider independent evaluation of Connecting Care (formerly known as Care Closer to Home), being conducted by Niche Health and Social Care Consulting (Niche) and supported by Healthwatch Wakefield. Niche is an independent organisation which undertakes consultancy support, including external evaluation of complex transformational projects, across health and social care. Healthwatch Wakefield is an independent consumer champion, set up to help people get the best out of health and social care services and to make sure that the views of the public and people who use those services are taken into account in both improving and shaping them.

The Connecting Care teams include:

- Community Matrons
- Physiotherapists
- Occupational Therapists
- Social Care staff
- Age UK workers
- Carers Wakefield workers
- Pharmacist

Helping and supporting carers is a key aim of the Connecting Care approach. Specifically the aim of:

- carers being supported and prepared to care for longer.

We were therefore asked to carry out interviews with unpaid carers of people who have received services from Connecting Care staff in order to answer the following question:

- what is the impact of Connecting Care (CC) on the quality and experience of services for both patients and their carers, in the opinion of carers of people directly receiving services as patients?

As well as answering the research question above and providing findings and case studies of interest and value to the staff commissioning and providing services in Wakefield, we would hope that many of our findings will be of interest to counterparts in other areas.

2. OVERALL DESIGN, METHOD AND APPROACH

At the outset we proposed to conduct around 50 face to face interviews with carers about their experiences of the Connecting Care services. We defined carers, for these purposes as:

- people who are receiving services from Connecting Care teams, and who also self-identify as a carer of another person receiving services from a Connecting Care team;
- people who are known to a Connecting Care team and to Carers Wakefield, but who are not personally receiving any other services from Connecting Care;
- people identified as carers via the patient interviews, but not otherwise known to services at all.

Niche and Healthwatch worked together to agree the framework of questions to be asked. The resulting 14 question qualitative semi-structured interview schedule was approved by the Connecting Care evaluation steering group and piloted on five carers. After making some minor amendments, we proceeded with the full evaluation. A copy of the interview proforma is included at appendix one.

Our sample

We planned to obtain as large a sample as possible (around 200) so that we could randomly select from the names put forward, following Connecting Care staff gaining their consent to share their contact details with us.

It was agreed with Connecting Care service managers that we would obtain carers' details (name and contact details) from three sources:

- Carers Wakefield staff
- Connecting Care staff
- Healthwatch staff (who were concurrently conducting face to face interviews with service users during which they often had contact with carers).

The staff who obtained the carer's details were also responsible for obtaining consent from each carer (to share contact details with Healthwatch) and explaining why they were being asked to participate in a carer's interview. It was anticipated that we would select equal numbers from each source. In reality, referrals from Connecting Care staff were slow to come through. It was not just a case of getting a signature to consent to being approached by Healthwatch at initial assessment (which was a process set up for service users). This would quite possibly have given us carers with a lot of experience of caring, but not necessarily a lot of experience of Connecting Care support. It was necessary for both Connecting Care and Carers Wakefield to pro-actively contact carers and ask for their permission to pass on their details to us so that we could contact them. This took time for Connecting Care and Carers Wakefield to do and was an additional duty for them.

In addition there were some practical difficulties due to the lack of a shared patient/service user record, meaning that carers' contact details might only be known to one of the services involved. In some cases, carers' details were not recorded at all. It was therefore, extremely fortunate that Healthwatch were concurrently undertaking a large review of service users and that this (which again had faced ongoing issues in gaining details of consented service users) was much farther forward and was able to be used as an excellent source for recruiting carers.

In the end we sourced referrals as follows:

Source	Number referred
Carers Wakefield staff	13
Healthwatch via patient/service user interviews	37
Healthwatch via other source	3

As the process of receiving referrals took so long to put into place we had to accept and interview all carers whose details were provided to us, except for two who subsequently cancelled due to ill health.

Governance

The survey processes and approach were overseen and signed off by the Connecting Care evaluation steering group, which consisted of representatives from Wakefield MBC Public Health (who commissioned this piece of work), Wakefield CCG, Healthwatch Wakefield, Mid Yorkshire Hospitals NHS Trust, Age UK, Carers Wakefield and Niche Health and Social Care Consulting.

Contact and consent

Contact processes differed slightly, depending on the source of the consented carer. Some carers had already met the Healthwatch interviewer when she came to carry out an interview with the patient/service user. However, all consented carers were either phoned or spoken to directly to explain or confirm the purpose of the interviews, ask if they were still happy to be involved, answer any questions they might have about the interview process and to agree a date, time and venue for the interview. They were then told the name of the people who would be interviewing them and this was confirmed in writing.

We offered to meet carers at a venue of their choice. Interviews were carried out by two interviewees, one employed by Healthwatch Wakefield, and one by Niche. This enabled one person to conduct the interview whilst the other took notes, alternating between interviews, and enabled ongoing confirmatory discussion of the themes arising. The same Healthwatch interviewer was used for the face to face interviews throughout. The same Niche interviewer was used for all but four interviews when she was unavailable and replaced by a Niche colleague for two interviews and a different Healthwatch colleague for two further interviews. Niche staff analysed the findings and pulled together the findings and conclusions detailed in this report.

All interviews were carried out face to face in the carer's or service user's own homes except for two which were conducted by phone (as the carers involved lived in Scotland and London). The length of interview varied from around 25 minutes to an hour. In total we spoke with 53 carers between July 2015 and April 2016.

On arrival for the interview, following introductions, the interviewers:

- explained once again (verbally) the purpose of the interviews
- explained that carers could withdraw from the process at any stage
- explained that we were independent from the services we would be discussing, but would be feeding anonymised views back to those services
- explained how the process would work
- read out loud a written consent form which they asked the carer to sign (in one instance the carer was illiterate but agreed we could sign on his behalf)
- upon completion of the interview, left a FAQ (frequently asked questions) sheet containing answers to questions plus name and contact details should they have any future questions.

The interviewers took time to put carers at their ease and to make it clear that they really were interested in them. Some interviews were very emotional – just talking about the difficulties and stresses that they had faced was hard for some. Some became tearful in taking. A considerable number thanked the interviewers for coming to meet them and for listening to them. The interviewers always left a contact name and details for the Healthwatch lead, in case they had any queries following the interview. They also left everyone with a leaflet about the health advice line, provided by the Wakefield Citizens Advice Bureau (CAB).

If, during the interview it became obvious that a carer was not aware of the services that Age UK and Carers Wakefield could offer, and it was clear that they might benefit from them, then they were advised about these at the end of the interview and offered the opportunity to receive further information about them or for a direct referral to be made.

Ultimately, we were able to recruit a wide range of carers, from across the whole of the Wakefield District, who were able to share a vast range of experiences and insights. We are extremely grateful to them for taking the time to talk with us.

*** All names included in this report have been changed. Where we have provided a more detailed case study we have received approval from the carer involved to do this.**

3. FINDINGS

We have structured this section into two parts. The first part provides some description about the carers whom we met – some facts and figures and details about what their caring role included. The second part details the themes which emerged from our interviews, drawn together into three overarching themes:

- **Theme one** details what the carers told us about what their lives are like. This covers areas such as, the support they receive from their family, findings around their own health and that of the person (or people) they are, or were, looking after.
- **Theme two** describes the impact of caring on the carers. This includes the impact on their own physical and mental health and on their finances. It also looks at the impact on social isolation and loneliness.
- **Theme three** focuses on the help and support which carers have received from Connecting Care staff (and where relevant from other sources) and captures their views on how easy they found it to access and use that help, what they found useful and their views on what other support would have helped them in their caring role.

Where possible, we have used the carer’s own words to describe what they told us.

Some facts and figures about the carers we interviewed

We interviewed 53 carers:

- two thirds of them were women;
- 79% of them lived with the person they cared for;
- most were spouses (61%) or children (24%) of the person they were caring for;
- the majority were over 60 years of age with 9% of carers in their eighties and
- all, but two, defined themselves as White British
- all, but three, lived in Wakefield district
- 43% were in Bullenshaw Hub area, 43% in Waterton Hub area, 6% in Civic Centre Hub area (with the remainder outside Wakefield district)
- four were in paid employment.

For more detail see the charts in appendix two.

The most common tasks that carers were undertaking were:

- housework including shopping, cleaning and laundry
- food preparation including helping service user to eat in some cases
- helping with toileting (and dealing with incontinence)
- ensuring medication was taken correctly
- helping the person they cared for to get into and out of bed
- helping with washing/personal hygiene/showering and getting dressed/undressed
- helping with mobility e.g. helping them to get around with wheelchair, or mobility aid
- taking the person to hospital and other appointments
- managing finances
- managing the person’s safety e.g. helping with re-positioning, making sure doors and windows locked, ensuring the person did not fall or picking them up when they did
- organising the person’s care and services
- re-assuring the service user and dealing with memory problems or other mental health problems such as anxiety.

What carers said about what they do
John’s (68 years) wife has a bowel condition and told us “... *I used to work full time and had never done house work before, but now I do everything……….M (his wife) has recurrent diarrhoea so I have to boil wash everything which is a burden*..”

Mandy (55 years) who lives with her mother, who has dementia said “...*I feed mum which can take up to one hour each meal*…”

Sharon’s (64 years) husband Adrian has severe arthritis with many fused joints and had a stroke about a year ago. Since then she has to help him to get dressed including putting his shoes and socks on. She has to clean up after he has been to the toilet. She has to go into the shower with him to help him which is difficult. She does all of the housework and cooking.

Bob’s (63 years) mother has dementia, but lives alone. He told us “...*It is a 24/7 job. I go over to see her twice a day and stay for quite a while. I organise all her shopping, meals, finances, washing, medication etc. I take around 30 phone calls from her each day. I sort out all her medical care and take her to hospital appointments, which can last all day long. She comes over to me all day on a Friday and one of my daughters has her over on a Sunday for the day*...”
Irene (56 years) said *“... I do everything for him. By 9pm I have had enough and just go to bed…”*

Themes arising from the interviews

Theme one - What are the carers and their lives like?

Family support for carers

Many carers that we spoke to were also being supported by other family members. Many had family who lived locally and provided help with practical tasks such as shopping, cooking meals and running errands. In addition they sometimes provided respite so that the primary carer could get out. They told us that this was often the difference between coping and not coping, although it was still hard for them. 14 of the 53 carers interviewed had significant extra support from other family members with visits from them up to several times a day. Others had family or friends who supported them at least a couple of times a week.

What carers said about the support they got from family members

Norma (72 years) said "...my son takes my husband out every week twice weekly even if only for a couple of hours so I can get some respite, I can then do my shopping, this is my time and I need this.."

Alf (88 years) said "...my family do the big shopping, gardening, change beds and help with ironing. We couldn't manage without them..."

Dora (73 years) said "...my daughter or grand daughter visit every day and often bring meals or can run errands…. without my daughters I could not cope..."

Brenda (82 years) told us "...my daughter works full time but lives locally and helps me to look after him.."

Anne (60 years) said "...my son and daughter came several times every day but I don't think even they realised how hard it was. She was awake nearly every hour in the night and I was exhausted…"

Gloria (50 years) said "...we looked after Dad between us – my two sisters, my niece and me..."

Jackie (47 years) "...my brother comes twice a week to sit with them (her elderly disabled parents) so I can get out to do the shopping…"

Reluctance to want or accept help

Some carers told us that they had been offered help, either for themselves or for the person they cared for, but had chosen not to accept it. This had sometimes had a negative effect on them (as their health subsequently suffered due to their caring role) and some said that, in hindsight, they wished they had accepted it. In some cases the person they cared for had rejected help, which could be very frustrating for the carer.

A few carers said that they did not want strangers coming into their house and would "... prefer to struggle on…" Sometimes we could see that they really were struggling. Some carers did not want help for themselves as they did not want to talk about their situation with others, whether or not they were in the same position, saying it would be "too depressing".

Carers' health

Many of the carers that we interviewed were themselves in poor health, even without taking into account the impact of their caring role on their health (which for most was significant and is discussed in more detail below). This is perhaps not unexpected, given the age profile of carers. The level/severity of the health problems with which some carers themselves were coping was significant. Despite these they were struggling on, often with quite limited (or no) help. In some cases it was difficult to establish who the carer was, as both carer and service user relied very heavily on each other.

Carers who had significant health needs of their own included:

- Madge (78 years) has spondylosis and arthritis and can hardly walk and yet does everything for her husband who spends most of his time in bed.
- Paul (66 years) was an amputee himself and cares for his wife who also needs a wheelchair when outside the house.
- Jackie (51 years) is registered disabled with a crumbling spine and sometimes has to use a wheelchair. She cared for her diabetic, blind, amputee husband at home until his death from cancer.
- Dora is a 67 year old lady with a chronic lung condition and tremors who has been unable to work for many years due to ill health. She looks after her 92 year old mother.
- Both Ada (84 years) and her 93 year old husband use mobility scooters.
- Linda (65 years) has MS and is able to stand for only short periods herself and can walk just short distances. She cared for her terminally ill, incontinent husband more or less single handedly during the last few months of his life.
- Bill (75 years), is diabetic and on insulin, has been diagnosed with asbestosis and other complaints which are age related. He can't see very well, cannot write well and states he cannot manage without his wife (the service user.) He says "...*we work as a team*..."

Some carers told us that there was sometimes little consideration given to their own health needs by the services which were supporting their loved one.

What carers said about the consideration given to their own health difficulties

Linda (65 years) told us "…because of my MS even simple things are difficult for me like putting my shoes on. One day I was told they needed a urine sample from my husband. They told me to go the GP to get the right bottle. Then I had to come back and get the sample. Then I had to go to the GP again. Then the same day they asked me to come and get a prescription and get it made up for him. Each trip was like a marathon for me. I was exhausted. There was no consideration for my health problems at all. The worst was all the washing and changing the beds often several times a day due to ongoing leaking of the catheter…"

Jackie (51 years) said "….there was no consideration for my health and disability. It has definitely had an impact on my health. And it has screwed my son's head up seeing his father suffer so much without help…"

Bill (65 years) has a problem with his hand and needs an operation on it but he can't have an operation because he would not be able to push the wheelchair or look after his wife. He told us that his knees are "*going*" because his wife is mainly in bed and he goes up and down stairs at least 20 times a day. He is tired all the time.

Looking after service users whose health was declining

The service users whom carers were looking after, or had looked after, had a wide range of needs, often having complex and multiple diseases and disabilities. In a number of instances, the Healthwatch interviewer had previously interviewed the service user (as part of the service user survey which is also informing the overall Connecting Care evaluation). She commented on how their health had deteriorated and how their needs had increased even during a relatively short period of a few months.

Some carers found it difficult to understand why, given the expected trajectory of deterioration and decline (e.g. where they cared for people with terminal or long term conditions), some services had just visited them a couple of times and then left them to cope.

- one lady (in her late seventies) caring for her terminally ill husband had been discharged by the Macmillan service just months before his death and told to "ring them if she had any concerns"
- several carers had struggled to get services for their relative with deteriorating dementia
- several carers were worried that they had no plan in place to deal with an emergency, particularly if anything happened to them
- some lamented the lack of ongoing support such as that which the community matron service had provided in the past.

For several people

Eight of the carers we interviewed were looking after several people, not just one. This comprised:

- sister and brother with dementia
- mother, mother-in-law and wife
- husband and man next door
- friend and neighbour
- both parents
- wife with multiple problems and disabilities and son with Multiple Sclerosis
- husband with heart disease and grandson with mental health issues
- wife and brother with mental health/alcohol issues

Theme two - The impact of caring

The impact of being a carer on the carer's own health

Even with excellent support almost all carers report that their caring responsibilities had had a huge impact on their own mental and physical health. Just eight of the 53 carers interviewed told us that they felt that their health had **not** been affected by their caring role. Many described the physical impacts of caring, such as torn muscles, bad backs, worsening eczema and joint pain. Some examples of such situations are shown below.

- Marie (aged 78 years) had a hip operation last year, before her (terminally ill) husband became ill. She was making a really good recovery and was getting out and about. However, caring for her husband and lifting him so much had left her with a torn muscle in her leg/hip and she now walks with a Zimmer frame, has very limited mobility and is in constant pain.
- Elsie (aged 84 years) looks after her husband who is 93. She told us that helping him onto the toilet, and picking him up from the floor when he fell, had made her bad hip a lot worse.

By far the biggest impact was on carers' mental and emotional health. Many carers told us they were exhausted, shattered and tired all the time. A number were in tears as they discussed this. Although we didn't ask specifically, ten carers chose to tell us that they had had to go onto anti-depressants "to cope". They felt exhausted by the relentlessness of their role as a carer. In a significant number of cases they also felt that their mental health had been affected by the difficulties and obstacles they had faced when they first tried to get help and did not know where to go, or were refused help when they felt they desperately needed it. Several said that they had had to put their own lives on hold.

Carers told us that they were frequently irritable and often felt down as a result of their caring role, and a number were very tearful when speaking about being a carer. One carer told us he was self-medicating using alcohol, and one was self-harming.

Phrases we heard over and over again, included *"...tired all the time…" "..I am shattered…" "..on edge and snappy" "...tearful..." "..I am just frustrated and short tempered all the time. "..I have good and bad days..." One carer said "...some days I could go out and not come back*..."

What carers said about the impact of caring on their own health

Anne (64 years) told us: "*…I was exhausted, in tears a lot of the time and had to go on anti-depressants, looking after Mum with severe dementia. When I needed a cry I could go up to my son's house……sometimes I would go upstairs for a cry so I did not upset the grandkids. You don't realise what you are taking on or how hard it is. That's why I had to go on the anti-depressants. It was the mental side that got to me. It was so hard. No one knew how hard it was…*"

Peter (66 years) said he had never admitted it to anyone but his health has suffered. He feels stressed and tense all the time and can't relax. He is always waiting for the next phone call. "*…If I hadn't retired then I don't know how I could have done this*…"

Deirdre (64 years) At first she said that it had not impacted on her health but then admitted that she does get very tired and on a recent visit to the GP he said that he thought she had depression and put her on anti-depressants. She doesn't sleep well at night.

Claire (59 years) got very upset when we asked if she thought that being a carer had affected her health and said it's really hard to cope with everything- mum, job, teenager and she is shattered.

Steve (53 years) told us that his health and his brother's health have definitely been affected by having to care for his Dad and find out about and organise everything. They both suffered from anxiety as a result and have been put onto medication.

Several carers also told us that they were worried about the future and what would happen to the person they were caring for if anything happened to them. Several carers were concerned that they did not have ". . . *a backup plan*..." or crisis plan or safety net. "…W*hat would happen to them if anything happened to me*...? "was a frequently expressed concern. Understandably, carers with significant health problems of their own, or who were much older than the person they cared for seemed to have this as more of a concern, although it was also articulated by some younger carers too.

Others felt guilty that that they were unable to care as well as they felt they should. Or, if they had had to put the person they cared for in a home, they felt a lot of guilt from that too. The emotional impact of this was often considerable as some also felt resentful about the impact on their own lives and then felt guilty that they felt resentful.

Some carers were clearly trying to protect the person they cared for, and sometimes the rest of the family, from their own emotional distress. We experienced this with several carers who started the interview very upbeat, in front of the person they cared for, but then, when we moved into another room alone, became very tearful and distressed and 'opened their heart' about how hard it all was for them.

What carers said about feeling guilty

Gloria (48 years) said "*the stress was massive; I felt a failure at home because I could not look after my dad and out of all the family I have been the one who has usually taken control. I felt really guilty. I was exhausted. I felt a failure at work…*"

Robert (63 years) said *"…I promised my Dad that I would never put her (Mum) in a home and feel guilty even thinking about it, so just got to plod on…"*

Social isolation and loneliness

Although we did not ask a specific question about loneliness or isolation, it quickly became clear, when speaking about their lives, that many carers were quite isolated and/or felt lonely for much of the time. Many of them were unable to leave the person that they were caring for long periods and often as little as one hour a week.

What carers said about being lonely and isolated

Dora (65 years) speaking of her 92 year old mother who has dementia said "…*I don't dare go out and leave her as there is a chance she will fall down the steps and if she falls down behind the door I would never get in*…"

Brian (72 years) told us *"…It's very difficult to get out as I can't leave A on her own for any amount of time…"*

Margaret (68 years) said "...*the only time I have to myself is when I go to Aldi or Asda*..."

Ron (85 years) told us that he and his wife were very isolated and had no family or friends around

Marie (78 years) "…*my husband spends quite a lot of time in bed as he gets very tired and so I get lonely*..."

Winston (72 years) said *"...I do get lonely. These days people do not speak to each other, It is very lonely for both of us. I can only leave my wife alone when she is asleep early in the morning…"*

Peter (75 years) "...There is nobody who has come and said how are you coping and how can we make it better? Someone should come and see us just to have a cup of tea now and then..."

Arlene (60 years) "…*We need someone to listen to us. Sometimes I just need to have a cry it's so bad….*"

Many faced additional practical difficulties in getting out which made them feel quite trapped. Reasons for this included:

- their own poor health and the fact that they felt exhausted and “run down”
- lack of accessible transport,
- expense of having to take taxis,
- limited time to get out in between (paid) carers’ visits
- poorly managed incontinence
- in a couple of instances the service user/patient did not want the carer to go out, because they did not feel safe at home without them.

Poorly managed incontinence stopped a number of people going out due to the practical and embarrassment impact of dealing with leaks in public. One lady (aged 78 years) told us that her husband was incontinent of faeces and has to go to the toilet very urgently. This is not always possible when out and they had had an embarrassing incident when he had soiled a friend’s carpet which has made them reluctant to go out. She has not told anyone about this problem. She explained that at the GP surgery they have notices “all around” which tell you not to introduce extra topics during a GP consultation as they are short of time and so she did not feel she could raise this, leading to increased isolation.

Another, Brenda (82 years), said “*I would love to go out more, but he has had a couple of falls and we worry about his pants/pads leaking, which they have before, leaving him soaking wet in public. He is also incontinent of faeces which is very difficult to deal with*...”

Few people that we spoke to had respite care. Some said that it had been offered but, that because it had to be paid for they were unwilling or unable to take this up. Some had family members who could sit for them so they could go out. Even if they did have some respite from friends or officially they were sad that they had to go out alone and that their partner would not be able to join them, or was unwilling to go out.

For some carers this had been alleviated by services they had received from Carers Wakefield or Age UK.

What carers said about how Carers Wakefield had helped them combat loneliness

Brenda (82yrs) had recently received support from Carers Wakefield and told us several times during our interview how much she was looking forward to going out to a forthcoming carers’ meeting which was going to involve trying out alternative therapies such as Aromatherapy.

Anne (60 years) “*...the lady from Carers Wakefield was not like a support worker she became a friend…”*

Jean (78 years) “...*T from Carers Wakefield is a great support and now a friend…*”

However a lot of those who told us that they felt lonely or isolated were not aware that Carers Wakefield or Age UK could offer a one to one service, but said they would definitely be interested in such a service. Following the interviews (and with carer’s consent in all cases) Healthwatch referred carers to the following services for additional support:

Onward referral to	Number referred
Age UK (Wakefield)	6
Carers Wakefield	8
Other third sector service (City of Sanctuary and Total Voice)	2
Back to another service within Connecting Care	1

Financial impact of caring

In addition to the physical and emotional impact of being a carer, many carers reported financial pressures that had been caused or made worse as a result of being a carer. A number of people had taken early retirement in order to care for a relative (usually a parent) and had had to give up their job because they could not cope with the demands of caring and the demands of their job.

On a positive note, almost all carers were aware of and in receipt of carers' benefits such as attendance allowance. A significant number were also aware of the "My Time" money which was available for carers. Several reported that they had been helped by the Connecting Care social workers or Carers Wakefield and Age UK to claim everything they were entitled to which had really helped them.

Mabel (74 years) has a social worker who got her and her husband a £100 reduction off their rent which had been a great help. "..*the extra money made a real difference to us…"*

Irene (56 years) told us "…*we had big financial problems and J from Carers Wakefield helped us to sort them out…*"

Theme three - Carers' experiences of, and view on, the care and support received

How easy was it for carers to access help and support when they first needed it?

However good the Connecting Care service is, it is no help to people if they are unable to access it. We only spoke to carers of people who were receiving (or had received) services from Connecting Care and it was not always clear how they had been referred into these services. In terms of specific support for carers themselves (from Carers Wakefield) there appeared to be a wide range of routes through to this including:

- referred by Connecting Care staff
- referred by non Connecting Care staff
- self-referral after being given information by Connecting Care staff
- self-referral after seeing information in GP's surgery
- self-referral after seeing information elsewhere e.g. Internet

For many, accessing the help had been straightforward as they were referred by their GP or other source. Twelve carers, however, told us about significant difficulties that they had had to access help or support from services (both for the person they cared for and for themselves) when the need for more assistance first arose. They described a frustrating and often exhausting process to get help. Often people started with their GP or Hospital, but in some cases the carer had approached many services in an attempt to get help, both for the service user and for themselves.

What carers said about accessing help and support when they first needed it

Mabel (74 years) told us *"….After his (her husband's) diagnosis I was given three numbers to ring and told they would sort out everything and they have. We both have marvellous help. I can't believe it..."*

Ada (84 years) said "…*you don't know where to look for help when you start, you are lost at first. I had no idea where to go for information*…"

Helen (73 years) said "….*I just think that when something like this happens that you don't have a clue and you don't get any information. You don't know and don't get given any….."*

Arlene (60 years) said "…*you can't ask a question if you don't know what questions you should be asking……."*

Steve (50 years) said, of trying to get help for his father who had worsening dementia "...*As a carer, you are out there on your own. You have to find out everything for yourself. All the information is separate so you have to go to each separate organisation to find out what they can do. It should all be together in one place. It's not a very efficient way to work…."*

Many carers told us that, they felt, their GP should be the common gateway to the support which they needed. Others, like Patrick (see story below) were put on a "waiting list" to access services, during which time they had struggled to cope.

One carer's story of his struggle to get help and support

Patrick (53 years) lives alone and took early retirement a few years ago, when the chance became available. He is the only child of 85 year old Mary who lives alone on the other side of Wakefield. Last year he became increasingly concerned about Mary's health and safety. She had become progressively frailer, with her mobility getting worse. He discovered that she had not been able to get in the shower for 8 or 9 months as she did not feel safe in there. She had poor eyesight and a number of medical conditions such as diabetes and heart disease. She was struggling to prepare meals and could not get out alone. Patrick was her only living family member. He was driving 10 miles each way to see her each day and to do her meals, shopping and housework but could see that she needed much more help.

He said that "*...despite being very ill and frail she didn't seem to be on anyone's radar…*" He tried to get a wheelchair for his Mum but was told it would take 3 to 6 months for an appointment. He was told that before any other services could be provided Mary would have to be assessed by social services, but that there was a waiting list for this. He was told that the service was working to capacity and basically he would have to wait for someone to die before his mum got allocated anyone. He asked how long they would have to wait but was told that it was policy not to say how long the waiting list was.

Patrick found the phone number for SPOC (community nursing single point of contact) and phoned there, but was told Mary was not on the system as she didn't have a social worker and they couldn't help her. He found the number for Carers Wakefield on the internet, and approached them and they sent him "a pack in the post".

In the meantime his Mum's condition was getting worse. As Mary's son he did not feel it was right to do her private care – such as showering, so he managed to find a private carer who came in to help with meals and to help Mary to have a shower. After a few months a physiotherapist or occupational therapist came to assess Mum. Shortly after this (in early 2016), five months after he first tried to get help for her, Mary died. Patrick got a phone call from Social Services to say she had come to the top of the list for an assessment, and the appointment from the wheelchair service, after her death.

Who would carers turn to for advice or information about the care and support of the person they were caring for?

One of the aims of Connecting Care is to keep people safely in their own homes for longer and so it is clearly an advantage if carers know whom to contact (both in and out of hours) if they have queries or concerns. We were therefore interested to know whether carers knew whom (within the Connecting Care team or outside it) they would turn to for non-emergency information, advice or support either within or outside office hours. As shown below, the most common answer was the GP. Given that these carers are looking after some very frail and vulnerable service users, it is of concern that a considerable minority did not know who they would call or where to go for information either within (20%) and outside (35%) office hours, and that 16% said they would call 999.

Within hours:

- 33% said they would call their GP
- 22% said they would call a member of the Connecting Care team (e.g. Social Worker)
- 20% said they didn't know who they would call

Out of hours people were less certain who they could call.

- 35% said they didn't know who they would call
- 16% would call 999 or an ambulance
- 8% said they would call their GP
- 8% said they had been given a number that they could call out of hours

Carers also told us that, when they had tried to get information and advice about the service user's care, support and treatment that this had sometimes been a difficult process for them. This appeared to be a particular difficulty for carers who did not live with the person that they cared for, although not exclusively so.

This was not just an issue with regard to Connecting Care staff, but also GPs and other community services and hospital services. Some carers had received help with this issue from Connecting Care staff (particularly from Carers Wakefield workers) and therefore we feel it is relevant to include concerns about those other services here too.

Carers told us that:

- services would not always share information with them about the service user citing "data protection" and "confidentiality" even though it was likely to be to the potential detriment of the service user for this not to be shared with them,
- services did not always explain to them what they were doing (for the service user) or why they were doing it – or carers did not understand or remember these explanations,
- services did not always ask carers for their opinion about the service user even though they were with them 24/7 and, for example, where the service user clearly had a mental incapacity such as dementia.

This left carers feeling marginalised and frustrated, and in some cases they felt that this had compromised the safety of the care given to the service user.

It is notable that none of the carers quoted above had received help or support from Carers Wakefield. Some carers who did have a good relationship with a support worker from Carers Wakefield told us that they had received help to write letters or fill forms in to enable them to get the information they needed. A couple of the carers quoted above, went on to get support from Carers Wakefield or Age UK which helped them to overcome these problems by ensuring that they were "registered" as carers on all relevant health and social care records and appropriate permissions or consents were put in place on the patient/service user records to indicate that information could be shared with them. Once this was done, their lives became easier.

What carers said about trying to access information about the care and treatment for the person they were caring for

Lionel (66 years) has insisted that the people who can have access to his wife's records be documented on System 1. This is proving to work well but he had to push for it and it took a lot of time and effort for him to set this up. He said it would have been "...*much better if this had been set up from the start*..."

Debbie (62 years) told us that health and social care professionals don't always ask her opinion even though she knows her neighbour Phyllis (who is in her eighties, has dementia, is registered blind and lives alone), best and is with her for hours every day and does everything for her. For example when the GP visited Phyllis he found her crying and put her on anti-depressants.

Debbie had to contact the GP to tell him that the reason Phyllis was upset was she had just been registered as blind. So he took her off the anti-depressants. But it would have been better if he had spoken to Debbie as part of the assessment, particularly as Phyllis has dementia and can't remember things. GP said he could not discuss Phyllis's care with Debbie as she was not the next of kin. After this incident, however (with the permission of Phyllis) the GP did register Debbie as a person he has permission to talk to.

Janet (57 years) went to see her mother's GP because of concerns about her mother's worsening mental health - including neglecting herself, being violent towards her father and threatening suicide. The GP told her "...*we cannot and will not discuss your mother with you*..."

Irene (56 years) wanted to find out more about her husband's care and condition as she had concerns about it getting worse and wanted to know how this might impact on her as a carer. She made an appointment to speak to the GP and told the receptionist that it was about her husband. She was told this would be OK. However when she got there the GP said that it was not OK to talk to her about her husband "...*behind his back*..." and would not discuss this and so she has been left not knowing who she can ask.

Fiona (48 years) told us that she approached her Mum's GP, as it became obvious that her dementia was getting much worse, but said she was *"... fobbed off…"* because she was not registered as a patient and the GP would not discuss this with her.

What carers said about trying to access information about the care and treatment for the person they were caring for (continued)

Fred (82 years) and his partner Betty care for their neighbour Jerry. They have been friends for a long time, holidaying and socialising together for many years. Jerry has a neurological condition, which affects his mobility and he falls frequently. He has recently been diagnosed with terminal cancer. Fred also has cancer ("*but... it's under control*...") and Betty has high blood pressure. They spend most of their time helping and caring for Jerry who lives in the house opposite. They pop in to see him 3 or 4 times, or more, each day. They manage his money and do all his shopping, run errands, help re-position him when he gets uncomfortable, take him to hospital appointments (which can last all day), deal with all services (e.g. the private carers which Betty organised for him), collect his medication, get him drinks, check his curtains and doors are closed at appropriate times etc etc.

Sometimes, when Jerry is well enough, they take him out to the local garden centre. The nurse visits each week but they have no idea what she comes for and she has had no contact with them. They said "... *we have tried to catch her but we don't know when she will come and she's in and out so fast we can't catch her. No one seems to care when you are after a certain age. We are not given a lot of information as we are not family…*" They also told us that Jerry had recently had a raised toilet and mobility rail put in, and said "...*it's good but we don't know who told them to come...*"

When they had concerns about Jerry's deteriorating health they were told, by the carers, who Jerry pays to come in, that they are only neighbours and not allowed to phone the doctor. They do not see themselves as carers, but as friends. Betty said "...*We do it with a good heart and don't want thanking. We just want him to be happy…*"

Co-ordinating the various services and support

Another key aim of Connecting Care is that the experience of care should be co-ordinated and seamless from the service user (and carer)'s point of view. We therefore asked carers what their experience had been of this. It should be noted that a number of them said that few services were involved so there was little for them to co-ordinate or comment upon.

Around a quarter of carers that we spoke to said that the care and support received had been well co-ordinated. Staff who visited them at home worked well together and things were joined up. Sometimes they told us the name of the person who co-ordinated things for them – for example a social worker or Age UK worker.

What carers said about how well co-ordinated services were that they received at home

Norma (72 years), Pat (61 years) said of Connecting Care staff *"...I like the people, they work well together…"*

Kitty (84 years) said *"….they all work well together in my experience. They are based in Bullenshaw and I feel they communicate well with each other…"*

Lionel (66 years) told us that he is very active in ensuring his wife gets the care that she should, but said the services are "...*very good and joined up well….for example it was great that the OT and physio came to visit on same day*"

Martine (33 years) told us that her social worker co-ordinates everything

Darren (35 years) told us that his wife's care and support had been "*all joined up*" and he did not have to co-ordinate things, which he appreciated as he works full time.

Deirdre *(64 years*) told us that her Age UK workers had been very helpful generally in organising things and told her that she could ask her anything which was very helpful.

Debbie (64 years) said "…*services don't seem to share information. I know everything but the GP only knows his part, the social worker only knows her part and I have to co-ordinate things…."*

Fred (82 years) said *"It's all organised and paid for privately (carers, respite, aids) and so we have to coordinate everything. The district nurse comes but we don't know what for and she does not talk to us…"*

Bob (63 years) told us that he has had to coordinate everything. He said "…*the health side has been a nightmare trying to find your way through. There should be more cohesion and working as one. It feels like a jigsaw puzzle but at the moment all the pieces are on the floor and, as a carer, you have to pick them all up and put them together yourself…"* He added that he can't believe that he has to keep telling the same thing to all the different organisations involved and that they don't share information.

Mandy (55 years), whose Mum has dementia said "…*the services do not work well together. I co-ordinate all her care. I feel like I am fighting all the time. I need more practical support for mum now as her needs have increased. We have had four different Social Workers and it's difficult as I always feel I have to start again with each one, I am always repeating myself*."

Sandra (47 years) said "...*one of the most difficult and frustrating things about being a carer is that the services are just not joined up and you keep having to repeat the information over and over again…*"

She told us that when her Dad was sent home from hospital with a catheter no one told them what they were supposed to do. As her Dad was confused he kept pulling it out. He was unable to empty the bag, but no service was available to do this during the day when his son and daughter were at work. Sandra contacted the district nurses to ask them if they could do this, but they said it was not their job. She was left trying to phone lots of different services to try to find who could help with this. She said "… *Amazon can keep a shopping history and yet people from health and social care just keep asking you to repeat the same story time and time again……."*

Just over a quarter said that there was very little co-ordination of services and that having to co-ordinate services and constantly repeat information was one of the most time consuming and frustrating aspects of being a carer. Service users did not always see this extra work and their care did not necessarily suffer as a result, but it clearly had a very negative impact on the lives of carers who experienced this. On the other hand, for those whose care and services were well co-ordinated by the Connecting Care team, this impacted positively on both the service user and the carer.

How are the services and support that carers have received helping them to care for longer?

Carers' lives were made easier when services were well co-ordinated and the person they were caring for was well supported. As several carers said "...*what helps him, helps me*..."

Sometimes quite small interventions had made a big difference to carers. One lady told us "…*Carers Wakefield got a stool that my Mum could sit on in the shower and that made all the difference to us*…" A number of carers told us that aids and adaptations had been made quickly available to them and that this had really helped them.

For others it was services such as daily visits from paid carers which were enabling them to cope for longer by taking over some of the burden of domestic and personal care.

A couple of carers mentioned the Community Matron as having really helped them.

A few carers had access to regular respite care, which they said really helped them, although only if the quality of that care was good. Carers reported very variable experience of residential respite care, which they had used, from what they considered the truly excellent to the truly appalling. Sending a loved one to a residential placement for respite which was of poor quality (in their experience) had in some cases caused additional stress to the carer and produced the opposite outcome to that which was required. They vowed never to use such provision again.

A growing number of carers seem to be aware of and making use of the MyTime money which enables them to go away, if they would like this. Those who had accessed this were very grateful.

Another service (not within the Connecting Care team but which staff often signposted to) was Care Link (a paid for response system) which many carers said had made a real difference to them in being able to continue caring. They told us it gave them peace of mind knowing they could call them, and that it was helpful if someone fell but did not need to go to the hospital.

The Connecting Care services which were most frequently mentioned by carers as helping and supporting them were Age UK and Carers Wakefield. The fact that Carers Wakefield could develop an ongoing relationship with carers was something which carers who had experienced this, particularly valued and found helpful.

In addition, one carer said that he found it helpful and reassuring to know what services are available "*down the line*..." as his wife had a terminal illness which would only get worse. He had been told what help would be available then and how to access it.

What carers told us about services that help them to care for longer

Alan (71 years) said "*…the OT came and got us a stair lift and some equipment which has really helped us…*"

Joan (78 years) has a bad back and difficulty standing long enough to cook told us that the daily "home help" carers who get husband up and dressed have been a great help to her.

Sheila (84 years) who had a bad hip and was finding it difficult to pick her husband up off the floor when he fell said that being able to call Care link "..*makes all the difference*..."

Brenda (82 years) told us that her Carers Wakefield worker has been "*really great*" and found her a befriender. She had also been able to support them to get help with getting incontinence pants/pads as her husband was doubly incontinent. They had been buying all of his pads themselves and having frequent "accidents".

Jean (78 years) told us that after her husband had a stroke some years ago they received no aftercare or help. However in the last year or so this has changed and "...*the help has been abundant and it's wonderful*…" She has a worker from Carers Wakefield, who visits every other month and she considers to be a friend and gets information about lots of services. She also said "*… I got £100 MyTime money to help us go on holiday and we would not have been able to do this without this money so it was very helpful*…"

Lionel (66 years) said that all the services they currently receive are good and that "...*I am well aware of the support that we can access and may well do so later down the line but for now we are where they feel they need to be*…."

Bob (63 years) said "...*The community matron was brilliant and got lots of things sorted*..."

Bert (65 years) told us that this wife used to have a really good community matron who has now left, but now worked in their local practice and so they could still access help from her.

Anne (60 years) said *"...I could sit and talk to X from Carers Wakefield. I don't think I could have got through this without her. I have been very lucky. I had lots of support and lots of information eg about Alzheimer's Café and I knew what was around…."*

Bill (65 years) told us of two quite different experiences following his wife (Vera)'s discharge in recent months. The first hospital (outside Wakefield) discharged Vera after two days with no after care and only a walking stick. She could hardly walk and her husband literally had to carry her out of the hospital because they needed the bed for someone else. There was no after care, no walking aids or adaptations provided. Within a few days of being at home and struggling Vera fell and broke her ankle and had to be re-admitted to Pinderfields. After discharge from Pinderfields Bill said the aftercare was fantastic. They were seen by someone from Age UK who got them a wheelchair from the Red Cross plus a Zimmer frame and commode. He felt that if his wife had had all this after discharge from the first hospital then she would not have slipped and broken her ankle.

Arlene (60 years) said "…we *have a monthly meeting with the Carers Wakefield. Our only help is from them…… but we need so much more….*"

What has been unhelpful from the carer's perspective?

Carers told us of some very poor experiences of health and social care, which were unrelated to Connecting Care. Where these were raised, Healthwatch recorded these and will feed them back separately (and still anonymously) to the organisations concerned. In all cases interviewees were told that this is what would happen.

These included:

- poor care in hospital and poor communication between hospital and GP
- difficulties in accessing or receiving care from the Macmillan service
- difficulties with care received from the community nursing service
- poor care received from private care companies
- poor residential respite care
- poor support after someone had died including from funeral companies.

In most cases, the poor support that we were told about was the flip side of the good support described above. For example staff promising to get back to them, but never hearing from them again, poorly coordinated care, lack of services, lack of information etc.

Whilst paid carers provided a great deal of support to many carers, dealing with paid carers and care companies could also be a source of stress. In some cases carers had had to change carers' company several times before they found one that was reliable. We heard a number of very concerning stories about paid carers. We were told about paid carers who:

- were inexperienced (for example - one paid carer sent to look after a disabled lady with very complex needs had less than 2 weeks experience)
- did not turn up for visits so that people missed meals or toileting
- were rushed and did not have time to carry out required tasks
- did not stay for the allocated time
- did not understand how to speak with or look after someone with dementia
- left doors unlocked
- took no notice of the care plan e.g. turned up one at a time to use a hoist which required two people
- spoke to the person being looked after in a very patronising way
- were dismissive when carers tried to raise concerns with them
- left a mess behind which the unpaid carer had to tidy up – dirty washing, dirty and untidy bathroom, dirty crockery etc
- stole food and goods from vulnerable service users (two carers told us of incidents of stolen jewellery and money which they had reported to the police)
- were pressurised to work when ill, therefore spreading infections to vulnerable service users.

Many carers that we spoke to told us that they had never heard of Carers Wakefield, but were very interested to find out more. Other carers were aware of Carers Wakefield, having been told about it, or been given a leaflet by Connecting Care staff, but had an incorrect understanding of what services it offered. For example they thought it only offered support groups, but were unaware of the 'one to one' support that it could offer. In these instances the interviewer from Healthwatch agreed to provide further information to them or make a referral (again with their consent).

An example from a carer who was struggling to get help, and how Connecting Care helped her and her family

Fiona is 48 years old and lives in Scotland. Her Mum Moira lives in Wakefield and is supported by her son, Fiona's brother, who lives locally and visits her every day. This interview was conducted by telephone, but Fiona feels it is important that her story is heard.

Mum was admitted to hospital I the autumn of 2015. After her discharge home it became apparent, very quickly, that she needed to be assessed, as she was forgetting to eat, leaving the gas on at home and becoming very confused. Fiona and her brother tried to get their Mum assessed by Social Care and described this process as a nightmare and a battle.

They also approached Moira's GP but said they were "*.fobbed off*..." and told this was because they (her children) were not registered as patients. The GP was slow to respond and she had to battle with the practice when she felt it was very clear to a lay man that Moira had dementia. Fiona was becoming more and more concerned about her Mum's safety and getting extremely frustrated and angry because Social Care would not assess her Mum. As she describes it *"...I went into battle and sent three letters of complaint to Social Care and a letter to the MP. I made more than 12 phone calls and sent e mails…"* She told us that the whole experience was stressful and exhausting. She felt completely desperate and scared for her Mum and the family. It felt like no one would help.

She eventually heard about Carers Wakefield and went into their office and found them very helpful and supportive. Carers Wakefield involved Age UK who were also really good. They took time to listen and understand the issues and then started to organise help and support.

Age UK pulled the whole process together and provide information, advice and guidance around Moira's condition. Fiona and her brother attended a four week course in Wakefield delivered by Age UK which covered how to live with people with Alzheimer's, finances and the carers role. This course, she said, was very well run and they both found it beneficial.

Eventually, with the help of Age UK and Carers Wakefield, Social Care conducted a two hour home visit and Moira was diagnosed with Alzheimer's just a few months ago and she will now get the services and support she needs. In the event that Fiona needed to ask questions about her Mum's condition, treatment or support either in or outside of working hours she said she would contact either Age UK or Carers Wakefield.

They now have information regarding activities that their Mum can become involved in i.e. cafes and both she and her brother fully understand the services offered by Carers Wakefield and may access more of these in the future.

Fiona felt so strongly about the fantastic service of Carers Wakefield she visited her Mum's GP practice and told them to display Carers Wakefield leaflets because there are people like them that need to be able to access these services. She has since been into the surgery to check they are on display and is pleased to report they are displayed prominently.

What other services would have been/would be helpful for carers?

We asked all the carers what other services would have been/would be helpful to them. Whilst many were unable to think of any services which they felt would have been helpful to them a number were able to come up with some helpful suggestions which are listed below. We have used the exact words of the carers where possible.

1) More **practical support for carers** such as help with shopping or cleaning or moving furniture
2) **Support for young carers** – e.g. Glenn (35 years) would like more support for his young daughter as she is doing quite a lot of the caring for her Mum and would benefit from some support
3) Someone to **ring carers occasionally** to check they are OK
4) Better **procedures for sharing information** so that carers could access information when they needed it and didn't need to keep repeating themselves
5) **Ensure carers are always involved** in decision making
6) A **support network** for the family of people living with a relative with **severe mental illness** to help you to understand and to cope.
7) **Regular home visits** from GPs or other services when someone is seriously and chronically ill. "...*they should not wait for you to send for them*…."
8) **Someone to talk to** would be really great. Someone who could listen to carers even if they could not do anything to help.
9) Health service staff should **explain things clearly** so carers can understand what was happening or might happen in the future ". Bill (65 years) said "...*it would be good if people could explain what will happen (to my wife) to me and what to expect. I don't understand what is happening or why, with her care*..." His wife has degeneration of the spine but he doesn't understand what that means or what the consequences might be. She only had one physiotherapy session at home and he doesn't know why. Another carer said "...*it's not knowing things that makes it really difficult*…"
10) **Support from social care even if you are self-funding**. Sandra (47 years) had tried to get help from social services, but as her Dad was self-funding was told that no help was available. As she pointed out, at some point her Dad will run out of money and "*the service will have to deal with him then*" and she felt that support from social care before that point (e.g. giving information and signposting and getting to know her Dad) would be really useful.
11) There should be a **widely publicised single point of contact** for Connecting Care services. Patrick (53 years) said "…*some sort of one call number that you could phone for advice would have been really good. Someone who could give you advice and sign post you. I got the number for SPOC but they just kept telling me that Mum was not on the system (because she had not been given a social worker) and they couldn't help me*…"
12) It would have been good to have a **back-up plan**. One carer said he was doing everything and coordinating everything, He had no other family or other support. If he had become ill then what would have happened?
13) It would have been good to have **information regarding what aids and equipment they health or social care will provide** and what we could buy ourselves especially where it was quicker to buy it.

4. DISCUSSION AND IMPLICATIONS OF FINDINGS

It a rare opportunity, and a privilege, to be able to meet so many carers, face to face, have time to get to know them and to find out about the reality of their lives and experiences of caring. The majority, of carers that we met, would not have been able to participate in this project if we had not been able to go and meet with them where they lived. Many were only able to get out for short periods of time due to their caring responsibilities or other restrictions, such as their own poor health.

We have tried, as far as possible, to keep the focus on the needs of the carer. However, in reality it is often difficult to separate the needs of the carer from the person that they are caring for. And so our focus is also on the services received by the service user/patient as these have a substantial impact on the carer too.

Having detailed the findings from our interviews we now discuss, in this final section, what the implications of these findings might be, both for current service delivery and future service developments.

Some overall comments

Based on our overall analysis of the interviews completed, once we had completed them, we estimate that around a quarter of carers had experienced really excellent care and support from Connecting Care, whilst a quarter had experienced very poor care or support (usually because it was very limited). The others that we met had experienced a mixed picture.

This was a qualitative piece of work; we have not undertaken any statistical review of our findings. The purpose was to really listen to carers' experiences and views and understand from this how Connecting Care had impacted on their lives. Our impression, from the interviews, was that there was not any area of Wakefield where support for carers was better or worse than any other.

The carers who had experienced the best levels of support were not concentrated in one particular area. Carers who had experienced the most problems appeared to be more concentrated in the group which did not live with the person that they cared for. It is not difficult to understand why this may be so - it is clearly easier for Connecting Care (and other) professionals to communicate with someone who is there when they visit or phone. This group of carers (who did not live with the person they cared for), were also generally younger and were caring for parents or friends/neighbours.

In some cases they appeared to be unknown to services which were supporting the patient/service user. This meant that they were less likely to be involved in decisions about the care of the patient/service user and their opinion and views, which could have usefully informed better decision making about care planning, were often not taken into account. Only one carer who did not live with the person they cared for (Fiona in the case study on page 25) had had support from Carers Wakefield and that was only because she had found out about this herself.

Communicating with carers, both to give and receive information, is clearly vital both to ensure the best possible service for the patient/service user and for the carer themselves. It would appear that sometimes services need to give more thought as to the best way to include and communicate with carers, particularly when they do not live with the person they are caring for.

Accessing help

As detailed in the findings section, the carers that we met and interviewed:

- were predominantly elderly themselves, or caring for someone elderly
- often had their own significant health needs
- often had additional support from other family members, without which, they said, they would struggle to cope
- often felt lonely and isolated
- were mostly caring for someone whose health was declining, and
- were occasionally unknown to supporting services.

In almost all cases, without the support and input of the carer, the patient/service user would be unable to cope and would most likely end up needing to be cared for in some kind of residential provision, be it care home, nursing home or hospital. Supporting carers is not just "the right thing to do", but is clearly an area where focusing effort and resources has the potential to deliver substantial savings in both the personal cost to carers' health and wellbeing as well as to the public purse.

If carers are to be supported to care for longer it is paramount that the considerable impact of caring, on their own mental and physical health, is prevented or minimised as far as possible. Of course, each carer's circumstance is unique and an assessment of each individual carer's needs will be vital, but what was striking, during the interviews, was just what a significant impact caring had had, and was having, on so many carers' mental health and wellbeing.

We met many carers who were well supported and even with first class support, carers told us that their roles could be extremely emotionally and physically draining. As mentioned, some carers received extensive help and support from members of their own family or (occasionally) friends. We also met many carers for whom Connecting Care had brought all the support they needed and helped to make a challenging and difficult role easier. These carers had been able to access the support that they, and the person they cared for, needed, when they needed it, and in a way which was able to meet both of their needs.

In some cases, however, despite the Connecting Care team approach, some carers (and service users) had experienced mixed or only minimal input and it felt as if an opportunity to bring in more services to support them (especially from Age UK and Carers Wakefield) had sometimes been missed.

Sometimes, carers appeared not to be known to Connecting Care services. If the service is not aware of the existence of a carer (which was more likely for the 21% of carers who did not live with the person they cared for) then it will clearly not be able to help them. It appears that some GPs and hospital staff are still not referring eligible people to the Connecting Care service and that members of the general public often just don't know where to turn when someone needs an additional level of care and support in their own home.

Some carers had really struggled whilst on the Social Care waiting list. We know from talking with staff that it is possible to refer carers to Carers Wakefield (e.g. as part of the initial triage process) whilst they are waiting for a full Social Care assessment, but we are not aware how often this happens. It might be, given the financial constraints affecting Adult Social Care, that this approach needs to be taken more consistently and robustly to ensure that carers can access support from third sector services, whilst they are waiting.

For others, however, it was difficult to work out why carers themselves had not been offered some of the support that services such as Age UK and Carers Wakefield could offer.

In some cases carers had been offered services which they had refused (for a variety of reasons) or been given information which they had not retained or had misunderstood. Many staff told us during the staff interviews (which are reported elsewhere) that they always leave a leaflet for carers about support services available and yet many carers that we spoke to expressed no knowledge of these services.

Given the following factors:

- the mental and emotional stress which many carers are under
- the fact that many are elderly themselves, and
- with well documented poor literacy levels across Wakefield,

it may be that an approach based on leaving a leaflet and telling people once about these services is not the most effective one. A more robust approach may be needed to ensure that carers understand and retain information about other support available to them and can therefore access it, should they need to, either then or in the future.

Some carers had come to Connecting Care via a hospital discharge (or had been discharged from hospital without being referred to Connecting Care and had to find another way into the service) and again, we know from discussions with Connecting Care staff that there is scope to increase the awareness of carers' needs from hospital staff. A minority of GPs also seem to be difficult for carers to access, as demonstrated by some of the stories that we heard.

Our findings suggest therefore that there is scope to improve access to services for carers through:

- raising awareness of the need for, and availability of, support for carers, amongst hospital staff so that more carers are referred sooner directly from hospital
- continuing to raise the need for and availability of support for carers amongst GPs and practice staff
- ensuring that carers who are waiting for a Social Care assessment are referred to Carers Wakefield at point of triage or whilst waiting
- Identifying an approach for raising awareness amongst carers of Connecting Care service users about the support services available to them in a way which they can retain.

Providing information as standard to carers

Many carers had been frustrated by a lack of information or access to information about how and where to get help and support. A number told us that they just didn't know where to go or even what questions to ask, when they first took on the carer's role and this had often been a huge source of stress for them and the person they were looking after. Some carers had some really good suggestions as to what information it would have been helpful for them to know at the beginning of their journey as a carer. A summary of what they suggested is listed below:

- information about aids and adaptations – where to get them (either privately or state funded)
- information about finding, managing and paying care companies
- information about how long you might have to wait for various services
- information about how to put consent processes in place so they can access and provide information to/from health and social care professionals
- information about how to get help for them as a carer
- information about respite care available – privately or state funded
- information about benefits and financial allowances for carers

- information about managing incontinence and where to get products from – either privately or state funded.
- **all** of this information in one place.

Ensuring carers know what to do if things get worse

Our understanding is that the Connecting Care service has been designed, for the most part, to offer intensive and rapid support and interventions, and to set things up so everyone is supported - the focus being on rehabilitation and crisis intervention. However, for many of the people we met (both carers and service users) the likely future is one of worsening health and decline. Elderly people will become older and frailer, and people with conditions such as dementia and terminal disease face a clear future of declining health. For some carers, looking after people such as these, there also seemed to be an absence of planning for the inevitable declining future of service users which left some them (the carer) struggling and frustrated.

Many carers were worried that they:

- did not know who to contact if they needed increased levels of help and support
- did not have a “crisis” plan or “plan B” or any kind of plan in place to deal with inevitable decline or if they as a carer, became ill and/or could no longer cope.

Given the age and health status of many of the carers, these were realistic and very legitimate concerns. Even where the carer was relatively young and fit, they were often holding everything together and it was clear that, without them, the service user would be unable to live safely in their own home without the involvement of the main carer.

For some it might have been that, at the time of their last contact with Connecting Care staff, carers were coping a lot better, but then later, due to the deterioration in (their own or) the health of the person they were caring for, that their needs for support had increased. We know, from Connecting Care staff, that on discharge from the service, people are given a contact number and advised to ring back if they need the service again, but

- elderly people in particular are often reluctant to pro-actively “bother” health and social care professionals
- information or contact details may be lost or forgotten
- carers are often unable to identify or prioritise which services to speak to and end up being “passed around” and end up frustrated
- some carers or service users may have originally been referred to Connecting Care for service A, but now require service B. Most carers had no idea that these services are based and work within the same team and so would not automatically come back to the team for advice and guidance.

The impact all of the above is likely to be that carers are more likely to struggle on until their own health is further damaged or to phone 999 for help and end up with their loved one as an inpatient. Unnecessary hospital admissions are one of the things that Connecting Care is seeking to reduce and therefore developing an approach for agreeing a plan with carers which is explicit about what to do if things deteriorate (for them or the service user) would seem to be a useful way forward.

In addition, making short and longer term plans and expectations clear to carers would be helpful as some struggled to understand why some services were not available to them or were only available for certain periods of time.

Offering ongoing support

Carers who received ongoing support from Carers Wakefield or another source, told us how helpful they had found this. In particular, they valued an ongoing, relationship with a worker who they felt really cared for them as an individual.

For some carers, their need for ongoing support might be something as simple as a phone call.

As one carer put it "... *it would be good if someone could just phone you every now and then*..."

Other carers also said they would have found this helpful and reassuring. For those carers who receive one to one support from Carers Wakefield this is already provided. People with a close relationship with a Carers Wakefield or other staff member, consistently felt that they could go back to that person to ask for help (or for signposting or referral to help) if their needs, or the needs of the person they cared for, increased. We met (and referred on with their consent) some carers who did not currently get this level of support, but felt that they needed it.

It is possible, however, that there is another group of carers who would benefit from a lower level of support both to provide reassurance and to more pro-actively identify any deterioration in the health and wellbeing of carer or service user/patient before carers reach crisis point.

The impact of this would be that, rather than relying on carers to remember where, when and how to source the support when they need it (which also presupposes that they are clear about what criteria justify this - i.e. how desperate do they need to be?) that a lower level of input, involving a short phone call at agreed intervals, would be helpful to signpost and support those carers who do not need more intensive support.

There may be other and better solutions and it would be good to get the views of Connecting Care staff as to how this could best be managed to ensure that carers do not reach breaking point before trying to get more help.

Social isolation and loneliness

It is well documented, through national research and survey, that many carers suffer from social isolation and loneliness[3] and that this can impact significantly on their health and wellbeing. The Campaign to End Loneliness[4] reports that social isolation and loneliness have been proven to cause depression and have a negative impact on physical health equivalent to smoking 15 cigarettes a day.

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[3] *Carers UK(2014) The State of Caring*

[4] *Campaign to End Loneliness (2016) http://www.campaigntoendloneliness.org/loneliness-research/*

Our findings definitely support this. It was clear from our interviews that many carers in Wakefield were socially isolated and felt quite lonely. We know from the user survey results that this is also a problem (apparently increasingly so) for patients and service users.

It would appear that there is a need for Connecting Care staff to address this problem more consistently for the carers who support their patients and service users. The first step in doing this would be to ensure that there is better identification and assessment of social isolation (for carers) – maybe as part of the initial (and ongoing) assessment of all patient/service users by any of the Connecting Care services. Doing this would require:

- identifying and getting contact details for all unpaid carers
- getting consent to contact them
- assessing and identifying whether loneliness or social isolation is a problem for them

Staff could then signpost or refer carers to services, such as befriending services, community groups etc that could help them, in a way that works for them (as individual needs are likely to differ). It may be that, whilst the befriending services offered by Age UK and Carers Wakefield are useful for some, that other solutions are needed for carers who want to go out to socialise such as:

- arranging good quality respite or replacement care whilst they are out
- arranging transport for them
- finding suitable places where they can go to socialise and meet others.

As this appears to be an area of increasing need, it may be, in addition to local solutions within the Connecting Care team, that a more strategic, cross Borough approach to this problem is needed and that this needs to become more of a priority across the public sector.

Shared patient records

The lack of one shared patient/service user record is likely to make some of the above difficult (e.g. sharing information about social isolation and carers' other needs), but it needs to be an aspiration for the Connecting Care services that they should capture and share basic information about all carers (of people using their services). This should include, as a minimum: name, relationship, contact details, consent to share information with them - and should specifically include speaking to them either face to face or by phone. This would also be an opportunity to capture information about:

- carers' own physical, mental and emotional health
- carers' views on the health and social care needs of the service user
- whether carers feel they are lonely or feel socially isolated
- whether carers needed to be referred for a full carer's assessment.

This would then enable staff to ensure that all required information has been accurately captured and that all carers can be properly supported and signposted or referred to other services as required. This process should also ensure that carers have systems set up so that they can access information held by healthcare professionals such as GPs, as we know that this had caused problems for a number of the carers that we spoke to.

Some carers complained that they had to keep telling the same story and sharing the same information over and again with different health and social care professionals. Having one shared patient/service user record (or shared, easy access to all records) would also help carers in reducing the number of times they have to tell their story to different people. Having said that, in some cases the people they were telling their story to over and again were from the same service (e.g. the lady who said they had had four different social workers and so had to keep telling their story again) or from a service external to Connecting Care, e.g. primary care. And so to be truly effective, the shared record would have to be accessible to (and used by) these services too.

Community Matrons

We know, from other local work, that during the period of these interviews, the community matron service has been substantially reduced and the role re-defined several times. It is not therefore surprising that so few carers mentioned having received help or support from this role. The two carers who did mention this service were effusive about the help that had been provided by them and it seemed that the role (as they experienced it) had been able to provide really useful help and support both to the service user and to them as carer. We would suggest, therefore, that considerations regarding the future of the community matron service need to take into account, not just its impact on vulnerable service users, but also on their carers.

What can we do about poor service from care companies?

It would be disingenuous not to discuss the implications of what carers told us of their experiences with paid carers. Although this service is not provided by Connecting Care staff they have often been involved in commissioning it and/or signposting to it. Whilst these services had been enormously supportive for many carers and patients/service users, they had also caused some significant problems due to the poor or erratic quality of the care provided. We met a number of carers who had had to change the care company that they used several times (one person had used four different companies) before finding one which was reliable. The same was true of residential respite care. The carers that we met had little experience of day centre care and so we are unable to comment on the quality of this service.

This is not an easy issue to address, but it is certainly the case that many carers could have benefitted from some support to help them deal with the issues that they had with these companies, as it was a source of great stress to them. One carer did tell us that Carers Wakefield had been able to help her write a letter of complaint and to change care companies, so it might be that, providing Carers Wakefield support to more carers could also help them with this issue.

The wider issue of the poor quality of care provided by some of these companies is one which Healthwatch will continue to monitor and pursue.

Young carers

There is national data (ONS, 2013a) showing an increase in the number of young carers across all areas of England and Wales since 2001. However, we only interviewed one young carer, as part of this project, although we met another young girl, who was caring for her disabled mother, when we interviewed her father. This means that we have limited experience of what their needs and views might be. It may be that more work is needed in Wakefield to capture and identify the needs of this group in order to ensure that there are appropriate services to identify and meet them.

Conclusions

There is no doubt that it is very difficult to separate the needs of the carer from the person that they are caring for. However well the carer is supported, if the person they care for does not or has not received the care and support that they need, then this is likely to impact negatively upon the carer themselves; both on their day to day lives and on their health and wellbeing.

The Connecting Care approach potentially offers an integrated local team approach which is able to offer this “holistic” support. During our interviews we heard some fantastic examples where both carer and the care recipient had experienced a high level of well co-ordinated support delivered to them in their own home. For these people, the service was clearly enabling them to safely and effectively support the service user in their own home (where they wanted to be) and to enable the carer to care for longer. The Connecting Care service and approach had most definitely been effective for these people.

The Connecting Care services which were most frequently mentioned by carers as helping and supporting them were Age UK and Carers Wakefield. It is clear that having these two services within the Connecting Care teams is enabling a greater and more comprehensive service to be offered to carers. The fact that Carers Wakefield could develop an ongoing relationship with carers was something which carers who had experienced this, particularly valued and found helpful.

We met other people where the picture was mixed. Maybe the services delivered to the service user/patient were good, but the carer felt isolated and unsupported personally. Or the carer had found it difficult to access services, which were good once accessed, but the process of trying to organise things had taken their toll. Around half of the carers we spoke to, fell into this middle group.

There was an additional group of people (around 25%) who had received very poor support and services. In some cases, this was around difficulties in accessing the services in the first instance – both finding out about and locating services and waiting (e.g. on a waiting list) for access. For other people it was really not clear why, despite very clear needs (both for service user and carer), they had not been offered the support which they obviously required. Several of these stories related to end of life care. The carer was not always clear why they had not been able to get the help that they needed.

There may be a useful further piece of work to be undertaken, carrying out some “deep dive” case reviews (subject to proper consent procedure) to establish where there were opportunities to offer support that had been missed and how this might be used to drive service improvements.

A final word to the carers that we interviewed:

We would like to end by saying thank you once again to all of the carers that we interviewed as part of this project. Thank you for taking part in this work and taking the time to talk to us honestly, in the hope that services can continue to be improved for other people like you. Thank you for all your work as carers. Health and social care services, and society as a whole (as well as the person that you care for) benefit immeasurably from the valuable role that you do.

5. RECOMMENDATIONS

<table>
<tr><th>Number</th><th>Recommendation</th></tr>
<tr><td>R1</td><td><u>Capture and share information about carers</u> The service should consider how to better capture and share information about carers (with their consent) in order that they can
- ensure they have details for all carers
- identify those who need more help and support
- ensure that carers go on to access or be provided with this support

This should include special efforts to identify and offer support to those carers who do not live with the person they care for, and young carers.

The work on bringing together patient/service user records and information across the Connecting Care teams should be asked to ensure that data on carers can also be shared across the team.</td></tr>
<tr><td>R2</td><td><u>Improve the provision of information about services and support for carers</u> Connecting Care team members and their managers need to consider how they can make information for carers much more easily and quickly available and accessible whenever they need this. This should include information on all those areas, identified by carers, as important to them (listed below)

▨ information about aids and adaptations – where to get them (either privately or state funded)
▨ information about finding, managing and paying care companies
▨ information about how long you might have to wait for various services
▨ information about how to put consent processes in place so they can access and provide information to/from health and social care professionals
▨ information about how to get help for them as a carer
▨ information about respite care available – privately or state funded
▨ information about benefits and financial allowances for carers
▨ information about managing incontinence and where to get products from – either privately or state funded.
▨ Information about the quality of paid-for care services (where available) to allow people to make informed choices
▨ Information about what to do if they or the service user/patient requires more support
▨ all of this information in one place.</td></tr>
<tr><td>R3</td><td><u>Improve access to information for carers about the person they are caring for</u>
The service needs to consider how services can more proactively share information with carers and recognise their value in sharing the care of the patient/service user.

It should be made easier for carers to access information about the person they are caring for and equally for them to provide information to services which support that person. Again, extra efforts may be needed to communicate with those carers who do not live with the person they care for.

There is a need to consider whether flagging up consent to share information with the carer could be done routinely for all carers early on, so that systems and consents are in place, especially with GPs.</td></tr>
<tr><td>R4</td><td><u>Improve access to support for carers when they first need it.</u> It was clear from the interviews that a substantial number of carers had struggled for some considerable</td></tr>
</table>

	time before being able to access help and support for themselves and the person they were caring for. Work needs to be done with GPs (and primary care in general) and hospital staff (particularly those staff who discharge patients) to ensure that they are aware of the services available to carers and listen to and support carers to get the support that they need following discharge (or in some cases this could be initiated before discharge.) For example, a carers' information pack, provided to carers during a hospital admission, could be a useful approach alongside good discharge planning. Consideration should also be given to publicising the services of Carers Wakefield and the Hubs more widely to the general public.
R5	Address poor service from care companies. Healthwatch should collate and publish feedback from carers regarding poor service from care companies and push for improvement. Carers Wakefield, and other CC team members should support carers in addressing poor care.
R6	Reduce social isolation and loneliness. All Connecting Care team members should include ongoing assessment for social isolation and loneliness of carers during all contacts with them, ensure they are aware of the various services available to help with this and refer or sign post on carers to these services. There is a need to ensure that all staff are clear what services are available to address this, and that any information provided to carers is easily available, user friendly and accessible whenever they need it.
R7	Reduce social isolation and loneliness. Consider whether the Council could do more to raise the profile of loneliness as an issue, and put in place a more strategic and wide ranging cross Borough plan to reduce this.
R8	Consider creating a care navigator/co-ordinator role specifically for carers, who would work with, or support the development of, other schemes in the district including social prescribing, counselling, telebuddying and proactive contacts to check how carers are coping
R9	Improve support for carers of people with terminal illnesses. Based on the interviews that we did with carers who had cared for someone who was dying, there is a need for far more proactive support to be offered to carers who are caring for loved ones who are dying. They should be supported to understand what is going to happen and what they should do, and offered help to cope with the practical and emotional strain.
R10	Improve support for carers whilst awaiting a social care assessment. A number of carers and service users had struggled whilst awaiting a social care assessment. The service needs to identify how they can be more consistently supported during this time, eg through signposting to services such as Age UK and Carers Wakefield.
R11	Identify those patients and carers who would benefit from a crisis plan and work with connecting care staff and carers to identify how this could most effectively work.
R12	Understand why some carers did not get the support they needed. It would be good to undertake "deep dive" review of those cases where support had clearly been lacking, to identify why this was not delivered. It might be useful to present/discuss some of these cases at Connecting Care team meetings such as network meetings so that lessons can be learned across the team, with regard to better supporting carers.
R10	Ensure that when service changes or reductions are made that the impact on carers is taken into account, as well as the impact on service users and patients. For example the role of community matron had clearly been helpful in supporting those carers who had access to it.
R10	Co-produce improvements with carers and service users. In order to ensure that improvements are focused on what carers really need (rather than what

	professionals think they need) it would be helpful to include carers and service users in co-production of relevant service improvements.
R11	Capture views of Connecting Care staff on how improvements could work best. Improvements need to work both for carers and for Connecting Care staff, as they have the best understanding of how services currently work and the realities of delivering such support.
R12	Ensure that Carers Wakefield and Age UK services are funded to cope with the impact of the extra workload which should occur if a wider number of carers are identified and signposted/referred to support from them (through implementing the above recommendations)

APPENDIX ONE

COPY OF THE CARERS SEMI-STRUCTURED INTERVIEW PROFORMA USED

APPENDIX ONE

CARER INTERVIEWS
Connecting Care evaluation – semi- structured interview proforma

Date of interview: **Name/initials of interviewers:**

Please could you start by telling me a bit about yourself

Prompts: e.g. how long have you lived here, what did you do before you took on caring role. Any hobbies or other responsibilities, volunteering? The purpose is to get the person to start to talk and think about themselves.

What is a typical day like for you?

Prompt: Good day/bad day

Please tell me about the support and care that you have (have had) to give to <name>

Prompt: e.g. washing and dressing, toileting, cleaning, help with medication, help with shopping, food preparation, washing and ironing clothes, taking the person out, coordinating services.

How long have you been giving this care for?

What other help (or services) does <name> have?

Could you tell me a bit more about <name> (the person that you care for)

Prompt: this could include anything not already raised such as any more information about their health or social circumstances which are relevant

If several different people or services are involved….what is your experience of how (well) the different services work together?

Prompt: Does the carer have to play a role in co-ordinating services? Does the same information have to be provided to different people?

As a carer, what help and support do you get?

Prompt: if not covered prompt financial support, access to respite breaks including My Time carer breaks. Any contact with carers support organisations or other voluntary sector?

Has this been helpful for you?

Prompt: explore how this helped or did not help if not covered

If you need to ask questions about your relative/friend’s condition or treatment or support who would you contact/ask? a) in hours b) out of hours

Prompt: non-emergency

How is your health and how are you coping with all your work as a carer?

Prompt: if not mentioned, ask about social contact, mental and physical health

What (other) services or support do you think would be (or would have been) useful to help you as a carer?
Are there other things that could be (or could have been) improved to make your caring role easier?
Do you have any other comments (either good or bad) about the services which you or <name> have received which you think would help to improve them for other people?

CARER DETAILS

Sex: Male ☐ Female ☐

The Carer is the service users: Friend ☐ Spouse ☐ Sibling ☐
Child ☐ Other ☐
Neighbour ☐ Partner ☐
If "other" state here ___________________________

Age of carer: ☐

Do you live with the person you care for? Yes / No

Ethnic origin:

White

1 ☐ British
2 ☐ Irish
3 ☐ Any other White background

Mixed

4 ☐ White and Black Caribbean
5 ☐ White and Black African
6 ☐ White and Asian
7 ☐ Any other mixed background

Asian/Asian British

8 ☐ Indian
9 ☐ Pakistani
10 ☐ Bangladeshi
11 ☐ Any other Asian background

Black/Black British

12 ☐ Caribbean
13 ☐ African
14 ☐ Any other Black background

Chinese and other ethnic groups

15 ☐ Chinese
16 ☐ Any other ethnic background

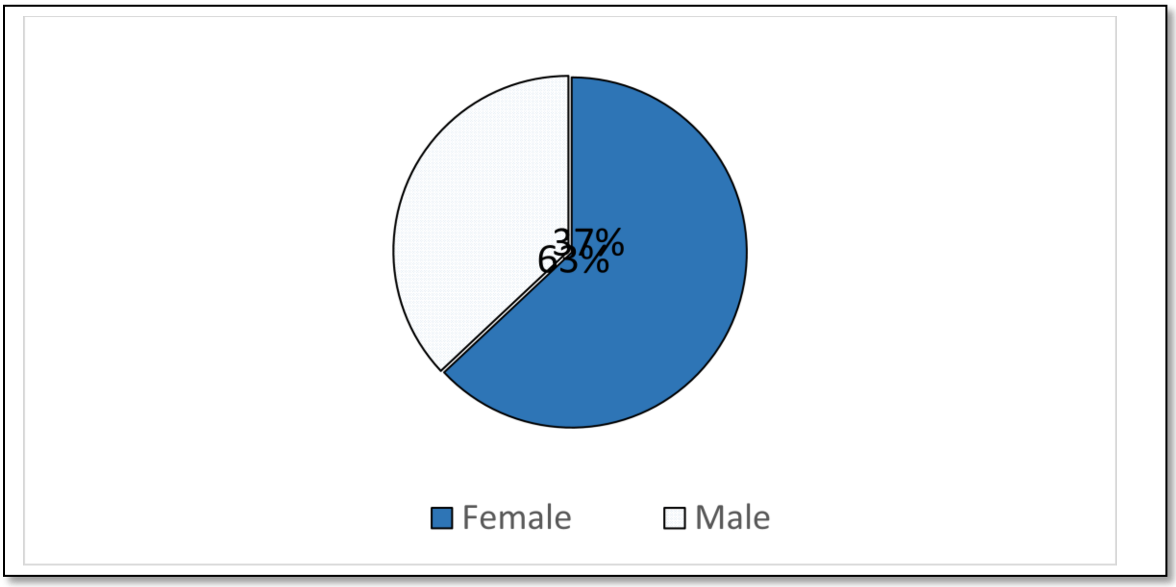
Postcode: _________________________

APPENDIX TWO

CHARTS SHOWING DETAILS OF CARERS INTERVIEWED

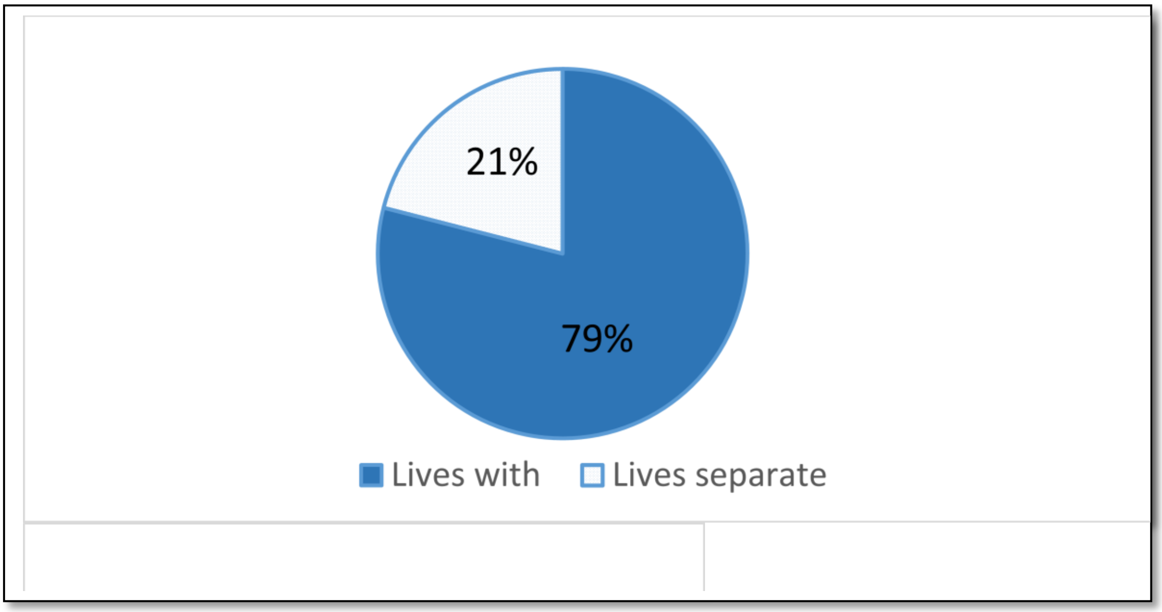
APPENDIX TWO

Chart one – Carers interviewed by sex



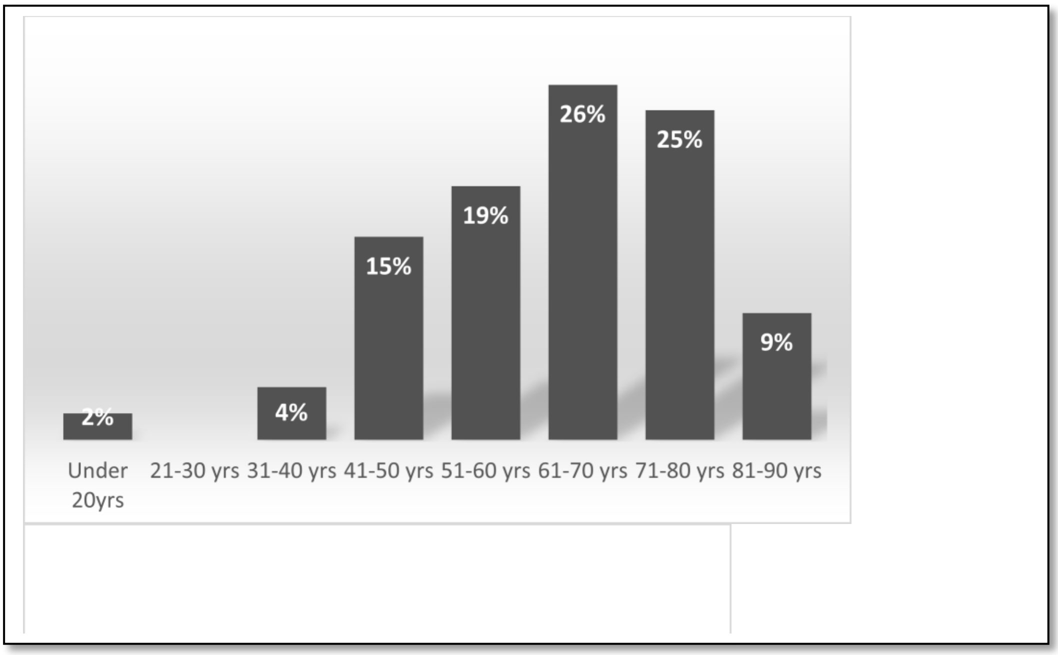
Just under two thirds of those interviewed were female

Chart two – Carers interviewed by place of residence



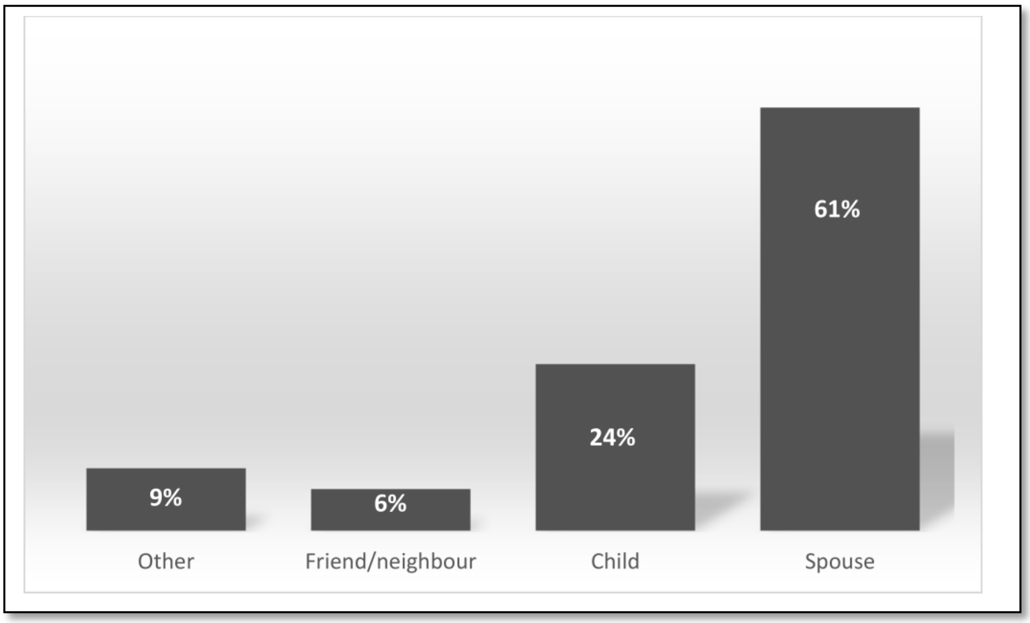
79% of carers lived with the person they cared for.

Chart three – Age range of carers interviewed



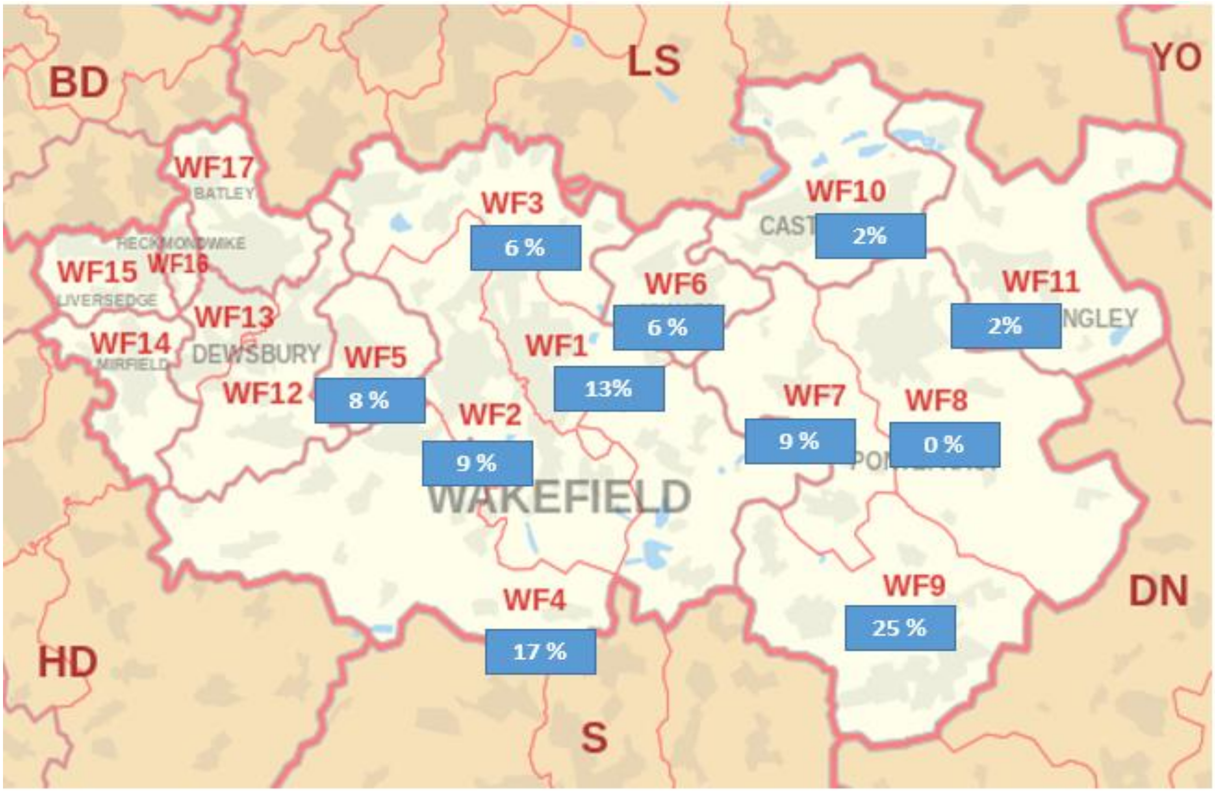
The majority (60%) of carers were 61 years or over, with 9% in their eighties.

Chart four – Carer's relationship to the person they were caring for



The majority of carers were spouses or children of the people they were caring for. The "other" category contained one grandparent, one grandchild, one mother, one ex cleaner and one sibling.

Chart five – post code of carers interviewed (Wakefield only)



Interim Report on Care Home Resident Interviews

Phase one implementation: Care Homes not in Vanguard

August 2016

Highlight findings

- Residents reported mostly having contact with their GP, district nurse, practice nurse, physio and occupational therapist.

- 47% of the people interviewed said they felt that health and care services worked well together.

- 88% felt they could see their GP when they wanted to.

- 57% said that when they went to hospital their medication and other needs were known.

- 84% said they know who to contact with questions about their health and care needs and 74% felt that that person understood them and their condition.

- Only 30% had discussed their health care plan with someone, but 83% felt that the health and care provided met their needs.

- There were mixed responses to the qualitative questions about independence and wellbeing, but broadly speaking people valued being safe and taken care of, being able to take part in activities and go out, and having contact with other people.

Overarching outcome

That Wakefield care home residents who are experiencing the Care Homes Vanguard programme have the opportunity to actively take part in the evaluation process.

The objectives of the evaluation are as follows:

- To provide a valid and reliable means by which to engage residents in the Care Homes Vanguard evaluation
- To industrialise the resident engagement process to provide it at sufficient scale to be valid.
- To use local volunteers to conduct the interviews via Healthwatch.
- To provide the process in a way that overcomes barriers of literacy, language and access
- To add value to the Wakefield programme by working in alignment with both the proposed national evaluation and the other five Care Home Vanguards.

Sampling method

Public Health colleagues identified the five care homes to take part in the baseline survey. These are homes currently outside the scope of the care homes Vanguard interventions and will therefore provide some comparator data. Five care homes of similar size, function and occupancy will be identified for the second phase of surveying in quarter 3 or 4 of 2016/17. These care homes will have had the full range of Vanguard interventions. Three of the homes in the first phase are being brought into the second phase of Vanguard, so data from these homes will provide directly comparable information from residents.

The survey

The survey was designed in three parts, to include a small selection of National Voices ‘I’ statements to measure the variety and integration of services going into the care homes, a validated wellbeing measure (ONS-4) and a couple of qualitative questions about independence and wellbeing. It was designed with public health colleagues and input from the NHS England national team.

Outcomes to date

January to March 2016

1. Survey questions were developed and shared with stakeholders for comments.
2. The initial survey questions were piloted in a care home outside the Vanguard programme, and adjustments made.
3. Volunteers were recruited to take part in the interviewing.

April to June 2016

1. Five care homes were identified for baseline resident interviews, two outside of the Vanguard programme and three that are due to be included in the second phase of Vanguard.
2. Resident interviews in these five care homes were conducted.
3. The model was adjusted after the first set of interviews were conducted to use staff only as interviewers, not volunteers.
4. Pathways were set up to allow for referral of residents to voluntary sector support (Age UK and/or Carers Wakefield) or an alert to the MDT where interviewers identified a need.
5. Interim report produced.

Methodology

Healthwatch staff approached the identified care homes and secured dates and times for their visits. On arrival, information was sought from care home staff as to the cognitive abilities / health and wellbeing of residents to ascertain who was within and out of scope.

A full verbal explanation was provided to each person approached. Written consent was obtained from each resident prior to the interview being conducted and information was left including Healthwatch Wakefield contact details should the person wish to ask any questions or provide more information at a later date or wish to share with their family, carers or relatives. Leaflets about other services such as Age UK and Carers Wakefield were also left with the residents. Consent for referral to other support services was obtained if relevant. We made it clear that taking part in the survey was voluntary. No pressure was placed on any person to participate and residents were able to withdraw from the interview at any time if they wished.

The residents vary in cognitive ability and concentration levels and therefore it was often necessary to take a short break or to steer the interviewee back to the present time and the survey. Occasionally residents found the interview upsetting, so Healthwatch interviewers ensured that sufficient time was spent with each person to ensure they had time to talk through any issues that had been raised. We also made sure that staff were made aware and would offer further support if necessary after the interview.

Learning in relation to methodology

The initial aim was for us to interview 50% of residents in each care home, but it rapidly became evident that this target was ambitious. This was confirmed by other Vanguard colleagues who agreed that it would be unlikely that 50% of residents of most care homes would have cognitive ability, be sufficiently well or even just awake at the time of interviewing.

Some residents seemed to have cognitive ability, but during interviews would respond to some questions with variable accuracy e.g. “I am 30 years old and don’t live here I just call in”

Despite several efforts to explain some questions some residents were unable to answer some questions or understand some services, e.g. community geriatrician.

The windows of opportunity to speak to residents is narrow so avoiding meal times, not expecting to interview people to early or late in the day, when entertainment is active, people at the end of life, whilst receiving medications, receiving personal care , visitors not wishing to be disturbed, hospital appointments and non-communicative people may reduce this window significantly. Although we tended to spend a full day at the care home and went back in some cases, it was still difficult to reach all eligible residents.

Not all people in the homes are residents as some were there for daily respite so did not qualify for this survey.

It was virtually impossible to give space and privacy to people when conducting interviews in communal areas especially when speaking to the hard of hearing. There were a number of times that other residents involved themselves in people’s interviews and staff were able to listen to the interview which sometimes has the effect of moderating people’s responses.
Seating areas were an issue as Zimmer frames and other walking aids cluttered the communal areas making it difficult to get close to the interviewee.

Many people did not have capacity to participate and many were asleep or unavailable due to nursing care and more than one visit was necessary to two care homes in an attempt to capture more completed surveys.

Healthwatch staff on several occasions aborted interviews but chatted to people who were clearly unable to participate.

Interviewers - training & experience

After the first set of interviews that involved volunteers, a decision was made that only experienced and trained Healthwatch staff conducted these surveys. This was due to the increased need in this project for sensitive and careful interviewing techniques and consistency of interviewing and recording. We also took into consideration the fact that the volunteers, who were involved initially, despite being trained in previous Healthwatch survey work, found the care homes interviews a bit too challenging for various reasons.

Robust process, policies and risk assessments are in place. Staff have had safeguarding, personal safety and dementia awareness training coupled with a thorough understanding of confidentiality and data protection. Some of the interviews were conducted in pairs, as this helps with more accurate recording of the findings and offers some mutual support and safety especially when interviews were conducted in non-communal areas.

Who we interviewed

Number of people interviewed – 70 (30% of residents at time of visits)
Number of people declined - 35
Number of people unable to participate who may have capacity - 44
Number of people unable to participate who do not have capacity - 74

97% of people interviewed were residents but some carers were also present at the time of interview. All interviewees were white British, 29% were male and 71% female. 60% of the people we interviewed were over 86.

24. What is your age?

			Response Percent	Response Total
1	55 or under		0.00%	0
2	56 - 65		0.00%	0
3	66 - 75	🟧	7.94%	5
4	76 - 85	🟨🟨🟨🟨	31.75%	20
5	86 +	🟩🟩🟩🟩🟩🟩🟩🟩	60.32%	38

Most people said they had a disability of some sort.

26. Do you consider yourself to have a disability? Please tick all that apply. (Under the Equality Act 2010 a disability is defined as a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities)

			Response Percent	**Response Total**
1	Long standing illness or health condition e.g. cancer, diabetes, HIV etc	🟥	15.56%	7
2	Physical or mobility	🟨	42.22%	19
3	Learning disability/difficulty		0.00%	0
4	Mental Health condition	🟩	6.67%	3
5	Hearing	🟧	13.33%	6
6	Visual	🟪	15.56%	7
7	Prefer not to say		0.00%	0
8	Other (please state)	🟨	6.67%	3

What they said about health and care can be found on the following pages.

5. Which health and care services do you have contact with?

		Response Percent	Response Total
1	Age UK	3.13%	2
2	Carers Wakefield	1.56%	1
3	Community Geriatrician	0.00%	0
4	District Nurse	43.75%	28
5	Doctor	90.63%	58
6	Occupational Therapist	18.75%	12
7	Pharmacist	7.81%	5
8	Physiotherapist	37.50%	24
9	Practice Nurse	40.63%	26
10	Social Worker	6.25%	4
11	Other	6.25%	4

Comments under ‘other’ included Chiropodist, hearing aid organisation and pressure ulcer people.

6. If several different people or services were involved in your care and looking after you, did you find that everyone worked well together (that is they worked together as a team, sharing information and organising things so that everything ran smoothly)?

		Response Percent	Response Total
1	Yes	46.97%	31
2	No	1.52%	1
3	Sometimes	3.03%	2
4	Not Sure	19.70%	13
5	N/A	28.79%	19

7. In your experience, would you say that you are able to see your GP when you need to

		Response Percent	Response Total
1	Yes	88.41%	61
2	No	4.35%	3
3	Sometimes	2.90%	2
4	Not Sure	4.35%	3

8. If you go to hospital they know your medication and any other needs you may have

			Response Percent	Response Total
1	Yes	🟥	56.52%	39
2	No	🟨	5.80%	4
3	Sometimes	🟦	1.45%	1
4	Not Sure	🟩	14.49%	10
5	N/A	🟧	21.74%	15

It was noted that more than half felt that if they went into hospital their needs and medication would be known and some of the care homes sent documentation to the hospital with the patients.

9. If you need to ask questions about your health care do you know who to contact?

			Response Percent	Response Total
1	Yes	🟥	84.29%	59
2	No	🟨	8.57%	6
3	Sometimes	🟦	1.43%	1
4	Not Sure	🟩	5.71%	4

We asked who this person was. 35 people said they would contact one of the care home staff, 22 said their GP, 18 said a nurse and 4 people said they would contact a relative or a friend.
9% of people did not know who to contact about their health care.

11. Do you feel this person understands about you and your condition?

			Response Percent	Response Total
1	Yes	🟥	73.53%	50
2	No		0.00%	0
3	Sometimes	🟦	1.47%	1
4	Not Sure	🟩	11.76%	8
5	N/A	🟧	13.24%	9

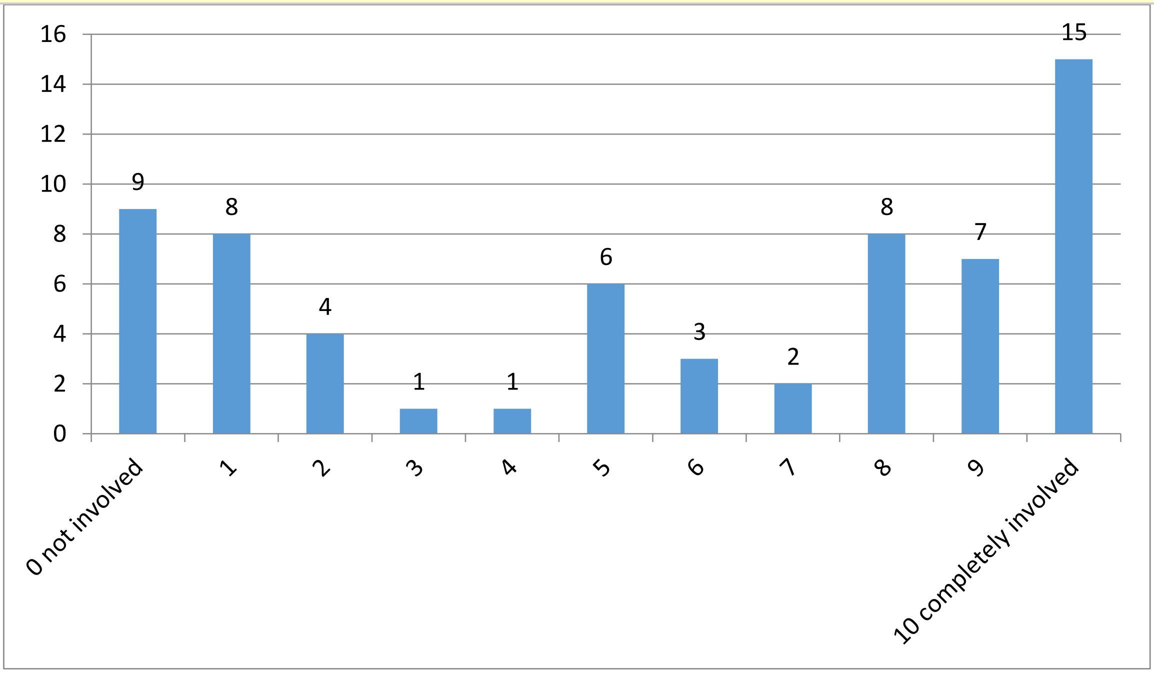
12. While you've been living here have you discussed your health care plan with anyone?

			Response Percent	Response Total
1	Yes	🟥	30.00%	21
2	No	🟨	45.71%	32
3	Not Sure	🟦	24.29%	17

13. Do you feel that the health and care provided meets your needs?

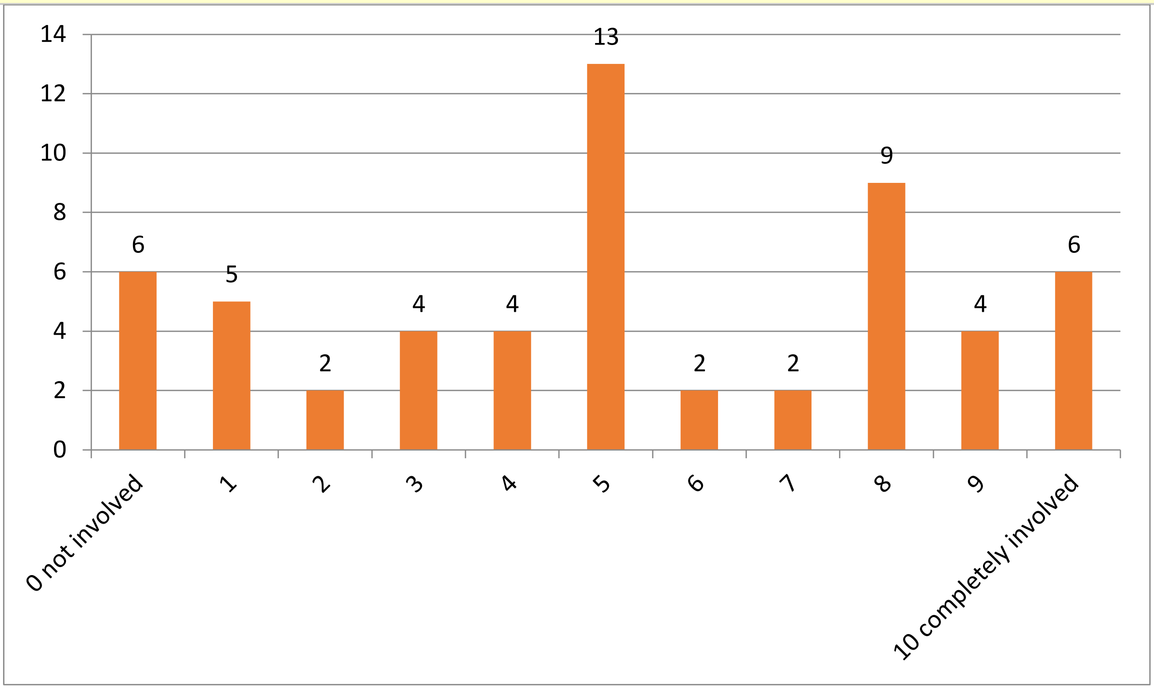
			Response Percent	Response Total
1	Yes	🟥	83.33%	55
2	No	🟨	4.55%	3
3	Not Sure	🟦	12.12%	8

14. How involved do you want to be in decisions about your health care?



Some comments included “I want a quiet life” and “no, I let them carry on”

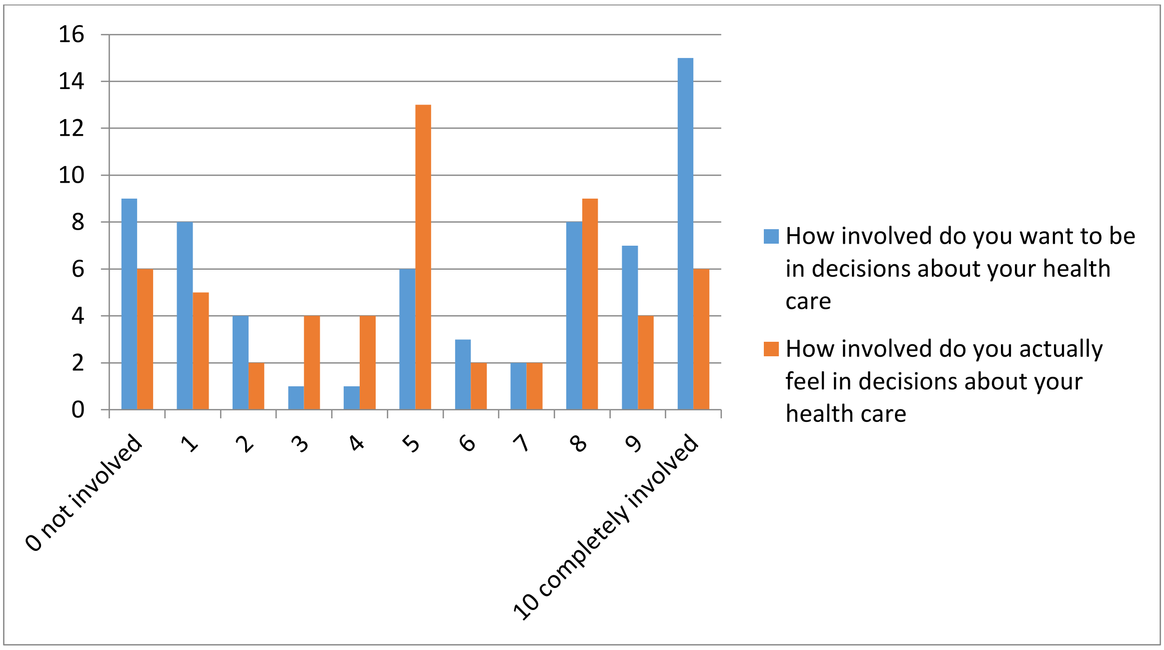
15. How involved do you actually feel in decisions about your health care?



Comments were varied:

> “Oh yes, they come around and talk to me.”
>
> “I want to know what is wrong with me. I often wish I was dead. I have no family that bother with me.”
>
> “They ignore you and talk over you even when you are the person they should be talking to i.e. doctors.”

If we put these two findings together, the graph looks like this:



Although there was the highest number of people saying they wanted to be completely involved in decisions about their health care, far fewer said they actually felt completely involved. Mostly people indicated somewhere in the middle of the range for how involved they actually felt.

Qualitative questions

We included some qualitative questions in the survey, to elicit richer information about residents' feelings of independence and wellbeing in a care home setting. We found that responses were as varied as the residents themselves and much depended on their attitude to life and their resilience.

6. What kind of things do you like to do that help you to feel independent? For example, I can choose when to get up/go to bed or have a cup of tea: I get to go out to places I enjoy; I can be with people I like.

While some residents said that independence was not a big issue for them - "I'm not desperate to have lots of independence"; "I don't think about those sorts of things", "I'm not interested. I can't be bothered", others simply said that they weren't independent – "I don't feel independent" or "I can't be truly independent, I'm stuck here, I can't do much other than sit here and sleep".

Many mentioned the importance of visits and going out - "I can ring for a taxi and go out, walk into town if I want", "my daughter visits".

Activities were important to many "I get puzzle books I like", "They include me in activities. Exercise, bingo…"

Choice of meals and menu was another theme mentioned as important as was timing of activities - "I can sleep or have a shower when I want".

Some also mentioned possessions - "I can have plants in my room", "I have my own furniture".

Personal care was also mentioned - "brushing my hair, creaming my face, they do my nails".

17. Do these things help you feel as independent as you want to be?

			Response Percent	Response Total
1	Yes	🟥	51.43%	36
2	No	🟨	25.71%	18
3	Not Sure	🟦	22.86%	16

18. If 'No' what kind of things would you like to do that would help you feel independent?

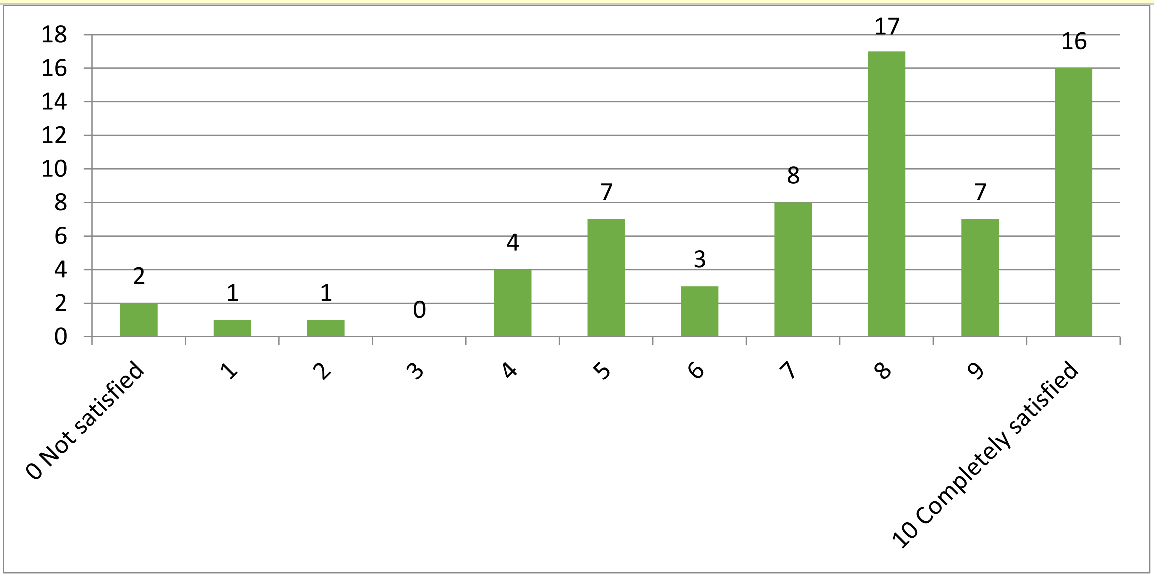
The most common theme was that to be more independent residents simply wished they had better health and fewer sensory impairments – better ability to walk, see hear and so on.
Getting out and about more with more visits and use of a car were also mentioned.

Some had specific requests relating to the home - “I would like a bath every day”, “I would like water with my meals to help me digest my food” I would like to be able to have the gates on bed down so I can go the toilet in the night”.

Others had requests such as “I would like to be able to watch my passion - rugby league”, or “I’d like a tea chest - to keep my memories and stuff in”.

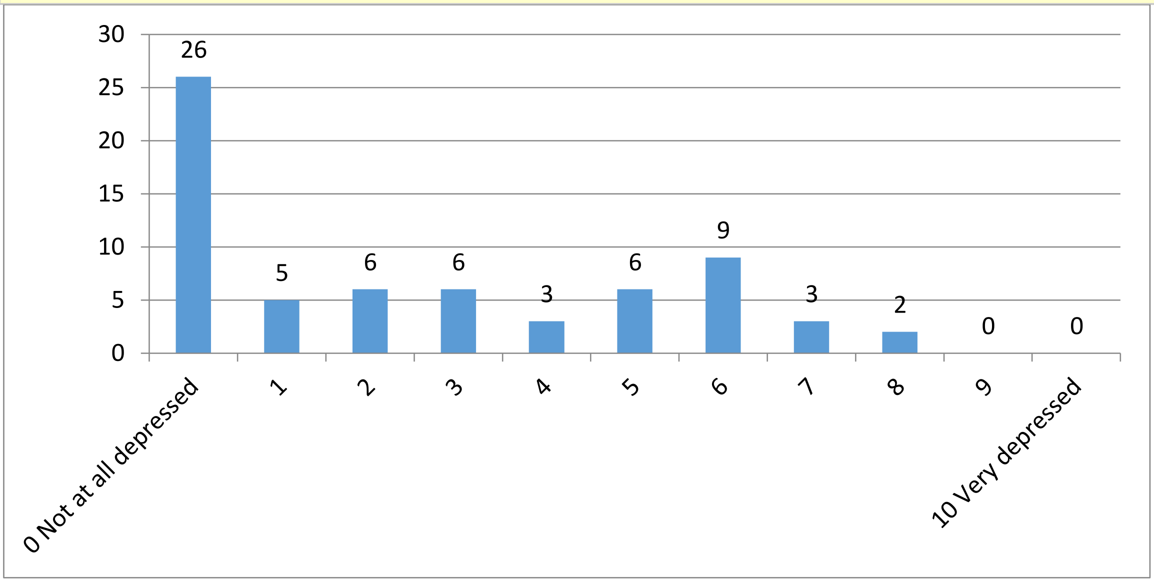
The survey included a section with ONS-4 the Office of National Statistics subjective personal wellbeing questionnaire, which has four questions. After the pilot interviews one of the questions was removed from the survey as it caused the interview to take an unhelpfully negative trend. The question was 'overall to what extent do you feel the things you do in your life are worthwhile'. We had been aware from the outset of this piece of work that care had to be taken not to leave residents having stirred up feelings of regret or sadness. After piloting, we felt that this question was not appropriate to ask in a care home setting. The other three did not seem to cause significant problems to residents however, and in fact the trend in response for these questions is actually quite positive.

19. Overall how satisfied are you with your life nowadays?



25% of people said they were completely satisfied with their life.

20. On a scale where nought is not at all depressed and 10 is very depressed, overall how depressed did you feel today?

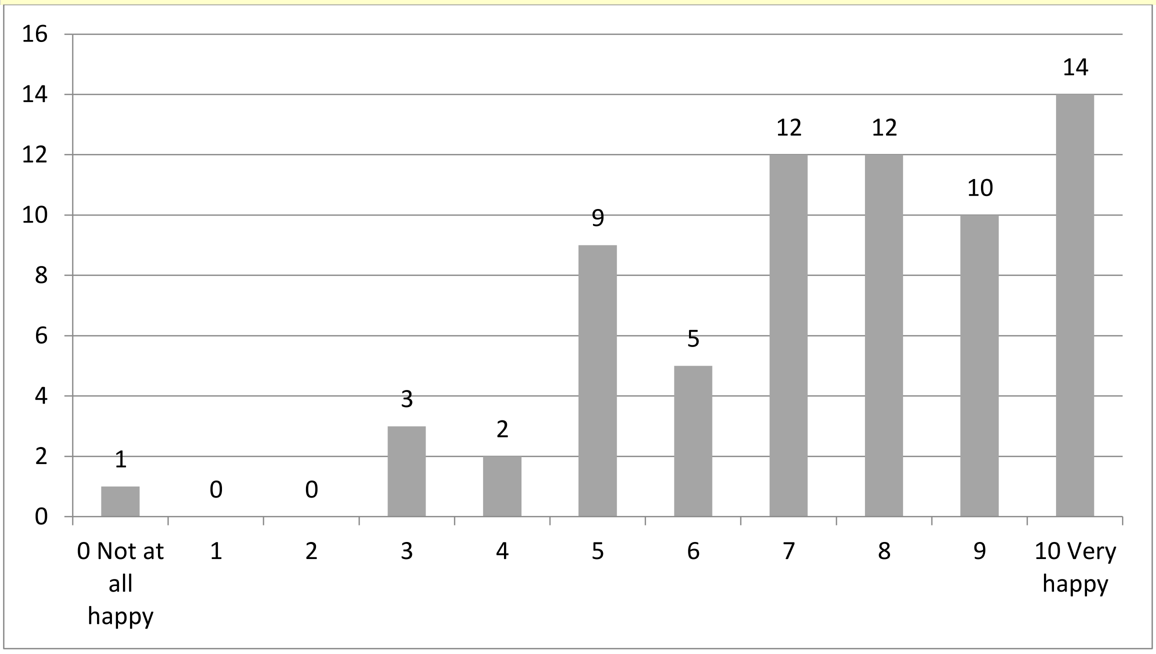


One lady described herself as lonely and said "This morning I was very depressed but I'm better now I have someone to talk to"

"On anti depressant tablets. Was very depressed."

"I accept things."

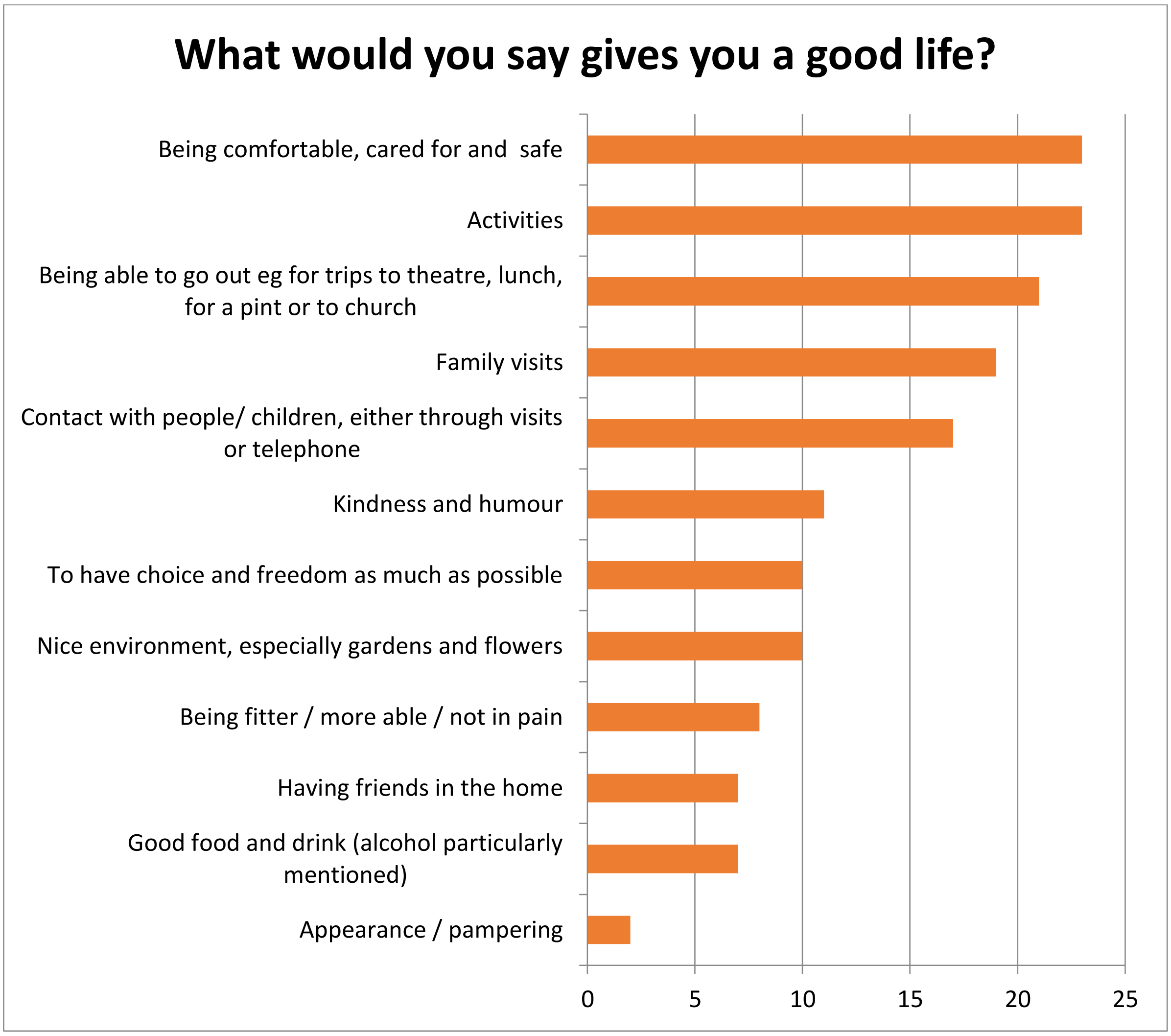
21. On a scale where nought is not at all happy and 10 is very happy, overall how happy did you feel today?



The final question of the survey was 'what would you say gives you a good life?' This was a qualitative question and elicited varied responses. Some residents found this a difficult question to answer and a few people didn't give us any information beyond "I do alright", or "Just to be left alone". Others took the opportunity to have a lengthy chat about their lives so far.

We analysed the answers and recorded the number of times certain things were mentioned.
As can be seen, people said that being comfortable, cared for and safe was a key element of having a good life. After that, it seems to be that activities, visits, trips out and contact with other people are things that allow residents to feel socially included and part of a community. Choice and freedom were also mentioned quite frequently.

Activities that were mentioned included singing, reading, dancing, games, writing, films, gambling / cards, memory classes, watching sports on TV mentioned. Singing was mentioned specifically five times. An attractive environment, including gardens and flowers was important, as was good food and drink (particularly the odd glass of wine, whiskey or beer).


What would you say gives you a good life?
Being comfortable, cared for and safe
Activities
Being able to go out eg for trips to theatre, lunch, for a pint or to church
Family visits
Contact with people/ children, either through visits or telephone
Kindness and humour
To have choice and freedom as much as possible
Nice environment, especially gardens and flowers
Being fitter / more able / not in pain
Having friends in the home
Good food and drink (alcohol particularly mentioned)
Appearance / pampering
0
5
10
15
20
25

Care Homes in first phase - record of participants

Walton Manor Care Home

187 Shay Lane, Walton, Wakefield WF2 6NW

Dementia • Learning Disability • Old Age • Physical Disability • Parkinson’s Disease

Number of beds	39	
50% target	**19**	
People approached	20	
Interviewed	**14**	36%
Unable to participate but may do another day	1	shingles
People the CH feel unable to participate	11	dementia lounge
People Healthwatch feel unable to participate	3	
Declined interview	6	
Not yet approached	1	at hospital

Earls Lodge

Queen Elizabeth Road, Eastmoor, Wakefield, Yorkshire, WF1 4AA

Dementia • Old Age • Physical Disability

Specialist Care Categories: Alzheimer's • Cancer Care • Motor Neurone Disease • Multiple Sclerosis • Parkinson's Disease • Stroke

Number of beds	50	45 occupancy
50% target	**25**	
People approached		
Interviewed	**14**	31%
Unable to participate but may do another day	2	hospital
People the CH feel unable to participate	8	non speaking residents
People Healthwatch feel unable to participate	9	dementia
Declined interview	6	
Not yet approached	2	asleep
	2	non English speaking residents
	2	end of life with family

Croft House Care Home

52a High Street, Gawthorpe, Ossett, West Yorkshire WF5 9RL

Dementia, Old Age Care

Number of beds	66	49 occupancy	
50% target	**25**		
People approached	20		
Interviewed	**15**		30%
Unable to participate but may do another day	2	hospital	
People the CH feel unable to participate	21	dementia lounge	
People Healthwatch feel unable to participate	22		
Declined interview	5		
Not yet approached	7	asleep	

Vicarage Court

Vicarage Gardens, North Featherstone, Wakefield WF7 6NH

Residential dementia, general nursing and elderly residential.

Number of beds	65		
50% target	**33**		
People approached	39		
Interviewed	**13**		20%
Unable to participate but may do another day	1		
People the CH feel unable to participate	30		
People Healthwatch feel unable to participate	31		
Declined interview	13		
Not yet approached	1		
Asleep	11		

Carleton Court

108 Carleton Road, Pontefract WF8 3NQ

Nursing or personal care, Dementia, Mental health conditions

Number of beds	35	33 occupancy	
50% target	**16.5**		
People approached			
Interviewed	**14**		42%
Unable to participate but may do another day	0		
People the CH feel unable to participate	5		
People Healthwatch feel unable to participate	9		
Declined interview	5		
lounge 1	4	asleep	
lounge 2	3	asleep	
lounge 3	2	asleep	
lounge 4	4	asleep	

healthwatch
Wakefield

RESIDENTIAL CARE HOME SURVEY 2016 VANGUARD

Are you:

A Resident ☐ A Carer/Relative ☐

Our first questions are to find out if the services that are taking care of you are working well together

1. Which health and care services do you have contact with?

Age UK	☐	Doctor	☐	Practice Nurse	☐
Carers Wakefield	☐	Occupational Therapist	☐	Social Worker	☐
Community Geriatrician	☐	Pharmacist	☐		
District Nurse	☐	Physiotherapist	☐		

Other:

☐

2. If several different people or services were involved in your care and looking after you, did you find that everyone worked well together (that is they worked together as a team, sharing information and organising things so that everything ran smoothly)?

yes ☐ no ☐ sometimes ☐ not sure ☐ n/a ☐

3. In your experience, would you say that:

a) You are able to see your GP when you need to. yes ☐ no ☐ sometimes ☐ not sure ☐ n/a ☐

b) If you go to hospital they know your medication and any other needs you may have. yes ☐ no ☐ sometimes ☐ not sure ☐ n/a ☐

c) If you need to ask questions about your health care do you know who to contact? yes ☐ no ☐ sometimes ☐ not sure ☐ n/a ☐

d) Who is that? ____________________

e) Do you feel that this person understands about you and your condition? yes ☐ no ☐ sometimes ☐ not sure ☐ n/a ☐

4. While you've been living here have you discussed your health care plan with anyone?

Yes ☐ No ☐ Not sure ☐

5. Do you feel that the health care provided meets your needs?

Yes ☐ No ☐ Not sure ☐

6. How involved do you want to be in decisions about your health care?

For example, 0 = I don't want to be involved; 10 = I want to be completely involved.

0	1	2	3	4	5	6	7	8	9	10

not involved completely involved

7. How involved do you actually feel in decisions about your health care?

0	1	2	3	4	5	6	7	8	9	10

not involved completely involved

Any comments:

The next questions are about your quality of life

8. What kind of things do you like to do that help you to feel independent?

For example, I can choose when to get up/go to bed or have a cup of tea; I get to go out to places I enjoy; I can be with people I like.

9. Do these things help you to feel as independent as you want to be?

Yes ☐ No ☐ Not sure ☐

If 'No', what kind of things would you like to do that would help you feel independent?

10. Overall how satisfied are you with your life nowadays?

0	1	2	3	4	5	6	7	8	9	10

not satisfied completely satisfied

11. On a scale where nought is 'not at all depressed' and 10 is 'very depressed', overall, how depressed did you feel today?

0	1	2	3	4	5	6	7	8	9	10

not at all depressed very
depressed

12. On a scale where nought is 'not at all happy' and 10 is 'very happy', overall, how happy did you feel today?

0	1	2	3	4	5	6	7	8	9	10

not at all happy very happy

13. What would you say gives you a good life?

The final questions are about you for monitoring purposes

Equality Monitoring Form

What gender are you?

☐ Female	☐ Male	☐ Prefer not to say

What is your age?

☐ 55 or under	☐ 56 - 65	☐ 66 – 75
☐ 76 - 85	☐ 86 +	☐ Prefer not to say

What is your ethnic background?

Asian, or Asian British	**Black, or Black British**	**Mixed/ multiple Ethnic groups**	**White**	**Other**
☐ Chinese	☐ African	☐ Asian & White	☐ British	☐ Arab
☐ Indian	☐ Caribbean	☐ Black African & White	☐ Gypsy/Traveller	☐ Other
☐ Pakistani	☐ Other	☐ Black Caribbean & White	☐ Irish	
☐ Other		☐ Other	☐ Other	
If any other ethnic background, please state here:			☐ Prefer not to say	

Do you consider yourself to have a disability? Please tick all that apply
Under the Equality Act 2010 a disability is defined as 'a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person's ability to carry out normal day to day activities'.

☐ Long standing illness or health condition e.g. cancer, diabetes, HIV, etc
☐ Physical or mobility
☐ Learning disability/difficulty
☐ Mental Health condition
☐ Hearing
☐ Visual
☐ Prefer not to say
☐ Other (please state)

Thank you very much for taking part.

healthwatch
Wakefield

MULTI SPECIALITY COMMUNITY PROVIDER (MCP) ENGAGEMENT FOCUS GROUPS
DECEMBER 2016

CONNECTING CARE +

Connecting Care
Person centred co-ordinated care

CONTENTS

Background

Since 2014 in Wakefield District, local health, social care and voluntary sector organisations have been working together to provide an integrated care service called Connecting Care. In 2015, Wakefield was also successful in receiving funding from NHS England under the New Models of Care programme to support two Vanguards; a care homes Vanguard and a multi-speciality community provider (MCP) Vanguard.

The successful elements of all these local initiatives are now being aligned and consolidated under the next phase of development, informed by the emerging MCP framework from NHS England. This describes a Multi-speciality Community Provider as a ‘new type of integrated provider. An MCP combines the delivery for primary care and community-based health and care services – not just planning and budgets. It also incorporates a much wider range of services and specialists wherever that is the best thing to do[5].

There are three emerging levels of contracting for this MCP:

- Virtual MCP – providers enter into alliance arrangements with a shared vision, clear governance/risk sharing arrangements and a commitment to managing resources together.
- Partially-integrated MCP – commissioners procure, under a single contract, all services in scope of an MCP with the exception of primary medical services.
- Fully integrated MCP – single provider holds a single whole population budget for the full range of primary medical and community based services.

Wakefield is one of six areas being supported to develop this new model of care, and has chosen to work towards the virtual MCP arrangement in 2017/18, supporting existing providers to work together more closely under an alliance contract.

Purpose of Engagement

In September 2016, NHS Wakefield Clinical Commissioning Group (CCG) asked Healthwatch Wakefield to take the lead on some initial public engagement work around the local development of the MCP contract, working with the CCG Engagement Lead.

The key aims of the engagement were to discuss ideas around:

- developing existing integrated care being provided under the Connecting Care initiative
- the six outcomes developed for the new MCP contract
- information sharing and consent to share health and care records
- a single assessment form
- self care, early support and help for carers

Our knowledge of the results of the public engagement exercise in Dudley (another early MCP pilot site) led us to include some discussion also around the potential delivery structures of an MCP provider. We wanted to understand the extent of public concerns about where closer partnership working and a potential single contract was leading the health and care system.

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[5] NHS England New Care Models ‘The multispecialty community provider (MCP) emerging care model and contract framework’, July 2016, p5

Methodology

Initial engagement took the form of eight focus groups held in community settings in November and December 2016.

Focus group	Location	Date	Number of participants
Youth Parliament	City centre	21-Nov	5
St Georges Community Centre Tuesday Leisure Club (also open to general public)	Lupset	22-Nov	11
Local health campaigning group (also open to general public)	Newmillerdam	28-Nov	10
Pontefract New College - health and care students and one teacher	Pontefract	28-Nov	19
Wakefield Deaf User Partnership	City centre	30-Nov	12
Airedale Neighbourhood Management Group	Airedale	01-Dec	10
Kinsley and Fitzwilliam Pharmacy User Group	Fitzwilliam	01-Dec	10
Well Women Centre	City centre	05-Dec	6
			Total 83

We were very aware of the complexity of the subject matter, both in the detail and the scope. Our approach was carefully planned to ensure that participants were given enough information about the context and the specific details of the proposals to enable them to answer the questions.

In order to be as clear as possible in our descriptions of the proposed new model of care, we built on existing material and information about the Connecting Care programme, and presented the MCP model for Wakefield as Connecting Care+.

We developed a presentation that incorporated descriptions of the various elements of the engagement with integrated sets of questions. The CCG produced an excellent video that was used to supplement the presentation and help to explain what the aspirations and outcomes of Connecting Care + might be.

The principles for the focus groups were as follows:

- We presented a balanced, unbiased view of the new model of care for Wakefield District.
- We facilitated open and honest debate within the focus groups and captured people's opinions accurately.
- We attempted to ensure a good demographic and geographic mix of participants.

Approach:

We provided two Healthwatch facilitators, one to present the proposals and the second to capture the discussions. We also had support from the CCG Engagement Lead at a number of the sessions. During the focus groups, we talked through the proposals in stages, asking questions after each section.

- Described background and context
- Described what it will look like and how it differs from now
- Talked about particular need therefore to change the way information is currently shared between health and care professionals
- Asked questions on three main areas:
- The model of care itself
- Self care and early help
- Information sharing and consent

Full explanations of the proposals were given and information provided for people to take away, including answers provided by the CCG to previously voiced concerns about the new model of care (appendix at page 40).

Participants were provided with their own copies of the survey which they could complete if they wished to ensure that their personal views were captured. 62 people completed their own surveys.

Participants:

Participants were resident or working in Wakefield District and eligible to receive health and care services. We occasionally had some health/social care/VCS staff or volunteers join the groups as well as members of the public. There were 27 men in the focus groups and 56 women, but this was slightly skewed by the 18 health and social care students at Pontefract New College, who were all young women.

There was a broad spectrum of knowledge of the health and care system amongst participants; some were long term users of multiple health and care services, some had worked previously or currently in health and care, some were interested individuals who didn’t have personal experience of receiving care. And some were individuals who didn’t completely realise what they’d turned up for, but were happy to share their views anyway!

Summary of key themes

The key messages from the surveys are summarised below, but these should be read in the context of some of the focus group discussions and provisos detailed in the main body of the report. The survey responses mirrored the focus group discussions.

- 83% of people agreed that the outcomes for the new model of care are the right ones.
- 78% of people agreed that people should take more responsibility for their own health and wellbeing.
- People gave mixed responses to the question about whether they, or someone they know, would actually access support to help look after themselves better.
- 95% of people think that the new model of care should include support for those caring for family or friends.
- Nearly 70% of people said they would be willing to help support friends and neighbours, but indicated some concerns about how that might work in practice.
- 74% of people agreed that giving health and/or care professionals access to their relevant health and care records is likely to make their care more effective.
- 73% of people agreed they would be happy for their own health and/or care records to be shared.
- Concerns about sharing health and/or care records included the risk that decisions detrimental to us might be made based on what people see in our records and that opening up records to a wider audience might make information more open to misuse.
- 80% of people agreed that a single, joint assessment shared by health and care professionals is a good idea.
- 85% of people agreed that organisations should work together more closely and 78% agreed that they thought this would make their care more effective.
- People were generally unsure whether fewer organisations delivering care under one contract would make our care more effective, with significant concerns about what this step might lead to in the future and the fear of large scale privatisation.
- 93% of respondents said they understood what was being planned in the new model of care and 63% said they thought it was probably the right thing to do.

Analysis of engagement responses

For the purposes of analysis, the results of the 62 individual surveys have been combined with the notes taken at the focus group sessions. Most of the questions that we asked were given response options on a scale of 1-5 in order to capture some of the nuances of opinion that would not have been evident with yes/no/not sure options.

The first section of the focus group discussion was about the outcomes for the new model of care:

- People can access information and advice that is clear, up to date and consistent
- Care and support is responsive, timely and joined up
- Support is provided by caring, considerate people with the right skills
- People live in safe and positive communities
- People are encouraged and supported to be healthy
- People are assured services and resources are efficient

Outcomes of the new model of care

1. Do you think the outcomes for the new model of care are the right ones?

1	No		0.0%	0
2			1.7%	1
3	Not sure		15.5%	9
4			25.9%	15
5	Yes		56.9%	33

83% of people answered with a 4 or 5 which gives a strong indication that people generally did feel that the outcomes were the right ones.

Discussion during the focus groups can be summarised with a quote from one individual who said ‘I broadly agree with the outcomes but I am sceptical that it will work.’ There was a concern that some of the outcomes would be difficult to measure, e.g. if people live in a safe and positive environment; so many don’t and it’s not easy to see how this new service would enable that. People commented that the skills and training of the individuals delivering the service were essential, especially to address conditions like dementia that are increasingly prevalent in our community and issues like drug or alcohol dependency. There was also a concern that the services are predominantly only available during working hours and that mental health services particularly are often far more necessary during night times and weekends.

One comment that was made at several groups was that the outcomes were great as long as the services that will be delivering on them are adequately funded, and that the exercise is not wholly about saving money. There was quite a lot of support for the final outcome around increasing efficiency and minimising waste, not just of resources but of people's time.

There was a question from three groups about provision for children and young people. The new model of care is for 18+ and it was thought that if this model is going to achieve such good outcomes for adults, why is it not also being developed for children and young people? There was discussion about transition issues for 16-18 year olds and that a 'cradle to grave' new model of care might help address some of these.

However, many people shared stories about when support hadn't worked for them because people didn't talk to one another and co-ordinate their care, and said how much better it would be if the joined up service that was described under Connecting Care+ could actually be delivered in reality.

2. Are there other outcomes you think it should achieve?

Although people were supportive of the existing outcomes, there were some suggestions of other outcomes that might be included or incorporated into the existing ones:

- A specific objective around dementia and frailty
- People staying in their own homes longer and being happy
- Care to be effective
- Qualifications and training of health and care professionals
- Training and support for care givers
- Quality mark or KPI for care homes
- Adequate funding
- That healthcare workers (e.g. practice nurses) should be able to say they've seen an improvement if asked in five years' time.
- Be more explicit about GP involvement – it's not clear how this will really impact on GP services

One of the focus groups we ran was with the Wakefield Deaf User Partnership, who had many concerns about existing levels of standards around accessibility and communication barriers. Healthwatch are aware from our work with other groups with access needs, that they have similar issues. A proposal from the Wakefield Deaf User Partnership was that the new Passport they are developing might be used as one of the indicators of success underneath one of the existing outcomes. There are also other locally developed initiatives to support better accessibility for people with additional needs around communication and access. It would be good to see a commitment to better accessibility being included specifically within the new care model.

Self care, early support and help for carers

3. Do you think people should take more responsibility for their own health and wellbeing?

1	No		0.0%	0
2			1.7%	1
3	Not sure		20.0%	12
4			18.3%	11
5	Yes		60.0%	36

78% of people agreed that people should take more responsibility for their own health and care, while the rest were more unsure. Nobody said no, they didn't think that people should take more responsibility, although there was one comment about the fact that 'responsibility' was a slightly loaded word, and that a shared ownership of our health and wellbeing needs might be more reasonable, particularly with some health conditions.

Discussion in the groups revolved around the fact that taking responsibility for our own health and wellbeing seemed like common sense and we should all be doing it, but acknowledging that often this is not the case. Issues like age, poverty, deprivation, particular needs, ability to access relevant information and support make it all less likely that people will be able to take responsibility, even if they are willing. There was also some degree of reflection amongst some participants that although they were able and could find out what they needed to do to keep themselves healthy and fit, that they still didn't do so. There was an agreement that behaviour change is difficult to achieve.

4. How likely would you, or someone you know, be to access support to help you look after yourself better, e.g. healthy eating, exercise, depression and anxiety support groups or services?

1	Unlikely		11.5%	7
2			18.0%	11
3	Not sure		26.2%	16
4			23.0%	14
5	Likely		21.3%	13

This question had mixed responses as can be seen above. Some of the specific points raised were:

- People need to know what's out there before they can access the help
- Funding for these kinds of services has disappeared so there seems to be less out there when people do look for help

- There’s still a stigma around seeking help for mental health issues early on, and sometimes that what might seem like a mental health issue is actually related to a practical issue such as debt or bereavement.
- The waiting time for mental health support puts people off asking for help.
- People with communication or access issues face even more barriers in accessing support to look after themselves better, e.g. a deaf person would find it impossible to attend a lot of support groups /exercise programmes because of the need for interpreters.
- Equally, people who are already suffering from depression are not going to feel motivated to ask for support.

5. Should this new model of care include support for people who are caring for family or friends?

1	No		0.0%	0
2			0.0%	0
3	Not sure	🟦	4.9%	3
4		🟩	11.5%	7
5	Yes	🟧	83.6%	51

During the focus groups, this question was often met with a unanimous ‘yes’, and the surveys show that 95% of people agreed that carers should be supported through the new model of care. (The other 5% were not sure, no one said ‘no’.) There were comments about how difficult it is for carers to find help and that people frequently do not identify themselves as carers. People also agreed that carers often do not ask for help for themselves as they see it as their duty to be caring for their loved one, or something that they are happy to do. It is not until later down the line that they start to struggle and might then need more support.

It was noted that for carers who have particular health or care needs themselves, e.g. sensory problems, dementia, physical frailty, this becomes even more of an issue. The particular needs of young carers was also discussed in two of the focus groups, with a plea that they should be supported as well.

There was backing for the involvement of the voluntary sector in providing this support for carers and fears that the purpose of this consultation meant that the current support available was going to be taken away.

6. Would you be willing to help support your friends and neighbours?

1	No		0.0%	0
2		🟨	3.3%	2
3	Not sure	🟦	28.3%	17
4		🟩	18.3%	11
5	Yes	🟧	50.0%	30

This question sparked quite a lot of debate in the groups. On the whole people agreed that it was a good and community-spirited thing to do, however there were many reasons why it doesn’t happen quite as much in our current society. People talked about the nature of our communities being very different, with families living further away from one another and people not really knowing their neighbours any more. Add something about data protection

There were risks identified both to the individual being supported and the person offering support. Some people described situations where they are currently supporting neighbours or friends, or had been previously and had run into difficulties as a result. These difficulties included not being recognised by services as being an advocate for a person, e.g. a neighbour trying to support a young man with learning difficulties to get his back door fixed, or an elderly lady needing support but the neighbour not being able to get health staff to take her request for help on her behalf.

Some people had concerns that voluntary support in this way could be relied upon too much, with the person offering support then feeling obligated to be part of a care package which might impact on their own lives too significantly or be too stressful, e.g. not feeling they can take a holiday or having to be somewhere at a set time.

There was general agreement that this kind of support would be dependent on the level of need of the individual. There was concern that voluntary support of this kind could lead to formal statutory support for the individual being reduced. There was also acknowledgement of the danger of people offering support for the wrong reasons and vulnerable people therefore being at greater risk.

However, despite the potential risks and concerns, there was general agreement that a move towards community support and care for neighbours and friends would be a positive step, and nearly 70% of people did say that they felt they would want to offer such support. In some of the groups, discussion focused around the fact that you couldn’t return to a community that no longer exists due to such significant changes to how people live, but that there were still going to be people who would be willing to offer support.

If you are, how might the new model of care support you to do this?

Most groups found it quite difficult to think how this might happen, other than addressing some of the issues above. There were some more concrete examples given in the survey responses, for example:

- Recognition from services that people other than next of kin might be appropriate to include in a person’s care plan or as identified spokespeople
- People to be given information about how best to support their neighbour/friend
- People to have clear guidance and access to services that is simple and easy
- Training and support might be needed
- Community network hotline
- Community volunteer co-ordinator / carers’ neighbourhood watch
- DBS checks and vetting for people taking on this role

Focus groups did talk about the value of community groups that help isolated people, bringing them together to chat or do activities. In this way, the support doesn't have to be on such a one to one, potentially burdensome relationship, but can be shared within a group or community. It was agreed that funding for this kind of group support was vital as groups cannot function in isolation and without funds.

Sharing our information

Prior to the focus groups discussing this section, the facilitator of the group went through precisely what the local plan is in relation to the sharing of health and social care information. The text for this can be seen in the presentation at appendix xx.

7. Do you agree that giving health and/or care professionals access to your relevant health and care records is likely to make your care more effective?

1	No	🟥	3.3%	2
2		🟨	3.3%	2
3	Not sure	🟦	19.7%	12
4		🟩	14.8%	9
5	Yes	🟧	59.0%	36

The majority answer to this question on the survey was yes, and 74% of people indicated a 4 or a 5 in their answer. One person said 'yes, it's a no-brainer'. In the focus groups, people had a lot of questions that are covered in questions 9-12 below, but on the whole the majority indicated that they thought that health and care professionals having access to relevant records was likely to make their care more effective.

8. Would you be happy for your relevant health and/or care records to be shared?

In order to test the practice against the theory, we then asked people if they'd be happy to share their own records.

1	No	🟥	8.5%	5
2		🟨	1.7%	1
3	Not sure	🟦	16.9%	10
4		🟩	18.6%	11
5	Yes	🟧	54.2%	32

Broadly the same spread of answers was recorded on the survey, although with a very slight migration away from 'not sure' towards 'no'. 73% of survey respondents in the focus groups agreed that they would happy for their own relevant health and/or care records to be shared. Again, there was a lot of discussion about provisos and concerns which are captured in questions 9-12, predominantly around who would decide what was 'relevant' in our health and care records.

9. Are there any things in our health and/or care records that you think people would not want to be shared?

1	No	🟥	18.0%	11
2		🟨	6.6%	4
3	Not sure	🟦	19.7%	12
4		🟩	8.2%	5
5	Yes	🟧	47.5%	29

Generally the focus groups agreed that there probably were things that people would not want shared, although nearly half of those who completed the survey themselves indicated that they weren't sure about this or disagreed. There was much discussion about how these specific things within our records might be hidden if people didn't want them to be shared, and whether or not it was possible or even desirable. People agreed that there may be occasions where it could be important for a health or care professional to know something that someone might otherwise not want shared. There was also some uncertainty about whether it was possible, given IT constraints, to opt in to sharing certain elements but not others.

Examples of things the focus groups thought people would not want shared included previous mental health problems, sexual health history and offending behaviour.

10. Are there organisations or professionals you would not want to be able to see your health and/or care records?

1	No	🟥	14.8%	9
2		🟨	6.6%	4
3	Not sure	🟦	26.2%	16
4		🟩	11.5%	7
5	Yes	🟧	41.0%	25

Again, the majority of people in the focus groups and the majority answer in the individual surveys was yes, there were organisations or professionals that they would not want to be able to see their health and care records. Examples included counsellors, receptionists/ administrators, insurers, employers, financial bodies, private sector organisations, PPI organisations and 'big brother'. Although there were different reasons and examples given for each of these, the overall feeling was that people might not want these organisations or professionals to have access because:

a) decisions that are detrimental to us might be made as a result of what they see in our records; and/or

b) opening records up to wider audience will make information more open to potential misuse.

11. What do you think might be good about sharing health and care records?

There was a general consensus in every group that there definitely were benefits to be seen in sharing health and care records. People talked about care being faster and more efficient, not having to repeat their histories over and over again, fewer mistakes being made and mistakes being picked up more quickly because more people were looking at the records. They thought that it should help to give better ‘wrap-around’ or holistic care, with more hospitals and relevant organisations being better informed. There was also a feeling that it would make health and care appointments more effective as ‘more time can be spent addressing the issue not the paperwork’.

Sharing health and care records was also seen as a potential positive for people with particular vulnerabilities. Examples included people with dementia, Alzheimer’s, learning disabilities or other health issues that can prevent support being accessed/received or being put in place, and people who have had traumatic experiences, e.g. rape or sexual abuse and who might need a more considered approach by professionals in relation to behaviours and language. It was agreed that where possible if these things are to be shared, ideally they should be agreed with the individual concerned.

The Wakefield Deaf User Partnership group commented that even though some issues are already flagged up and shared on health and care records, this isn’t always acted upon in reality, and communication and access continues to be a battle for certain groups.

12. What would worry you about sharing health and care records?

During the focus groups and from individual survey comments, the biggest concern was the potential for misuse of information if it is shared more widely than currently. There were frequent mentions of the danger of information falling into ‘the wrong hands’. Almost all of the groups had concerns about the idea of profit-making private companies or employers gaining access, and significant concern was voiced in one group about the risk of insurance companies getting hold of private health care records.

An equal concern was the potential for confidentiality breaches. People talked about levels of access granted to our health and care records, and that some staff may be given access because of the nature of their role, but may not have the required levels of integrity or trustworthiness. Examples given included ‘super-admin’ users responsible for co-ordinating care, or consultants’ secretarial staff who would have to type up notes. Although there was an acknowledgement that this activity takes place already, the concern was that wider access provided more potential for inappropriate access to our records.

Information security in relation to potential hacking was mentioned frequently. Although most people acknowledged that existing security measures would still be in place and that IT security is far more secure than previous paper based record keeping, the feeling still existed that increased information sharing might lead to an increased risk of information being sold or lost.

People also had concerns about certain things in their records needing to remain private and confidential, see answers to questions 9 and 10 above. They weren't sure how or whether certain elements of our health and care records would be protected from view if we wanted them to be. If shared access meant that everything was shared with no ability to hide certain elements, then people felt there were definitely times when they would not want this to happen. Just having the ability to opt in or opt out might be a bit too black and white to suit everyone.

13. At the moment all the people involved in your care undertake separate assessments for the services they provide to you. Do you agree that doing one single assessment that is shared by your health and/or care professionals is a good idea?

1	No	🟥	1.7%	1
2		🟨	1.7%	1
3	Not sure	🟦	16.7%	10
4		🟩	16.7%	10
5	Yes	🟧	63.3%	38

The facilitator described the new assessment / information gathering process that is being trialled in the Connecting Care hubs. It is a way to capture all the relevant information about an individual in one electronic template that is then shared with all professionals working to provide care. Although professionals will then need to go on to do further assessment work in relation to their specific roles, the individual will not need to repeat basic information as it will already be recorded on this shared assessment form.

All the focus groups thought that this was a good idea and that it could save time and avoid duplication and 80% of people gave positive responses to this question in the survey.

The element of uncertainty where 20% of people replied they were unsure or didn't agree that it was a good idea is reflected in some of the concerns or questions raised. People asked whether the assessment would be completed by someone with the necessary skills and training; an example was given of a Social Care Direct conversation where the person wasn't properly trained and couldn't help. There was a concern about what would happen if the system was 'down', who would hold the information and how things would be added to it.

There was a consensus that a single joint assessment seemed like a logical step, just some concerns about the practicalities and how it would work in reality, e.g. whether or not people actually use it and read it.

The way organisations may work together in the future

At this point the facilitator explained how the progress towards closer working is planned to happen in Wakefield, with existing providers signing up to an alliance contract in 2017/18 that binds them together to achieve joint outcomes. In later years this might turn to a closer collaboration of providers working to a single contract.

14. Do you think that all the organisations who deliver your care should agree to work more closely together through a partnership agreement?

1	No		0.0%	0
2			0.0%	0
3	Not sure	🟦	15.0%	9
4		🟩	15.0%	9
5	Yes	🟧	70.0%	42

In the focus groups and in the survey responses (85%), the majority of people agreed that organisations should work together more closely. Words like ‘of course’ and ‘definitely’ were used. Some people pointed out that this should have been happening already, given the way that Connecting Care had been operating for the last two years.

There were questions about whether this was the first step to privatisation and some concerns about the practicalities of contract monitoring and management. Clarity about who was accountable under an alliance contract was a concern for some.

People were wary of the possibility that ‘working together more closely’ meant that front line jobs might be lost as money is expected to be saved, also that these changes shouldn’t lead to ‘further layers of management’. There were discussions about who is ‘in’ and who is ‘out’; public health and mental health were mentioned, as were GP practices.

15. Do you think that a joint partnership of different providers working more closely together is likely to make your care more effective?

1	No	🟥	1.7%	1
2		🟨	5.0%	3
3	Not sure	🟦	15.0%	9
4		🟩	25.0%	15
5	Yes	🟧	53.3%	32

At this point in one of the focus groups, there was a challenge that the consultation questions had been framed in such a way that people were being led to give positive answers to specific questions while ignoring the main context of the changes, i.e. the danger of privatising not only the NHS but social care as well. In the other groups also, people started to be more concerned at this point about the fact that the proposed changes seemed like a sensible step, but that they might be opening the door to other more significant and damaging changes to the way our health and care is delivered. As a contrast, there were a small number of people who were quite supportive of a move towards privatisation of healthcare, particularly two of the young people in one of the groups.

In answer to the specific question in the survey however, 78% of people did agree with the principle that organisations working more closely together should make care more effective. They did have some provisos which can be summed up in this quote: ‘Yes if this is part of the true NHS, publicly funded, accountable, free at the point of use’.

16. In future years do you feel it may be helpful to explore if fewer organisations under one contract could deliver your care as long as this is likely to make your care more effective?

1	No	🟥	18.6%	11
2		🟨	11.9%	7
3	Not sure	🟦	30.5%	18
4		🟩	11.9%	7
5	Yes	🟧	27.1%	16

As can be seen from the chart, this question produced more mixed responses from participants, with the majority answer being ‘not sure’. This question prompted the most debate in the groups around the possibility of privatisation and the fear that healthcare may end up being something we need to pay for as individuals. An example given was the social care contract engagement and consultation in the 1990s which resulted in many social care services going to private companies and that following this step would be detrimental rather than beneficial.

There were concerns that a single contract may end up going to a single provider with a focus on profit rather than patient care; ‘the services should be not for profit’. One person wrote ‘here comes the ACO/HMO or whatever new acronym you care to give. This is not the NHS we need or want, but many of the ideas (although not new) are good’.

Some people challenged the idea that fewer organisations or single large organisation could be more effective, saying ‘jack of all trades, master of none’ was a concern and that if services are condensed too much that specialist areas and professionals might be lost. It was pointed out that smaller organisations can offer something large organisations may not.

The concern was raised again that if services are rationalised, this usually means funding cuts which leads to staffing cuts and a reduced service.

However, more people answered a 4 or a 5 for this question than a 1 or 2, and their responses can probably be captured in this quote: ‘As long as it is carefully worked out and gives value for money, and staff are protected.’

And finally

In order to check whether people felt they understood what they were being asked about, we asked:

17. Do you feel you understand what is being planned in the new model of care?

93% of people said that they did understand what was being planned.

18. Do you have any concerns about this model of care?

Most of the concerns had already been voiced by this point in the focus groups, but some remaining issues discussed were:

- How will it interact with other elements of health and care, e.g. GP practices? GPs need to know how the new model of care works and how to use it for their patients.
- Will pharmacies be included and if not, why not? Community pharmacies in particular could work well within this model.
- How will it interact with children and young people’s services, including education? Transition between children’s and adults services is problematic and this could help.
- Access to this model of care needs to be clear and not just by telephone – most people who are deaf cannot use telephones. Neither can people who are very poorly negotiate access to care – a co-ordinator is needed.
- If the services end up being delivered by one organisation on a longer contract, how do we ensure that safeguards are in place if things go wrong?
- We need to ensure that we don’t create new barriers while breaking down the old ones.
- Will community anchors be supported and used as facilities in delivering these new models of care?

Some specific quotes included:

> ‘The idea of 'outsiders' being used is worrying. Agency staff already cost the NHS £1000s. Private care companies have one aim; that is to make money for shareholders. I am very sceptical of the whole idea.’
>
> ‘[My concerns are] first that this is driven mainly by need for savings rather than improvement. Second, the pressures to keep people out of hospital admissions-discharge. Third, a back route for large scale privatisation.’
>
> ‘NHS is completely free at point of delivery, care element is means tested. How will it work?
> Is the whole exercise a way to privatise the NHS?’
>
> ‘Where it will lead in the future. I am not sure it's the right thing to do because the longer term vision is unclear.’
>
> ‘Anticipating change is always difficult and I feel this is such a large scale one I fear that as individuals, people would be lost.’

19. **From everything you've heard, do you think this is the right thing to do?**

1	No		0.0%	0
2		🟨	1.7%	1
3	Not sure	🟦	35.6%	21
4		🟩	25.4%	15
5	Yes	🟧	37.3%	22

By the end of the focus groups, 63% of people who filled in surveys thought that moving to the new model of care is the right thing to do. In the discussions also, people tended to agree; 'ultimately I guess yes. If it saves the NHS, makes care better. I have concerns but if it is better for service users then ok.' A lot of people still were not sure and felt some scepticism; 'can't answer', 'you've given a comprehensive presentation but we need to know the agenda that runs alongside it'.

Demographics

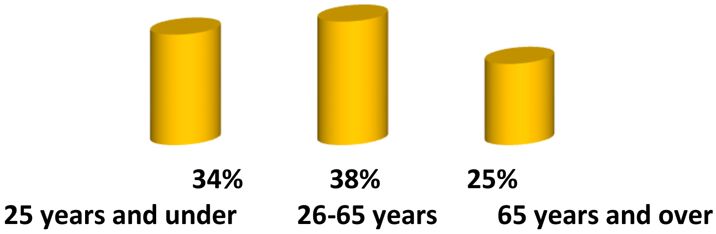
Survey respondents identified the following about themselves:

77% female

83% White British

16 people said they had a disability and/or long standing illness or health condition

28% had caring responsibilities



62 respondents / 47 answered / 15 did not answer
Some preferred not to say on some questions
Full demographics are available in the appendices

Appendices

- Survey
- Information for group hosts
- Presentation
- FAQ from CCG
- Full demographics

2 CONNECTING CARE+ SURVEY

What is it?

A new model of joined up health and care, building on what is already being delivered in Wakefield – Connecting Care.

What is Connecting Care?

In 2013 community health, social care and voluntary sector workers were co-located as a team for the first time. They provide a joined up service for people who are most at risk of becoming ill such as those with long term conditions, complex health needs but also older people who have been in hospital following an emergency or operation. At the moment there are three of these Connecting Care hubs in Hemsworth, Castleford and Lupset and they cover the whole district.

Does Connecting Care work?

84% of people interviewed by Healthwatch rated the Connecting Care service as very good or good. 66% said it helped them cope better at home and 62% said it helped them stay more independent. 54% said it helped them to stay in their own home rather than go into a nursing home/ hospital/ elsewhere. 2,900 people per month are helped by staff in the Connecting Care Hubs.

So why change it?

Although staff are based in the same building they are still finding it hard to share information and work together effectively. All the 'joined up' services are actually provided by lots of different organisations so working together well is hard to do. It would also be good to include more services and make it available to more people. There is evidence that this way of working is shown to have better outcomes for people and will help save money for the NHS and social care.

What would the new way of working achieve?

"Person-centred co-ordinated care"

What would that actually look like?

- Community hubs with health, mental health, social care and wellbeing staff working together either as a tighter collaboration of partners or as one organisation to look after us.
- Sharing our health and care information so professionals can make decisions about our care with us, using all the information that they need.
- Integrating IT systems and using technology in clever ways to make care better.
- More of a focus on wellbeing and preventing people getting more poorly.
- Fast access to care, helping people avoid being admitted to hospital or care settings if it's not necessary.

What does Connecting Care+ aim to achieve for you?

When experiencing the service you are able to say yes to all the following:

- I can access information and support that is clear, up to date and consistent
- My care and support is responsive, timely and joined up
- My support is provided by caring, considerate people with the right skills
- I live in a safe and positive community
- I am encouraged and supported to stay healthy
- I am assured that services and resources are efficient.

We'd like to know what you think...

Outcomes of the new models of care

1) Do you think the outcomes for the new model of care are the right ones?

- People can access information and support that is clear, up to date and consistent
- Care and support is responsive, timely and joined up
- Support is provided by caring, considerate people with the right skills
- People live in safe and positive communities
- People are encouraged and supported to stay healthy
- People are assured that services and resources are efficient

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

2) Are there any other outcomes you think it should achieve?

Self care, early support and help for carers

3) Do you think that people should take more responsibility for their own health and wellbeing?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

4) How likely would you, or someone you know, be to access support to help you look after yourself better, e.g. healthy eating, exercise, depression and anxiety support groups or services?

Unlikely		Not sure		Likely
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

5) Should this new model of care include support for people who are caring for family or friends?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

6) Would you be willing to help support your friends and neighbours?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

If you are, how might the new model of care support you to do this?

Sharing our information

One of the basic things that will help organisations work well together is to be able to share information better. The new model of care has plans to help do this, which includes sharing health and care records.

Everyone has a medical record that is held by our GP on a computer system. If we have help from any social care services, we will also have a social care record held on a computer system.

These records include information such as health and wellbeing information relevant to your care:

NHS number, Age, Contact details, Next of kin, Medication and allergies, Appointments, treatment and care, Test results such as blood tests, laboratory tests, X-rays, Details of contact you have with other health or social care professionals such as visits to clinics, Relevant information from other professionals and those who care for you

At the moment in order for a health or care professional to see our medical record, we need to give our consent at least twice. Once with our GP to ‘open up’ access to the data, and then again with the health or care professional to actually look at it.

The proposal is that this medical record is made available and shared automatically so that we only need to consent once, when someone needs to look at it to help decide how to look after us. Basically this means ticking a box on the computer system for everyone in Wakefield in one go, rather than doing it one by one as people give consent.

Only doctors, nurses, social workers and other health and care professionals will be able to see our medical records. They will only be able to see the relevant bits of our medical records so they can do their job. The computer system will be able to tell if people have accessed medical records inappropriately and action would be taken to prevent this happening. The same principles are in place for our social care records.

Sharing health and care records in this way means that the results of our tests, any allergies, medications and other relevant information will be immediately available to our health and care professionals so that decisions can be made about our care based on all the necessary information. It will also stop time being wasted while people try and find information from other organisations.

With these things in place:

7) Do you agree that giving health and/or care professionals access to your relevant health and care records is likely to make your care more effective?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

8) Would you be happy for your relevant health and/or care records to be shared?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Any other comments:

9) Are there any things in our health and/or care records that you think people would not want to be shared?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Any other comments:

10) Are there organisations or professionals you would not want to be able to see your health and/or care records?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

If so, why?

11) What do you think might be good about sharing health and care records?

12) What would worry you about sharing health and care records?

13) At the moment all the people involved in your care undertake separate assessments for the services they provide to you. Do you agree that doing one single assessment that is shared by your health and/or care professionals is a good idea?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

The way organisations may work together in the future

How will the changes happen?

Next year providers will sign up to an agreement known as an alliance contract that binds them together to achieve joint outcomes.
This will include more services than are currently in Connecting Care. For example there will be a focus on our wellbeing and helping us to stay well for longer. There will be help as early as possible when we are starting to struggle with our health or care needs.

In later years, this joint partnership might turn into a close collaboration of providers that will be awarded a single contract. National policy is developing to support Wakefield with this work.

14) Do you think that all the organisations who deliver your care should agree to work more closely together through a partnership agreement?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Any other comments:

15) Do you think that a joint partnership of different providers working more closely together is likely to make your care more effective?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Any other comments:

16) In future years do you feel it may be helpful to explore if fewer organisations under one contract could deliver your care as long as this is likely to make your care more effective?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Any other comments:

And finally

17) Do you feel you understand what is being planned in the new model of care?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

18) Do you have any concerns about this model of care?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

What are they?

19) From everything you've heard, do you think this is the right thing to do?

No		Not sure		Yes
1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Thank you

If you would like a chance to win a FitBit Tracker, please leave your name and email address or telephone number. Please also indicate if you would like us to email you a copy of the final report of this engagement. A copy will also be available on the Healthwatch Wakefield website.

☐ **Yes I would like the chance to win a FitBit**

☐ **Yes I would like to have a copy of the final report emailed to me**

Contact details:

Monitoring Form

What is your gender?

☐ Female	☐ Male	☐ Trans*	☐ Prefer not to say

What is your age?

☐ Under 16	☐ 16 - 25	☐ 26 - 45
☐ 46 - 65	☐ 66 – 75	☐ 76+
☐ Prefer not to say		

What is your ethnic background?

Asian, or Asian British	**Black, or Black British**	**Mixed/multiple Ethnic groups**	**White**	**Other**
☐ Indian	☐ African	☐ Asian/White	☐ British	☐ Chinese
☐ Pakistani	☐ Caribbean	☐ Black African/White	☐ Gypsy/Traveller	
☐ Bangladeshi		☐ Black Caribbean/White	☐ Eastern European	
☐ Other	☐ Other	☐ Other	☐ Other	☐ Other
If other, please state here:				
☐ Prefer not to say				

Do you consider yourself to have a disability? Please tick all that apply
Under the Equality Act 2010 a disability is defined as ‘a physical, sensory or mental impairment which has, or had a substantial and long-term adverse effect on a person’s ability to carry out normal day to day activities’.

☐ Long standing illness or health condition e.g. cancer, diabetes, HIV, etc		
☐ Learning disability/difficulty	☐ Mental Health condition	☐ Physical or mobility
☐ Hearing	☐ Visual	☐ Other
If other, please state here:		
☐ Prefer not to say		

Do you look after, or give any help or support to a family member, friend or neighbour because of long term physical disability, mental ill-health or problems related to old age?

☐ Yes	☐ No	☐ Prefer not to say

Information for group hosts

Wakefield's Accountable Care Approach – a new model of care

(also known as MCP (multi-specialty community provider) contract)

5 Focus Groups to be conducted in November and December 2016

At least ten people per group, each group to last approximately 2 hours

Principles for the focus groups

1. We will present a balanced, unbiased view of the new model of care for Wakefield District.
2. We will facilitate open and honest debate within the focus groups and capture people's opinions accurately.
3. We will attempt to ensure a good demographic and geographic mix of participants.

Approach

Two Healthwatch facilitators, one to present the proposal and the second to capture the discussions. During the focus group, to talk through the proposals in stages, asking questions after each section.

- Describe background and context
- Describe what it will look like and how it differs from now
- Talk about particular need therefore to change the way information is currently shared between health and care professionals
- Ask questions on three main areas:
    - The model of care itself
    - Self care and early help
    - Information sharing and consent

Full explanations of the proposals will be given and information provided for people to take away.

Participants

Participants should be resident or working in Wakefield District and eligible to receive health and care services. They can be staff or volunteers as well as members of the public.

Requirements

We will need a room that is big enough to seat at least ten participants.
There is a PowerPoint presentation to accompany the discussion. We can provide the laptop and the projector if needed, but we need somewhere to project onto.
There will be large posters that need to be visible to participants during the focus group, so we need to be able to put these on walls or propped up somewhere.
Participants need a table or something to write on as they will have their own personal survey to complete as well as joining the discussion.

Incentives

We can pay for room rental if required, and travel expenses for participants. We can also pay for some catering, e.g. tea, coffee, biscuits and/or cake. Each person filling in a survey and leaving their contact details will have an opportunity to win a Fitbit: a personal activity tracker that can help you stay motivated and improve your health.

Brief outline of Focus Group discussion

Healthwatch Wakefield have been asked to engage with the public about a new model of care for our district, which possibly represents the biggest change to local services in decades. These discussions give local people the opportunity to have their say and let commissioners know how they feel about the proposals.

The new model of care is part of the national initiative known as 'Multi-Speciality Community Providers' or 'MCP'. In Wakefield it is building on the existing Connecting Care model that has been running in Wakefield District for the last three years. Three hubs were created, in Hemsworth, Castleford and Lupset, and health, social care and voluntary sector workers were co-located as part of a team for the first time. Staff and patients have told us over the last two years that they think Connecting Care model is a good one and that it is helping people feel more looked after at home.

However, although health and care staff are based in the same buildings they are still finding it hard to share information and work together effectively. Some of the management and decision making structures make it difficult for front line workers to do the job they'd like to be doing. There are also differences in culture and risk management that mean people aren't working as a team as well as they would like to be.

The new model of care is also much wider than the current Connecting Care services. It includes health, social care and the voluntary sector but also some mental health, public health and other community based services.

The process

To try and help these services work more effectively together, commissioners and providers would like to take the next step. In 2017 they will do this by signing up to an agreement known as an alliance contract that binds all our major health and care providers together to achieve joint outcomes, or results.

This alliance contract will include more services than are currently in Connecting Care. For example, there will be a focus on our wellbeing and helping us to stay well for longer. Help will be put in place as early as possible when we are starting to struggle with our health or care needs.

In later years, this joint partnership might turn into a close collaboration of providers that will be awarded a single contract to deliver those outcomes. At the moment it is not clear how or when this will be achieved locally. National policy, through NHS England and others, is developing to support Wakefield District with this work.

The aim and outcomes for the new model of care

The aim of the new way of working is to create a community health and care service that will mean you are able to say yes to all the following:

- I can access information and support that is clear, up to date and consistent
- My care and support is responsive, timely and joined up
- My support is provided by caring, considerate people with the right skills
- I live in a safe and positive community
- I am encouraged and supported to stay healthy
- I am assured that services and resources are efficient.

Feedback

Participants who wish to hear the full results of the engagement can leave their name and contact details and we will send the final report to them.

Presentation

Connecting Care+

Public Engagement

What is it?

A new model of joined up health and care, building on what is already being delivered in Wakefield – Connecting Care

What is Connecting Care?

In 2013 community health, social care and voluntary sector workers were co-located as a team for the first time.

They provide a joined up service for people who are most at risk of becoming ill such as those with long term conditions, complex health needs but also older people who have been in hospital following an emergency or operation.

At the moment there are three of these Connecting Care hubs in Hemsworth, Castleford and Lupset and they cover the whole district.

Does Connecting Care work?

84% of people interviewed by Healthwatch rated the Connecting Care service as very good or good.

66% said it helped them cope better at home and 62% said it helped them stay more independent.

54% said it helped them to stay in their own home rather than go into a nursing home/ hospital/ elsewhere.

2,900 people per month are helped by staff in the CC Hubs

So why change it?

Although staff are based in the same building they are still finding it hard to share information and work together effectively. All the 'joined up' services are actually provided by lots of different organisations so working together well is hard to do. It would also be good to include more services and make it available to more people.

There is evidence that this way of working is shown to have better outcomes for people and will help save money for the NHS and social care.

What would the new way of working achieve?

"Person-centred co-ordinated care"

What does that mean?

When experiencing the service you are able to say yes to all the following:

1. I can access information and support that is clear, up to date and consistent
2. My care and support is responsive, timely and joined up
3. My support is provided by caring, considerate people with the right skills
4. I live in a safe and positive community
5. I am encouraged and supported to stay healthy
6. I am assured that services and resources are efficient.

What would that actually look like?

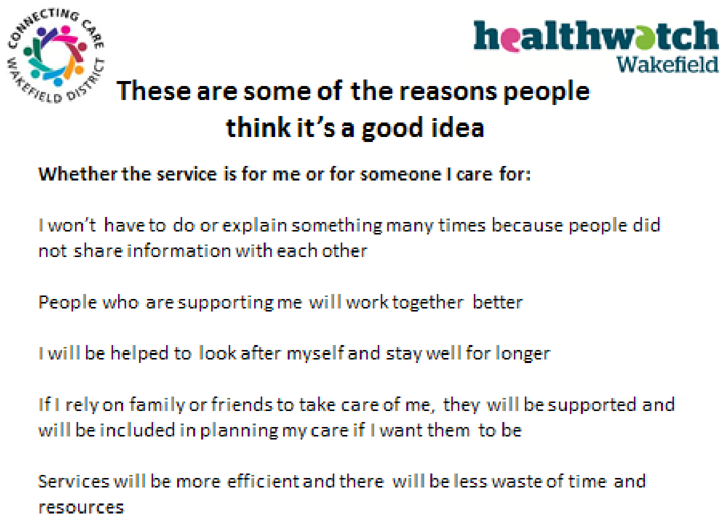
- Community hubs with health, mental health, social care and wellbeing staff working together either as a tighter collaboration of partners or as one organisation to look after us
- Sharing our health and care information so professionals can make decisions about our care with us, using all the information that they need.
- Integrating IT systems and using technology in clever ways to make care better
- More of a focus on wellbeing and preventing people getting more poorly
- Fast access to care, helping people avoid being admitted to hospital or care settings if it's not necessary.

How will it be done?

Next year providers will sign up to an agreement known as an alliance contract that binds them together to achieve joint outcomes.

This will include more services than are currently in Connecting Care. For example there will be a focus on our wellbeing and helping us to stay well for longer. There will be help as early as possible when we are starting to struggle with our health or care needs.

In later years, this joint partnership might turn into a close collaboration of providers that will be awarded a single contract. National policy is developing to support Wakefield with this work.



These are some of the reasons people think it's a good idea

Whether the service is for me or for someone I care for:

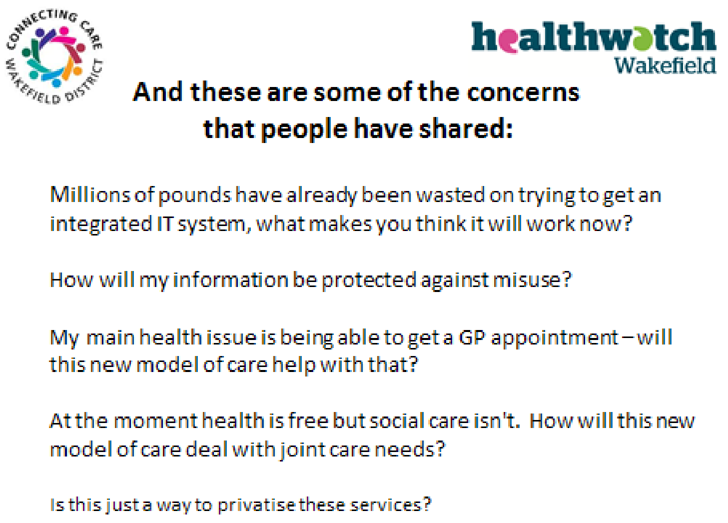
I won't have to do or explain something many times because people did not share information with each other

People who are supporting me will work together better

I will be helped to look after myself and stay well for longer

If I rely on family or friends to take care of me, they will be supported and will be included in planning my care if I want them to be

Services will be more efficient and there will be less waste of time and resources



And these are some of the concerns that people have shared:

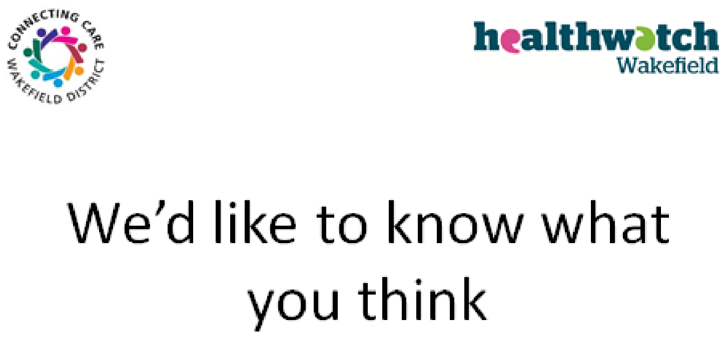
Millions of pounds have already been wasted on trying to get an integrated IT system, what makes you think it will work now?

How will my information be protected against misuse?

My main health issue is being able to get a GP appointment – will this new model of care help with that?

At the moment health is free but social care isn't. How will this new model of care deal with joint care needs?

Is this just a way to privatise these services?



We'd like to know what you think

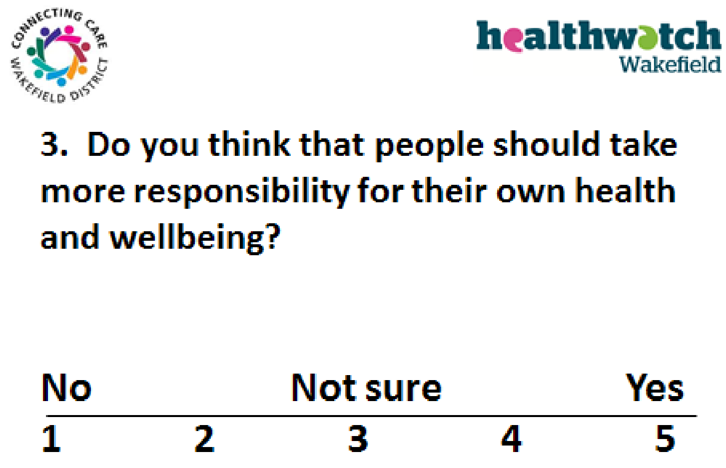
About the outcomes of the new model of care

1. Do you think the outcomes for the new model of care are the right ones?

No		Not sure		Yes
1	2	3	4	5

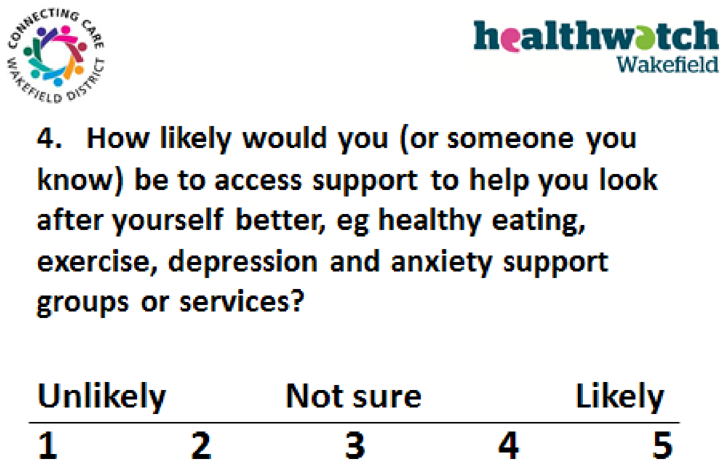
2. Are there any other outcomes you think it should achieve?

About self care, early support and help for carers



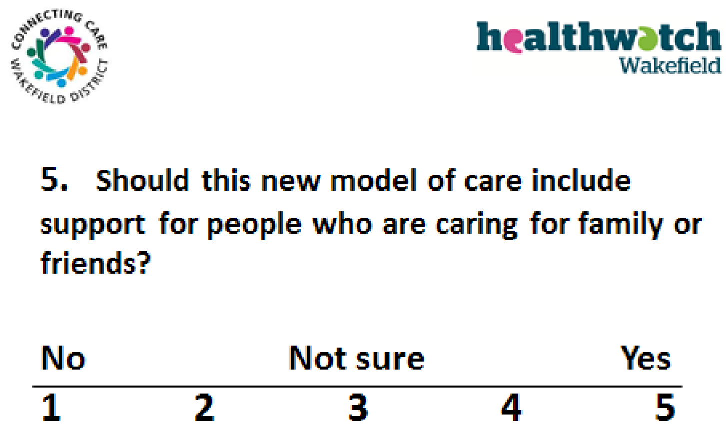
3. Do you think that people should take more responsibility for their own health and wellbeing?

No		Not sure		Yes
1	2	3	4	5



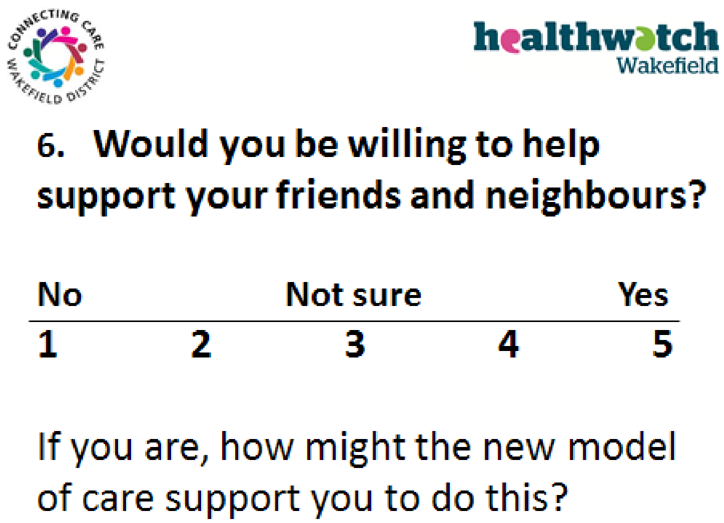
4. How likely would you (or someone you know) be to access support to help you look after yourself better, eg healthy eating, exercise, depression and anxiety support groups or services?

Unlikely		Not sure		Likely
1	2	3	4	5



5. Should this new model of care include support for people who are caring for family or friends?

No		Not sure		Yes
1	2	3	4	5



6. Would you be willing to help support your friends and neighbours?

No		Not sure		Yes
1	2	3	4	5

If you are, how might the new model of care support you to do this?

About sharing our information

7. Do you agree that giving health and/or care professionals access to your relevant health and care records is likely to make your care more effective?

No		Not sure		Yes
1	2	3	4	5

8. Would you be happy for your relevant health and/or care records to be shared?

No		Not sure		Yes
1	2	3	4	5

9. Are there any things in our health and/or care records that you think people would not want to be shared?

No		Not sure		Yes
1	2	3	4	5

What are these?

10. Are there organisations or professionals you would not want to be able to see your health and/or care records?

No		Not sure		Yes
1	2	3	4	5

If so, why?

11. What do you think might be good about sharing health and care records?

12. What would worry you about sharing health and care records?

13. At the moment all the people involved in your care undertake separate assessments for the services they provide to you. Do you agree that doing one single assessment that is shared by your health and/or care professionals is a good idea?

No		Not sure		Yes
1	2	3	4	5

About the way organisations may work together in the future

14. Do you think that all the organisations who deliver your care should agree to work more closely together through a partnership agreement?

No		Not sure		Yes
1	2	3	4	5

15. Do you think that a joint partnership of different providers working more closely together is likely to make your care more effective?

No		Not sure		Yes
1	2	3	4	5

16. In future years do you feel it may be helpful to explore if less organisations under one contract could deliver your care as long as this is likely to make your care more effective?

No		Not sure		Yes
1	2	3	4	5

And finally…

17. Do you feel you understand what is being planned in the new model of care?

No		**Not sure**		**Yes**
1	**2**	**3**	**4**	**5**

18. Do you have any concerns about this model of care?

What are these?

19. From everything you've heard, do you think this is the right thing to do?

No		**Not sure**		**Yes**
1	**2**	**3**	**4**	**5**

Thank you very much for your time!

Connecting Care
Person-centred care in Wakefield District

Connecting Care+

Some questions about the new proposals and answers provided by NHS Wakefield Clinical Commissioning Group:

NHS
Wakefield
Clinical Commissioning Group

Millions of pounds have already been wasted on trying to get an integrated IT system, what makes you think it will work now?
That was due to proposals for a national IT system roll out and what Wakefield are proposing is to do what we can locally to improve how our systems talk to each other. This will not include lots of new investment being spent of this type of IT system.

How will my information be protected against misuse?
Only people who are involved in your direct care will be able to access information about your health and social care records. This information will be safeguarded and protected as it is now through staff following policies to protect your information.

My main health issue is being able to get a GP appointment – will this new model of care help with that?
Yes it will and when you contact your GP if we believe that the care you need can be delivered in your GP surgery by another professional working in the practice we will give you a choice to access this service. This may be a physio or a pharmacist for example.

At the moment health is free but social care isn't. How will this new model of care deal with joint care needs?
Wakefield are not able to change the national policy that is legislated through the Care Act about the cost of accessing social care – however partners will work together much more closely in the future to plan for your joint care needs.

Is this just a way to privatise these services?
Absolutely not. This is a way of making sure you access the right care at the right time and in the right place. This is a way of strengthening how care is delivered in Wakefield. If in the future less organisations do deliver your care under one contract it won't necessarily mean these organisations will be different to those delivering your care now like the voluntary sector, the services of a GP or the local community nursing team.

Full demographics

What is your gender				
			Response Percent	**Response Total**
1	Female		76.60%	36
2	Male		17.02%	8
3	Trans*		2.13%	1
4	Prefer not to say		4.26%	2
			answered	47
			skipped	15

What is your age?				
			Response Percent	**Response Total**
1	Under 16		0.00%	0
2	16-25		34.04%	16
3	26-45		12.77%	6
4	46-65		25.53%	12
5	66-75		21.28%	10
6	76+		4.26%	2
7	Prefer not to say		2.13%	1
			answered	47
			skipped	15

What is your ethnic background?				
			Response Percent	**Response Total**
1	British		82.61%	38
2	Irish		0.00%	0
3	Other		6.52%	3
4	Indian		0.00%	0
5	Pakistani		4.35%	2
6	Bangladeshi		0.00%	0
7	Any other Asian background		0.00%	0
8	White and Black Caribbean		2.17%	1
9	White and black African		0.00%	0
10	White and Asian		0.00%	0
11	Any other mixed background		0.00%	0

What is your ethnic background?

			Response Percent	Response Total
12	Caribbean		0.00%	0
13	African		0.00%	0
14	Any other black background		0.00%	0
15	Chinese		0.00%	0
16	Any other Ethnic Group		0.00%	0
17	I do not wish to disclose my ethnic origin		4.35%	2
			answered	46
			skipped	16

Do you consider yourself to have a disability? Please tick all that apply

			Response Percent	Response Total
1	Long standing illness or health condition e.g. cancer, diabetes, HIV, etc		40.00%	8
2	Learning disability/difficulty		10.00%	2
3	Mental health condition		0.00%	0
4	Physical or mobility		45.00%	9
5	Hearing		25.00%	5
6	Visual		5.00%	1
7	Prefer not to say		20.00%	4
8	Other (please specify):		5.00%	1
			answered	20
			skipped	42

Other (please specify): (1)

1	28/11/16 4:49PM	epilepsy

Do you look after, or give any help or support to a family member, friend or neighbour because of a long term physical disability, mental ill health, or problems related to old age?

			Response Percent	Response Total
1	Yes		27.66%	13
2	No		70.21%	33
3	Prefer not to say		2.13%	1
			answered	47
			skipped	15

Contact us

11-13 Upper York Street, Wakefield WF1 3LQ

01924 787379 for staff and volunteers
01924 234007 for advice, information and signposting

enquiries@healthwatchwakefield.co.uk

www.healthwatchwakefield.co.uk

@healthywakey

Healthwatch Wakefield

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