ANNEX C

Discharge from health and social care settings

October 2015

Contents

Acknowledgements

We would like to thank:

- York Teaching Hospital NHS Foundation Trust, especially the staff at the discharge lounge
- All our volunteers who helped with the work for this report, especially Gabi Gorin for her work with people using the Age UK York Hospital transport scheme
- Everyone who shared their experiences, particularly our partner organisations who helped make sure their members experiences were heard

Discharge from health and care settings

Background

This report looks at the experiences of people in York being discharged from health and social care settings. It sets out how we identified this as an area to investigate and what we have done in response. It makes recommendations to tackle identified issues, and highlights areas of good practice.

Being discharged from hospital and other health and social care settings affects significant numbers of people each year. NHS hospitals dealt with 15.1 million admissions in 2012-13 - or about 41,500 admissions per day on average across England (HSCIC website). The majority of these people will leave hospital following admission.

When discharge goes wrong it is not only a problem for an individual, it can have a significant cost to the health and social care system. In 2012-13 there were more than one million emergency readmissions within 30 days of discharge, costing an estimated £2.4 billion. (www.nao.org.uk)

Why Healthwatch York decided to look at this issue

In our 2014 workplan survey, over 75% of people who responded felt that discharge from hospital should be part of our work plan. They told us we should look at planning for leaving hospital and getting home as soon as possible, involving patients and carers in plans and planning care for when patients get home.

Comments made by respondents to the survey included:

“Patients are being sent home far too quickly. Is there any verbal liaison between hospital and social carers?”

“I had difficulty in transferring my wife from hospital to a care home and finding suitable care for my wife.”

In addition to the comments from the workplan survey, during 2014 we received 20 individual pieces of feedback from people about their experience of hospital discharge. This feedback is included in Appendix 5. It raised issues about:

- Timing/speed of discharge
- Transport
- Personalised, co-ordinated care
- Community nursing and Social Care Support after discharge
- Involving carers in discharge planning
- Being discharged from mental health services

Feedback included:

- “The hospital did not inform my daughter that I was being discharged – it all felt very sudden when I was told to leave. Everything else was brilliant but I felt it all happened too quickly.”
- “I felt the drop off service could have stayed a bit longer – they saw me into the house but didn’t hang around. My wife is disabled and we could have done with extra support from them to settle me in.”
- A woman was discharged after 5 days on the acute stroke ward and had been told someone would be at her home to meet her and provide support. However, she was on her own from 9am on the day she was discharged until the following afternoon. There was no food in the house and she survived on coffee and water.
- “When my father was discharged from York Hospital, although staff had let his carers know he was going to be discharged, no one contacted me. If I hadn't phoned the hospital and found out he was to be discharged, he would have had no way of getting into his home (he cannot use the key box).”
- A young carer with mental health issues was referred to Limetrees. He needed to re-arrange appointments due to his caring responsibilities and was taken off treatment. He then had to go back to his GP for a new referral.

In 2014 Healthwatch England identified discharge from hospital as a national priority. We were able to share some of our initial findings with them. Their special inquiry, focussing on the experiences of older people, homeless people and people with mental health conditions, began in the summer of 2014. The resulting special inquiry report: ‘Safely home: what happens when people leave hospital and care settings?’ was published in July 2015. It is available via the Healthwatch England website: www.healthwatch.co.uk. Contact the Healthwatch York office if you need a paper copy.

Discharge of people with long term conditions back to their GP

In addition to the feedback we received about inpatients being discharged from hospital, during the period February to June 2014 we also received feedback from outpatients with long term conditions who had been discharged from their hospital consultant back to the care of their GP as part of a major system change. Patients with conditions including Myasthenia Gravis, Multiple Sclerosis and Rheumatoid Arthritis reported that GPs are not always confident dealing with their condition. (See Appendix 8)

What we did to find out more

We undertook actions 1-4 to find out more about discharge from health and care settings, and actions 5 & 6 to find out more about discharge back to GPs.

1) To support an evaluation of the Age UK York Hospital Discharge Service, we carried out a telephone survey of people who were supported by the service to leave hospital. During May 2014 we spoke to 31 people who had used the Age UK York escorted transport service following discharge from hospital between February and April 2014.
2) We carried out a survey (see Appendix 4) asking people about their experiences of being recently discharged from a hospital or care setting in York. The survey was available via the Healthwatch York website and in paper form from 1st August 2014 until 30th September 2014. There were 23 respondents in total.
3) We carried out an Enter and View visit to the Discharge Lounge of York Hospital on Friday October 24th 2014 to speak to patients as they were waiting to be discharged. Staff and trained volunteers were in the discharge lounge from 8am until 5pm. We used a specially designed questionnaire to capture peoples' experiences. During the visit we spoke to 22 patients in the discharge lounge and 2 on elderly care wards. At the end of each conversation we asked whether people would be willing for us to contact them 2 weeks later to find out how they were getting on. 15 patients gave us consent to do this. We were able to contact 8 of these patients to ask them some further questions. Our Enter and View report, which included a number of recommendations, was published in spring 2015. The full report is included at Appendix 1.
4) We gathered feedback on discharge from health and social care settings at a workshop following our Annual Meeting in July 2014. The workshop was attended by 45 people. Feedback from this workshop is included at Appendix 6.
5) We gathered feedback on discharge from hospital consultants to GPs at a workshop following our Annual Meeting in July 2014. The workshop was attended by 45 people. Feedback from this workshop is included at Appendix 7.
6) We sought feedback from people with long term conditions about their experience of being discharged from a hospital consultant to their GP. People with Rheumatoid Arthritis were identified as one group who often have issues with discharge, and specific feedback was sought at a York Rheumatoid Arthritis Support Group Meeting in May 2014. This feedback is included at Appendix 8.

What we found out

1) Findings from our telephone survey to evaluate the Age UK York Hospital Discharge Service

All 31 people we spoke to who had used the Age UK service said they were happy with the service and almost all (97%) commented that they could not say a bad word about it and had no complaints. Most commented that the physical support and the way in which they were given reassurance by the Age UK York worker when they returned home made them feel much more at ease and settled.

Some of the things which were particularly appreciated were: helping with bags, seeing people into their house/flat, making sure the heating was on, making a cup of tea or a sandwich, checking the house was safe, putting the TV on, passing efficiently over to carers, assisting people with stairs.

However, three people reported that they felt sufficient notice was not given to the patients' family members when they were being sent home from hospital, leaving them feeling as though it had been "sprung" upon them without warning.

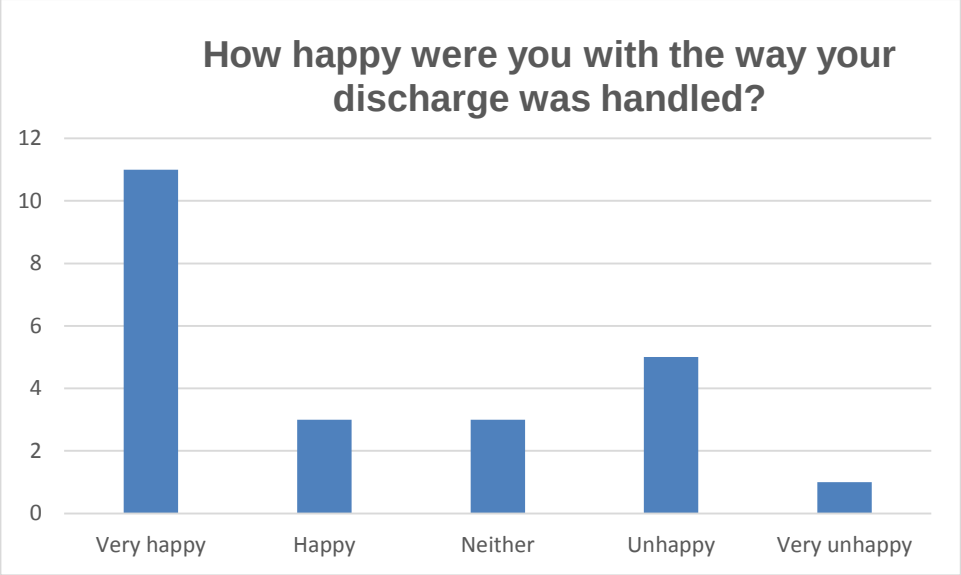
One woman speaking on behalf of her father explained that when her father was discharged from hospital they were given very little notice to prepare for his arrival home, which caused some distress to the patient's wife who has limited mobility due to a disability.

Another woman commented that her daughter was not informed of her discharge from hospital. She was concerned this may have led to issues had her daughter visited the hospital expecting her mother to be there, when she had already been discharged.

2) Findings from Healthwatch York's hospital discharge survey

The main issues identified by respondents around discharge were failings in communication. For instance one respondent felt 'un-listened to', one complained about the lack of a clear discharge time being given, one complained of their midwife not being notified of their discharge, whilst another implied that staff had not followed through on what they had said they would do.

In total 23 people responded to our survey of whom 21 had been discharged from York Hospital. 1 person had been discharged from Clifton Park Hospital and 1 from Nuffield Hospital; both of these respondents said they were 'very happy' with the way their discharge was handled. Over half of the total number of respondents were either 'very happy' (11 people) or 'happy' (3 people) with the way their discharge had been handled. 5 people were 'unhappy' and 1 person was 'very unhappy'.



One respondent, who indicated they were 'happy' with the way their discharge was handled said: "I was given a lot of paper information without very much explanation and found this quite hard to take in. I live on my own and did not feel ready to cope at home but quite understand that there are many people worse off than myself needing hospital care."

One respondent, who indicated they were 'unhappy' with the way their discharge was handled said: "It was not the right time to be discharged. I felt the reasons for discharge were primarily pressure on staffing levels."

Another respondent, who indicated they were 'neither' happy nor unhappy with the way their discharge had been handled said: "Staff were excellent but the process was slow, uncertain & I didn't know what time it (discharge) would take place as I was waiting for my medication."

3) Findings from the Enter and View visit to the discharge lounge at York Hospital

The full report of the Enter and View visit was published in early 2015. It can be downloaded from the Healthwatch York website and paper copies are available from the office. The following is a summary of the findings from the visit.

<u>Where patients were being discharged from</u>

Three of the people we spoke to were day unit patients, two had been discharged from Ward 23, two from Ward 29. The others were all being discharged from different wards.

How long patients had been in hospital

Four patients had been in hospital just for the day. Of the others:

4 patients	1 night
2 patients	2 nights
2 patients	3 nights
2 patients	4 nights
1 patient	5 nights
3 patients	1 week
2 patients	10 nights
3 patients	2 weeks

Arriving at hospital

Thirteen patients had arrived at hospital by ambulance, seven had been referred by their GP, one had been admitted via A & E, one arrived by bus and one was unsure.

How people felt about their treatment on the wards

There were a lot of very positive comments about the care and treatment patients had received during their stay in hospital. Comments included 'Very good', 'excellent', 'I was well looked after', 'absolutely excellent', 'no one could have been more hard working and kind', 'fantastic', 'I was treated with kindness and humanity', 'perfect treatment', 'very good – all the staff are excellent'. There were two positive comments about the food in hospital.

The only negative comments were: 'terrible mattress' (ward 25), 'very noisy at night' (ward 22), 'not enough information is given by doctors due to time restrictions and the use of jargon in explanations' (ward 22).

Additional health conditions

Thirteen patients had a health condition in addition to the one for which they were admitted. All these patients felt that their additional health conditions had been managed effectively.

Did patients feel ready to be discharged?

Twenty patients said they felt ready to be discharged. One said they 'were a little bit anxious', one felt they 'could have done with a couple more days' and one said they still felt a bit weak.

Did patients have everything they needed?

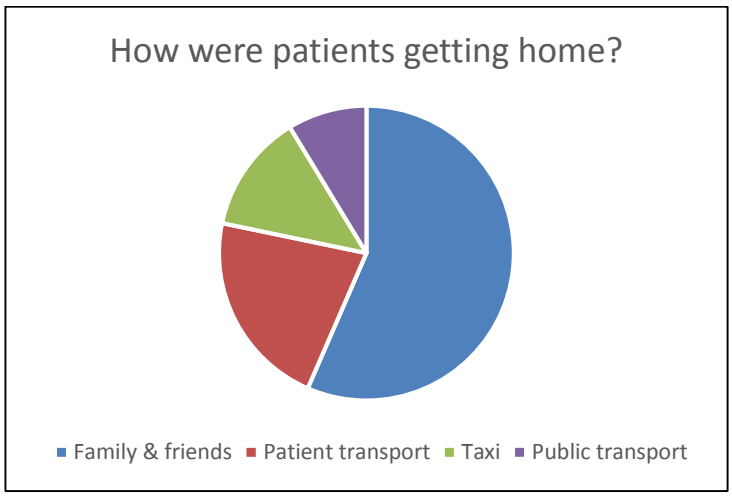
Nineteen patients said they had everything they needed. One was still waiting for their discharge letter, three were still waiting for their medication.

Where were patients being discharged to?

Eighteen patients were being discharged to their own homes, three were being discharged to care homes, one was being discharged to sheltered accommodation and one to St Helens rehabilitation hospital.

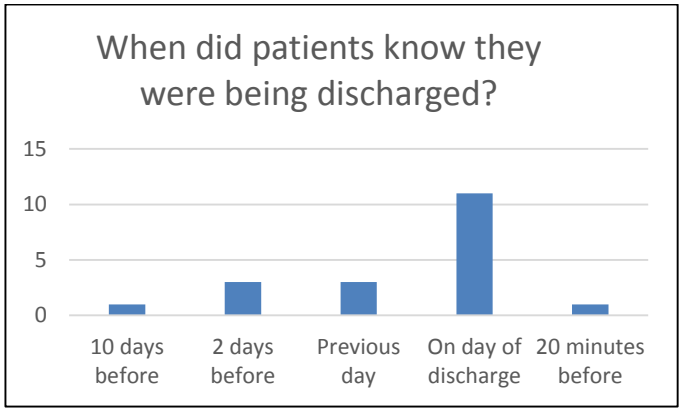
How were patients getting home

Thirteen patients were being collected by family or friends, five were using the patient transport service, three were getting taxis and two were using public transport.



When did patients know they were being discharged?

Four patients had only been admitted for day care. Of the rest, one patient said they knew when they were going to be discharged before they came into hospital, one knew ten days before. Three patients were told two days before, three were told the previous day. Eleven patients had been told on the day of their discharge. One patient who had been in hospital for two days was told they were being discharged twenty minutes earlier.



Were patients and their families involved in the discharge process?

Only one patient said that neither they nor their family had been involved in discharge planning. All the rest of the patients said that they and their families had been involved as appropriate.

Would people need help after they were discharged?

Ten patients said they would need help after they were discharged. Four of these people said they would be getting help from family members.

Were patients happy to go home in the clothes they were wearing?

All the patients we spoke to were happy to go home in what they were wearing, including the three patients in their nightwear.

What did patients think could be improved?

Three patients said that said getting their medication from the pharmacy more quickly would improve their experience. One patient said that they would have preferred to have a shower, and have more time to talk about their condition and medication. This patient was in the discharge lounge at 10.50am, and had only been told they were to be discharged that morning.

How did people feel about the discharge process two weeks later?

Two weeks after their discharge we were able to ask eight people how they felt about the discharge process. All eight people felt they had been discharged at the right time. No one identified any problems or suggested anything about the discharge process that they would change.

4) Findings from workshops following our Annual Meeting in July 2014

The notes from the workshops are in included in Appendices 6 and 7.

Feedback about discharge from health and social care settings revealed the following themes:

- Good communication between the patient, family, carers and all organisations is essential
- It is important to have the right care package in place at discharge with all relevant people being made aware of a patient's discharge. It is important that services are joined up.

Feedback about discharge from hospital consultants to GPs revealed two main themes:

- Poor communication - many people didn't know the change was happening. They were discharged from their consultant but they didn't know why, and didn't know how to get back into the system. The MS Society reported that patients had been informed by letter (which was described as 'blunt') or at the clinic and there was poor or no communication from the hospital.
- Concerns about GPs capacity to manage the extra workload and whether any extra resources, such specialist nurses, would be available.

5) Findings about discharge from hospital consultant to GP from people with long term conditions

Patients with Rheumatoid Arthritis were identified as a specific group who have issues with discharge from hospital consultants to GPs. Feedback from York Rheumatoid Arthritis Support group (YORKRA) and issues raised by other support groups and individuals is included in Appendix 8.

YORKRA expressed concerns around service users not being involved in discussions of transfer of care to GPs. There was also a feeling that the appointment system, where people are sometimes unable to change their appointment, but penalised if they miss two by being discharged, was unfair. It was also felt that GPs were not confident in dealing with the condition, but were often unable to contact specialists and unresponsive to patient's comments on treatment.

Feedback from other support groups and individuals included:

- Two patients with Myasthenia Gravis reported they were told by consultants at York Hospital that their discharge back to GPs was necessary to save money. Though their conditions were stable they were unhappy because it takes two weeks for them to get a GP appointment

and the patients feel that GPs do not know enough about Myasthenia Gravis, which is a rare condition.

- One patient reported that their consultant made it clear they were not happy discharging Myasthenia Gravis patients back to their GPs.
- An MS patient who was discharged by an MS nurse found that their condition deteriorated with no medication available from GP.
- Patients are being discharged from the Headache Clinic at York Hospital without consultation with the patient or their GP.
- One diabetes consultant told a patient that he had to remove 30% of his patient list by referring them back to GPs.
- A woman who saw a consultant at York Hospital over a wrist injury was told she could not be put on the waiting list for after care as they were not allowed to add anyone else to the list so she would be referred back to her GP.

Summary of findings

1) Communication between hospital staff and patients, families and carers about when they will be discharged is not always good.

People have a sense of their discharge being ‘sprung on them’ at the last minute. Only five of the 23 respondents interviewed during the Enter and View visit in the discharge lounge of York Hospital had been notified of their discharge more than 24 hours previously. As well as the distress this can potentially cause to the patient it can also have an impact on their family and carers who may struggle to make arrangements at short notice.

One woman described how she made the three bus journeys to meet her husband in hospital only to be told he would be not discharged. She set off for home, but shortly after arriving home she was notified that he would be discharged after all. This resulted in her making the journey again by public transport. On arrival she was told that patient transport could not take her home as well as her husband.

2) There is not enough affordable and safe transport to take patients home

There is a high level of reliance on family and friends to provide transport home. Thirteen of the 23 patients interviewed during the Enter and View visit said that family or friends were taking them home.
Two patients said they were using public transport and three were using taxis, neither of which provide any level of care for patients who are potentially vulnerable, particularly at night. Only five of the 23 patients were using patient transport.

> “York Hospital booked a taxi for me at 2am. I was dropped off at home and left on my own in a dark hallway feeling physically and mentally uneasy.”

Patients who had used the Age UK York escorted transport service were very strongly positive of it. Of 31 respondents 97% had no complaints and 100% would recommend the service to a friend.

3) The care and support people need after discharge is not always in place

There was a common perception that the current follow-up care provision is not sufficient.

- One woman was told someone would be at her home to meet her after leaving the stroke ward, however no one came until the next afternoon leaving her alone in the house with no food.

- One person suggested that a follow up GP appointment should be automatic whilst another commented a ‘follow-up at home would have been great.’
- One woman reported having received only 2 minutes instruction on her 88 year old husband’s catheter bag, and not receiving a visit from a district nurse for 3 days.
- A new mother said that she and her baby went without checks for 3 days because the midwife had not been notified of their discharge.

4) Some people have experienced problems with discharge from mental health services

There seems to be confusion as to whose remit a person comes under if they have multiple conditions. One woman reported that she had been ‘bounced’ between the Community Mental Health Team, a pain clinic and a GP. She felt that none of them provided the care she needed.

There was also a report of ‘waiting list management’, where a woman was encouraged to take a course not directly applicable to her, before being subsequently discharged against her will.

We received feedback that psychiatrists provided through Community Mental Health Teams and Crisis Teams are perceived to not listen well to patients and overrule their wishes, compounding feelings of despair in patients. There also seems to be a lack of personalised care. A young carer with mental health issues was discharged from Limetrees when he re-arranged appointments because of his caring responsibilities.

5) Being discharged from hospital consultants to GPs has caused concern and anxiety.

For a number of people, particularly with long term conditions such as Rheumatoid Arthritis, Multiple Sclerosis and Myasthenia Gravis, being discharged back to their GP has caused concern and anxiety. Communication seems to have been patchy and patients have received mixed messages. Since this feedback was gathered, Healthwatch York understands that the policy has been reviewed for a number of groups of patients.

NHS Vale of York Clinical Commissioning Group has provided assurance that such patients should have access to support and encourages anyone with concerns either to get in touch with them directly or through Healthwatch York.

Recommendations

Healthwatch York has made four recommendations to York Hospital in our report on the Enter and View visit to the Discharge Lounge.

1) Consider ways in which reliance on family and friends for transport home can be reduced. For example working in partnership with voluntary organisations such as Age UK York and York Wheels to make sure patients have access to affordable and safe transport home.
2) Patients should be given at least 24 hours' notice of their discharge time, and this time should be kept to as closely as possible.
3) Consider whether patients who are ready to be discharged could be 'fast tracked' so that they receive their medication from the pharmacy as quickly as possible.
4) Review the frequency with which the IT system is updated with the expected date of discharge for patients. This would help the facilitating rapid elderly discharge (FREDA) team correctly identify patients who were ready for discharge and not spend time with patients who were not actually ready to go home.

As a result of the Enter and View report York Teaching Hospital NHS Foundation Trust has produced an action plan. Key points of the plan include finding out about patient's preferences for transport home and reviewing key communication messages between staff and patients prior to discharge.

From the feedback we have received from other sources we make the following additional recommendations:

Recommendation	Recommended to
5) Consider giving patients the option to request that a family member/carer be notified of their discharge time at the same time as the patient themselves.	York Hospital
6) Consider how to improve the consistency of approach to conversations between hospital staff and patients about what follow up care they will be receiving and the organisations they are signposted to.	York Hospital
7) In order to increase awareness and understanding of patients' pre-existing	York Hospital

conditions, consider the use of health ‘passports’ which can be referred to at all stages of a patients’ hospital stay and discharge.	
8) Consider all the relevant feedback in this report when delivery of the new mental health contract begins in October 2015.	Tees, Esk and Wear Valley NHS Trust
9) Consider using patient participation groups at GP practices to gather feedback from patients who have been discharged back to their GP to make sure that the process is working effectively.	NHS Vale of York Clinical Commissioning Group, GP practices

Appendices

Appendix 1: Healthwatch York Enter and View report on Discharge from Hospital

Appendix 2: Enter and View visit questionnaire

Appendix 3: Healthwatch York Enter and View visit follow up questionnaire

Appendix 4: Discharge from hospital survey

Appendix 5: Discharge from health and social care settings. Issues raised with Healthwatch York during 2014

Appendix 6: Discharge from health and social care settings. Summary of information from workshops on 23rd July 2014

Appendix 7: Discharge from hospital consultant to GP. Summary of information from workshops on 23rd July 2014

Appendix 8: - Discharge from Hospital Consultant to GP. Feedback from York Rheumatoid Arthritis Support Group Meeting 10th May 2014 plus direct feedback received at Healthwatch York

References

[1] http://www.hscic.gov.uk/article/3674/41500-patients-admitted-to-hospital-every-day-in-England---up-nearly-13-per-cent-in-five-years Taken from HSCIC website 10.12.14

Appendix 1 - Enter and View report

York Teaching Hospital NHS Foundation Trust
York Hospital **24th October 2014**

What is Enter and View?

Enter and View is the opportunity for authorised representatives to visit publicly funded health and social care services to see and hear for themselves how services are provided.

Authorised representatives collect the views of people receiving services and observe service delivery. They can also talk to families and carers.

Healthwatch York authorised representatives are members of the public who have been recruited as volunteers and have received specific training. Training includes disability awareness, safeguarding (level 1 alerter) and Enter and View training (in line with Healthwatch England's recommendations).

Why did we carry out this visit?

Discharge from hospital was voted onto Healthwatch York's work plan by members of the public in our 2014 survey. Over 75% of people who responded to our survey felt that discharge from hospital should be on our work plan. Their concerns included:

- Planning for leaving hospital and getting home as soon as possible
- Involving patients and carers in planning discharge from hospital
- Planning care for when patients get home

We carried out this visit as part of our planned programme of work on this topic, in accordance with Healthwatch England guidelines. This Enter and View report will be included in our full work plan report on discharge from hospital, which will be published in spring 2015.

Disclaimer

This Enter and View report relates to the visit which took place on October 24th 2014. It is not representative of all users of the service, only those who were consulted at the time.

About York Hospital's discharge facilities

York Hospital's discharge lounge aims to provide patients who are fit for discharge with a safe, pleasant and comfortable environment. It's a place where they can wait for their transport home or relatives to collect them, freeing up space on the hospital wards. Whilst in the discharge lounge the

patient is under the care of a staff nurse/health care assistant at all times. Patients can be provided with food and refreshments and staff can help with transport issues. Patient transport staff always refer to the discharge lounge staff before taking a patient home – this makes sure that they are collecting the right patient, and that the patient has all the necessary medication and equipment they need.

The discharge lounge is located just off the main entrance to York Hospital, near the York Wheels office. There is a dedicated collection point outside the main entrance for safe and easy use by patient transport staff, taxi drivers and relatives.

York Hospital have a team dedicated to facilitating rapid elderly discharge (FREDA). Their focus is on getting people home at the right time. Healthcare assistants co-ordinate activities to help speed up morning discharge – helping patients get washed dressed and packed up. They also support elderly patients who are not on the elderly care wards.

What was the purpose of this visit?

The purpose of this visit was to speak to patients, families/carers and staff to find out about peoples' experience of the discharge process.

Who carried out the visit?

The following Healthwatch York authorised representatives took part in the visit: Fiona Benson, Karen Hukins, Laura Branigan, Lesley Pratt, Polly Griffith, Sheila Jackson.

Two members of the Healthwatch York staff team took part in the visit: Siân Balsom (manager), Carol Pack (information officer).

What did we do?

This was an announced Enter and View visit and we liaised with Kay Gamble, York Teaching Hospital NHS Foundation Trust's Lead for Patient Experience. We were aware that nationally Friday is the busiest day for hospital discharges and chose Friday 24th October 2014 for the visit. We formally notified the hospital in writing three weeks prior to the date.

We arranged a rota so that a member of staff and 2 - 3 authorised visitors were in the discharge lounge at any one time. We attended from 8am until 5pm. We put together a questionnaire (see Appendix 2) and used this when we spoke to patients to record details of their experience of the discharge process.

All authorised representatives introduced themselves to patients, briefly explained the role of Healthwatch York and outlined the purpose of the visit. Reassurance was given that all information would be treated as confidential

and no one would be identified in any report. All the patients we approached agreed to speak to us. We spoke to 24 patients in total, 22 in the discharge lounge and two on elderly care wards. 1 patient did not want to complete the questionnaire but enjoyed a conversation with volunteers.

At the end of each conversation we asked whether people would be willing for us to contact them two weeks later, to find out how they were getting on. Fifteen patients gave us consent to do this. We were able to contact eight patients to ask them some further questions (see follow up questionnaire Appendix 3).

What did we find out?

Where patients were being discharged from

Three of the people we spoke to were day unit patients, two had been discharged from Ward 23, two from Ward 29. The others were all being discharged from different wards.

How long patients had been in hospital

Four patients had been in hospital just for the day. Of the others:

4 patients	1 night
2 patients	2 nights
2 patients	3 nights
2 patients	4 nights
1 patient	5 nights
3 patients	1 week
2 patients	10 nights
3 patients	2 weeks

Arriving at hospital

Thirteen patients had arrived at hospital by ambulance, seven had been referred by their GP, one had been admitted via A & E, one arrived by bus, one was unsure.

How people felt about their treatment on the wards

There were a lot of very positive comments about the care and treatment patients had received during their stay in hospital. Comments included ‘Very good’, ‘excellent’, ‘I was well looked after‘, ‘absolutely excellent’, ‘no one could have been more hard working and kind’, ‘fantastic’, ‘I was treated with kindness and humanity’, ‘perfect treatment’, ‘very good – all the staff are excellent’.

There were two positive comments about the food in hospital.

The only negative comments were: ‘terrible mattress’ (ward 25), ‘very noisy at night’ (ward 22), ‘not enough information is given by doctors due to time restrictions and the use of jargon in explanations’ (ward 22).

Additional health conditions

Thirteen patients had additional health conditions when they came into hospital. All these patients felt that their additional health conditions had been managed effectively.

Did patients feel ready to be discharged?

Twenty patients said they felt ready to be discharged. One said they ‘were a little bit anxious’, one felt they ‘could have done with a couple more days’ and one said they still felt a bit weak.

Did patients have everything they needed?

Nineteen patients said they had everything they needed. One was still waiting for their discharge letter, three were still waiting for their medication.

Where were patients being discharged to?

Eighteen patients were being discharged to their own homes, three were being discharged to care homes, one was being discharged to sheltered accommodation and one to St Helens rehabilitation hospital.

How were patients getting home?

Thirteen patients were being collected by family or friends, five were using the patient transport service, three were getting taxis, two were using public transport.

When did patients know they were being discharged?

Four patients had only been admitted for day care. Of the rest, one patient said they knew when they were going to be discharged before they came into hospital, one knew ten days before. Three patients were told two days before, three were told the previous day. Eleven patients had been told on the day of their discharge. One patient who had been in hospital for two days was told they were being discharged twenty minutes earlier.

Were patients and their families involved in the discharge process?

Only one patient said that neither they nor their family had been involved in discharge planning. All the rest of the patients said that they and their families had been involved as appropriate.

Would people need help after they were discharged?

Ten patients said they would need help after they were discharged. Four of these people said they would be getting help from family members.

Were patients happy to go home in the clothes they were wearing?

All the patients we spoke to were happy to go home in what they were wearing, including the three patients in their nightwear.

What did patients think could be improved?

Three patients said that said getting their medication from the pharmacy more quickly would improve their experience. One patient said that they would have preferred to have a shower, and have more time to talk about their condition and medication. This patient was in the discharge lounge at 10.50am, and had only been told they were to be discharged that morning.

How did people feel about the discharge process two weeks later?

Two weeks after their discharge we were able to ask eight people how they felt about the discharge process. All eight people felt they had been discharged at the right time. No one identified any problems or suggested anything about the discharge process that they would change.

Conclusion

We observed that the discharge lounge at York Hospital provides a comfortable environment for patients to wait for their transport home and works well. The location of the lounge is very convenient and the dedicated collection point makes it easy for patients to be picked up from the lounge.

Staff manage the discharge lounge well and this helps facilitate an organised and professional discharge process. We observed that discharge lounge nurses ask patient transport staff to always go to the nurses' desk first. This makes sure that the right patient gets the right transport. The nurses check that the patient has everything they need before they go. This service is particularly valuable for patients who are confused or who have dementia.

Discharge of elderly patients often requires additional planning and co-ordination. The FREDA team is key to supporting and facilitating the discharge of elderly patients as quickly and effectively as possible.

We observed that the FREDA team were not able to be as effective as they would wish because the IT system is frequently not up to date. Staff we spoke to reported that frequently patients who were recorded on the system as due for discharge that day were not actually ready for discharge.

56% of patients we spoke to were relying on family and friends for transport home. Many people do not qualify for patient transport, and public transport is often not suitable for people who have just left hospital. Taxis are expensive and there is no onus on drivers to make sure people get into their homes safely. Eleven of the patients we spoke to had only been told

they were being discharged on the day they were discharged. This does not give either patients or carers very much time to prepare for discharge.

Recommendations

- Consider ways in which reliance on family and friends for transport home can be reduced. For example working in partnership with voluntary organisations such as Age UK York and York Wheels to make sure patients have access to affordable and safe transport home.
- Patients should be given at least 24 hours' notice of their discharge time, and this time should be kept to as closely as possible.
- Consider whether patients who are ready to be discharged could be 'fast tracked' so that they receive their medication from the pharmacy as quickly as possible.
- Review the frequency with which the IT system is updated with the expected date of discharge for patients. This would help the FREDA team correctly identify patients who were ready for discharge and not spend time with patients who were not actually ready to go home.

Thank you!

Healthwatch York would like to thank all the York Hospital staff who were involved in our Enter and View visit, both in planning the visit and on the day. We would also like to thank all the patients who spoke to us and shared their experiences with us.

Response and actions from York Teaching Hospital NHS Foundation Trust

In response to our recommendations in our draft report York Teaching Hospital NHS Foundation Trust have produced a draft action plan (April 2015).

- We will consider further what patient preference is in relation to transport home by speaking further with patients prior to discharge as feedback from patients and their relatives has not highlighted this as a concern.
- When a patient is admitted a plan for discharge is usually commenced and discussion between staff and patient takes place around approximate discharge date. Review key communication messages between staff and patients prior to discharge.
- The expected date of discharge is reviewed at least daily by the ward clinical teams as part of each patient's review and board round. Any

updates to the discharge date or reason for delay to discharge is recorded and updated as appropriate.

Appendix 2 - Enter and View visit questionnaire

Name of interviewer:	Time of interview:
I'm a volunteer with Healthwatch York. We're a local charity that finds out what people think about health and social care in York. We are working with the hospital to find out more about people's experiences of leaving hospital. Would you mind answering a few questions? Any information you give us will be kept confidentially. No details about you will be given to anyone else without your permission.	
QUESTIONS	**OBSERVATIONS**
1 Where have you been discharged from? Name/number of Ward: Name of Department:	**Interviewed in:** Discharge lounge ☐ Specialist medicine ☐ Elderly wards ☐
2 What were you being treated for?	**This person is:** Patient ☐ Carer ☐
3 How long have you been in hospital?	
4 How did you arrive at hospital? Ambulance ☐ Referred by GP ☐ A & E ☐ 111 ☐ Don't know/not sure ☐	
5 When you were on the ward, what was your treatment like? Do you have any comments about it – positive or negative?	
6 When you came into hospital, as well as the reason you were admitted, did you have any additional health conditions? (e.g. diabetes, MS) Yes ☐ (please specify) No ☐ **If yes, were these managed effectively while you were in hospital? Yes/No**	
7 Do you feel ready to be discharged now? Yes/No **If no – why not?**	

8 Do you have everything you need with you? Your medicines ☐ Your clothes ☐ Your personal possessions e.g. glasses, walking stick, keys ☐ Is there anything you need that you haven't got with you? (please specify)	
9 Are you going to your home when you leave hospital? Yes/No **If no, where are you going?**	
10 How are you getting there? Patient transport ☐ Other (please specify) ☐ Family friends collecting ☐ Taxi ☐ Don't know ☐	
11 When did you find out you were being discharged? **11 (a) Who told you that you were being discharged?**	
12 Have you been involved in the plans for you to leave hospital? Yes/No **12 (a) Have members of your family been involved in the plans? Yes/No**	
13 Do you feel confident you can look after yourself when you get home or will you need support? I can look after myself ☐ I will need help ☐ **If you need help, do you know what support you will get after you leave? If so, please give details:**	
14 Are you comfortable going home dressed as you are? Yes/No	**What is the patient wearing?** Regular clothes ☐ Nightwear ☐

15 Do you have any suggestions to improve things for people when they are leaving hospital?	
16 We'd like to contact you in a couple of weeks to find out how you're getting on – would that be ok? Yes, by phone ☐ Yes, write to me ☐ Yes, e mail me ☐ No ☐ If yes: Name: ..... Address: ..... Phone: ..... E mail:	
17 Finally, it would help us if you could answer some questions about yourself, but you don't have to answer these questions if you'd rather not: First half of your postcode: ..... (not needed if we have their address above) Age: ..... Do you consider yourself to be a disabled person? Yes/No Do you consider yourself to have a mental health condition? Yes/No How would you describe your ethnic background? White British ☐ Asian ☐ Black ☐ Chinese ☐ Other (please specify): How would you describe your sexual orientation? Heterosexual ☐ Gay ☐ Other (please specify):	**What gender is the patient?** Male ☐ Female ☐
Thank you very much for taking the time to answer these questions. We'll be using the information to write a report to let the people who organise discharge from hospital know what is working well and what needs to improve. No personal details about you will be included in the report. Can I give you a leaflet which tells you a bit more about Healthwatch York and what we do?	

Appendix 3 - Healthwatch York Enter and View visit: Follow-up Questionnaire

Patient's name:

1. Now you are out of hospital:

Do you feel you left at the right time? Yes ☐ No ☐

Was any support put in place for you? Yes ☐ No ☐

If so, what worked well?

Were there any problems?

2. When we spoke to you in hospital, you were getting home by X

Did that work well? Yes ☐ No

Did you get settled alright? Yes ☐ No ☐

3. Have you been given any details about support groups, etc who might be able to offer you help and support in the future e.g. Yes ☐ No ☐
If no, is there any information you would like Healthwatch York to send you?

4. Thinking about the whole process of being discharged from hospital, what could have been done differently to make it better or easier? What changes would you make if you were in charge?

5. We produce a newsletter every quarter with lots of information about health and social care in York. Would you like to be added to our mailing list so you receive this? Yes ☐ No ☐

If yes would you like a paper copy Yes ☐ No ☐

Or for it to be sent by email Yes ☐ No ☐

If by email please print your address here:

Thank you for completing this questionnaire. Your name and contact details will not be used within our report on discharge from York Hospital and will remain entirely confidential to Healthwatch York.

Appendix 4 - Discharge from hospital survey

Have you been discharged (sent home) from a hospital or care facility within the past 18 months? How was it? Did you feel ready to be sent home? Did you get good follow-up care?

Healthwatch York wants to gather feedback from as many people as possible to understand what works and what doesn't in the current discharge process. By getting feedback on your experiences we can see what is working well and what needs to be improved.

Our survey is anonymous and we will not publish any information to identify you. The combined findings will be shared with people who buy and deliver health and social care services in York. Our report will also contribute to the first Healthwatch England Special Inquiry looking at discharge planning across England.

Take part in our survey

1. **Who are you answering this survey for?**

○ myself

○ on behalf of someone I care for

2. **If you are answering for someone else, who are you completing this survey on behalf of? It could be a friend, relative, or someone you care for**

3. **Have you been discharged within the last 18 months?**

○ Yes

○ No

4. **Where were you discharged from?**
Please include as much detail as possible - for example, Anywhere Hospital, Ward 101, Neurology Department

5. What were you being treated for?

6. How long were you admitted for?

7. Did you have any additional health conditions at the time in addition to the reasons you were admitted?

8. How happy were you with the way your discharge was handled?

- ○ very happy
- ○ happy
- ○ neither happy nor unhappy
- ○ unhappy
- ○ very unhappy

9. What did or didn't work for you?
How did staff treat you? Did you feel involved in the decision to be discharged? Were you offered ongoing support? Did you have a treatment plan? Do you think all your circumstances were taken into account in planning your discharge? Please tell us!

The Discharge Process

10. Did you feel that your discharge was at the right time for you? If not, what would have been better? What did you think the reasons for your discharge were? If yes, what helped you feel ready?

11. Where were you discharged to?

12. How happy were you with your support after discharge?

13. What did or didn't work for you in your follow-up support? Where did you go? Did you have to be readmitted within 28 days? Were you given the support and help you needed?

14. What do you think could be improved for someone in your position when they are being discharged?

Monitoring Questions

You do not need to answer the following questions, but it would be helpful to us if you do.

15. Please tell us the first half of your postcode

16. Age

○ 0-21 ○ 21-35 ○ 36-50 ○ 51-60 ○ 61-70

○ 71-80 ○ 80+

17. Do you consider yourself to be a disabled person?

18. Do you consider yourself to have a mental health condition?

19. How would you describe your gender?

20. How would you describe your ethnicity?

21. How would you describe your sexual orientation?

And finally

22. How did you hear about this inquiry?

23. Are you happy for us to use any of your comments within our report?

24. Would you like to be kept informed of Healthwatch York news and activities through our quarterly newsletter? If yes, please leave your preferred contact details - either an email or postal address

Appendix 5 - Discharge from health and social care settings

Issues raised direct with Healthwatch York April 2013 – June 2014

Timing / speed of discharge

- Mother in York Hospital being fed by gastro tube. Staff spoke to her about discharge arrangements while tube still in and no family members present. Daughter feels that this was inappropriate and discharge plans are being rushed for financial reasons.
- Discharge from York Hospital: hospital did not inform patient's daughter that she was being discharged, all felt very sudden when told to leave hospital. Everything else was brilliant but felt it all happened too quickly.
- Discharge from York Hospital; discharge was 'sprung on her at last minute', patient said no warning was given.
- Discharge from York Hospital; Not much warning when being discharged. Patient's wife is disabled and was distressed to be told very last minute without warning. Daughter advised, she arrived home from work luckily just as patient was dropped off.

Transport

- Patient at York Hospital ready for discharge back to care home at about midnight. Moved to lounge to wait (with wife) for patient transport back to care home. By 4.30am, no transport had arrived, no updates given. Eventually wife called son to provide a lift back to home.
- Patient felt the drop off service could have stayed a bit longer as they saw him into house but didn't hang around. Patient's wife is disabled and could have done with extra support from them to settle him in.
- Elderly patient had a bad experience with a taxi that was booked by York Hospital for 2am. Patient was then dropped off at home and left stood waiting on his own in a dark hallway. Felt the driver could have waited until the patient was let into his home as he was physically and mentally uneasy and it was the early hours of the morning.

Personalised, co-ordinated care

- Woman with Chronic Obstructive Pulmonary Diseases (COPD) and arthritis needed surgery. Number of issues including lack of communication between providers and to her (3 hospitals, 4 consultants). For example lack of understanding of pre-existing conditions, differing information on provision of follow up services. No bed on arrival at St James University Hospital, Leeds, for pre-booked surgery. Lack of personalised care to support the needs of a person

with arthritis. Lack of care post discharge, for example no district nurse visits arranged, dressings given were unsuitable so ended up buying her own as nurses would not listen.

Community Nursing and Social Care Support after discharge

- Man has been readmitted to hospital after being discharged without good information on how to take his medication - iron tablets and morphine. District nurse attended the home and stated she wasn't able to help him take it and turned her back whilst he dosed himself. Meant to be administered by syringe but he and his wife are both blind and cannot do this without some adjustments being made. So he said he would drink it. She turned her back whilst this happened. When readmitted, he was anaemic and had overdosed on morphine. Wife believes this was entirely avoidable if he had received proper information and support on discharge. Nobody has offered information in alternative formats. They are worn out by dealing with his illness and are struggling. They do have a son who does not have a visual impairment but he does not live with them and has not been engaged in any discussions about this. Wife refused to have him readmitted to ward 16 as it was dirty and he previously had bad experiences there.
- Man, aged 88, discharged from York hospital after 11 days stay. Wife (who is also in her 80s) wants to complain as he was discharged home with little warning and no care plan in place. She got two minutes instruction on sorting out his catheter. District nurses did not attend for the first three days, and at one stage left him with wrong catheter bag. Wife struggling with his care, he is now in nursing home (self-funding) but query if this should be classed as part of recovery following hospital stay and thus free.
- Man had been in hospital, unable to get out of the house on discharge but needed dressings changing. District nurses refused to visit his home as said he was not normally classed as housebound / disabled.
- Woman expressed concerned that her mother's carers were coming from Scarborough to York every day. She thought that was too far and costly for them to travel. They were not private carers, the hospital had organised it.
- Discharged from York Hospital after five days on acute stroke ward. Was told someone would be at her home to meet her and provide support. However was on own at home from 9am on day of discharge until following afternoon. No food in house and survived on coffee and water.

Involving carers in discharge planning

- Woman went to visit husband following operation. They live in Sherburn in Elmet. Took three buses to get to hospital. Was told he was not being discharged so went back using three buses. Then received call saying he was being discharged. So she returned, using three buses. They were then told patient transport could not take her home as well as him. Age UK York intervened and took them both home as part of the Tour De France extra service. She was also told she needed to arrange a community nurse visit for Monday. She knew she would not be back at home in time to call her GP, but she received no help at the hospital to do this. She used the mobile phone of an Age UK York worker to contact her GP practice in order to arrange the visit. She was told she would need to take her husband to the GP practice. She felt this was not possible given his operation, which was not keyhole. She refused, and eventually was able to arrange a home visit.
- Carer wanted to speak with a psychiatrist about the person they care for. They have been discharged, and now live in a care home, but needed to speak with someone as feels more support is needed. Community Psychiatric Nurse (CPN) completed the discharge so no route there. Wants to speak about GP so does not want to pursue that route.
- Elderly father discharged from Ward 35 on Friday 6th June. His daughter had told staff on the Wednesday that he had no medication at home. They were told on Thursday that he would be discharged on Friday - daughter travelled from Middlesbrough to take father home. They both had to wait on Ward 35 for 2.5 hours because his medication had not been sent from the pharmacy. When her father had been discharged from York Hospital on a previous occasion, although staff had let carers know he was going to be discharged, no one contacted his daughter. If daughter hadn't phoned the hospital and found out he was to be discharged, he would have had no way of getting into his home (he cannot use the key box).

Being discharged from mental health services

- Woman who has depression, self-harms and has an eating disorder, and also has a chronic pain condition. GP referred to Community Mental Health Team (CMHT) who bounced her back without seeing her as felt pain clinic more appropriate. Pain clinic felt they were not the most appropriate, so referred back to GP for referral to CMHT or eating disorder team. Now feels she cannot manage without support but has been told by GP they are not hopeful she will be seen due to waiting lists.

- Woman has been on waiting list for talking therapies for three years. Was offered a course on stress management, which she agreed to take up only on condition she wasn't removed from waiting list. Found course was not helpful. Also received letter after missing one session when unwell saying she would be discharged unless she phoned to explain - but pre course information said this would only happen if missed two. Received letter after the course saying she had been discharged. Queried this and was told that she should have completed a form at the training if she did not want to be discharged. Feels there is a clear element of waiting list management here.
- Patient in 40s, has worked all life and has full-time job although has been absent for some months recently. Has had mental health issues since childhood but this was not disclosed until went off work with severe depression and attempted suicide a couple of years ago. Saw a GP at that time which led to a CPN being allocated so thought support would be given to get her back to full health. Over the past two years has had significant difficulties with CPNs, GP, psychiatrist and social worker. Has refused to be sectioned but did spend some weeks in hospital in Sunderland (out of area care) where started to improve significantly. A bed became free in Bootham so was transferred there but the situation deteriorated rapidly; she states her “life was ruined after this”. Discharged back to the care of the original CPN she had difficulties with. Appears to have attempted suicide a number of times and is talking of it again. Job is being held open for but may be facing imminent dismissal although wants to keep job as enjoys it but needs help to get back to a level of health where can return to normality.
- Young carer with mental health issues had referral to Limetrees. Was taken off treatment due to rearranging appointments due to caring responsibilities. Both Limetrees and his school know that he is a young carer. He feels very frustrated as he now has to go back to his GP for a new referral. Not having anyone to listen to him, no emotional release is making things worse. Feels the system is not set up to support him.

Appendix 6 - Discharge from Health and Social Care Settings. Summary of information from workshop on 23rd July 2014

Table 1 feedback

No thought is given to carers. There is a duty of care to carers to provide them with training in manual handling techniques. Sixty clinicians responded to a survey run by the Carers Centre on this subject; very different responses were received from the different departments and clinics in relation to the amount of training given.

An elderly person attending hospital on a regular basis was ordered a taxi by the hospital on discharge but was left to manage on his own once he had returned home as his relatives were not informed of his discharge. A number of voluntary groups do provide transport from the hospital to home so patients do not have to rely on the ambulance service but the patients do need to know how to access these services.

An example was given of a patient being taken from the ward to the discharge room and just left there.

Discharge should be assessed and prepared for from a patient's first day in hospital so that everything is in place at the time of discharge. This process should include both the patient and the carers at home or elsewhere and also the situation at home if relevant. Patients have been known to arrive home and the paid carers have not been informed that the patient has been returned home.

Some patients, primarily elderly people, have been known to bend the truth and say they do not need help when they are returned home probably due to a sense of independence and pride.

The Human Rights Act states that everyone has a right to life, liberty and personal security so not assisting discharged patients who do need further care at home may violate this.

It is not known how social care and health care will be integrated efficiently.

People have, on occasions, remained in Archways Community Intermediate Care Inpatient Facility for six weeks i.e. longer than necessary, due to lack of care at home. Again due to a lack of care at home patients keep returning to hospital.

Liaison nurses on wards do now co-ordinate discharge from hospital and the return home to ensure appropriate care is in place.

Crossroads Care provide paid carer respite in a patient's home but as this has been limited to 20 minutes this service will end as it is considered the time is too short to provide an adequate level of care.

Improved backup is needed when patients leave hospital. Communication between the patient, family, carers and all organisations involved is necessary.

An assessment of needs should start from day one in hospital and should continue throughout the period of stay in hospital. This must include the patient, medical and nursing staff, family, carers and the requirement of any extended needs e.g. speech therapy, physiotherapy, occupational therapy, etc.

Question: Will the above be done in the future in all situations for all patients?

Table 2 feedback

An example was given related to a very good experience of endoscopy day care with the staff being clear and giving explanations at every stage of the process.

An example was given of being the last patient out of the day surgery unit at 6pm where the person felt everyone was cleaning up around them, etc. She did not feel that she was getting all the information needed and felt rushed although the staff were polite.

Pharmacy – a patient came out of hospital with a week's supply of medication. Is this normal? The GP was waiting for the discharge letter so does no know about the medication.

Joined up services are so important.

Question 1: Adult social care – how do individuals set up a personal package and do they understand them? Do people know about them?

Question 2: Who follows up when elderly people are discharged?

Question 3: What about weekend discharge and does it happen?

Table 3 feedback

One individual had a good experience of discharge from day care on two separate occasions.

Better planning and communication with a patient's relatives is needed.

Patients are sometimes waiting in hospital all day for medications from the pharmacy, sometimes into the evening when support networks are no longer available.

There needs to be much better planning in advance for discharge.

Having the right care packages in place at discharge with all relevant people being made aware of a patient's discharge are needed. Communication between different services needs to happen, ensuring all those who need to know actually do know.

It is down to the individual to ensure they get the appropriate follow-up and not everyone can do or deal with this.

The admissions process should gather all appropriate information e.g. next of kin as, if this is not done, then it will affect discharge. For pre-planned

admissions this should be done prior to the operation or treatment. This information must be correct at the beginning and be looking forwards to discharge on admission.

One size will not fit all as people have different needs on discharge.

A befriending service for those with no relatives would be beneficial as many people are very isolated.

When patients are discharged they should be given details of voluntary organisations and support groups that could help them.

People need advice on how to live with conditions whether they are long-term conditions or a temporary setback such as recovery from an operation.

Table 4 feedback

An example was given of discharge from A&E following a seizure with no advice given, no follow-up and nothing heard from the patient's GP who did not appear to know about the incident. No medication was given as the patient needed it in soluble form and it was only available as tablets. The patient was a wheelchair user and was not allowed into an ambulance so a carer had to drive him home. There is no confidence in communication between the hospital and GPs.

Prevention does not seem to be taken into account and also the difference in levels of knowledge and expertise between GPs and consultants. There also appears to be differences inexperience in different areas so the system is a postcode lottery.

There is a concern about information being lost.

Clarity is needed about who will be involved in a patient's discharge plan, how it will be carried out and who will do it. The patient should be looked at as a person not just a condition.

Having good access to and relationships with people who can put things in place e.g. someone to phone for information, would be useful so the patient feels they can contact this person and ask questions easily perhaps avoiding a future crisis.

Who is involved in this consultation; are CYC services included? CYC services and relevant voluntary organisations should be involved.

Information technology systems need to communicate with each other providing real time data that GPs can access immediately to see when discharge has been made.

Question1: With these changes there is an increased need for GP and community services but where is the funding coming from? Any savings within the hospital should be passed to the community particularly with discharge to social or rental housing.

Question 2: What measures are being taken to ensure VoYCCG savings from the hospital will be invested into community services? Presumably this cannot be done until the savings are realised.

Question 3: Can things continue to run whilst this change in budgets i.e. dual funding, takes place? Will savings actually be made?

Table 5 feedback

There is no consistency between the different York hospitals with, at present, different processes at the district hospital, Clifton and Nuffield e.g. there is no care assessment before discharge or no patient transport arrangements for follow-up.

There is no transport for a carer within patient transport.

Where a patient needs ongoing care and is self-funding, they have to sort out their own care and this can take time which delays discharge.

There is an issue with home care packages at discharge as they are not always available. People sometimes just go home without care in place as they are fed up with being in hospital.

There is a lack of transition places. Over the past year there has been a problem with the lack of step up and step down beds.

Some patients with mental health issues have to go out of the area due to the lack of beds locally which makes the discharge process more difficult.

The discharge process is not clearly explained and patients have a lack of knowledge.

The hospital has misassumptions regarding what services can be provided by, for example, sheltered housing and also about the willingness of family members to provide care.

There has to be an assumption that a patient has the mental capacity to deal with their discharge unless there are specific medical reasons otherwise. This can complicate discharge if a patient is desperate to leave hospital and says everything is alright at home.

An example of good feedback was given for York hospital where there is a practice of assessment for discharge e.g. nurses monitor how independent a patient is getting dressed, etc. Occupational Therapists are also god at making assessments. But again there is a lack of consistency as there is not the same standard of care at Clifton or Nuffield.

There is an issue where people have been supported by staffed services in the community and then this service comes to an end leading individuals to have to rely on the voluntary sector.

It is not always communicated exactly when a patient will be discharged in order to ensure that a carer or family member will be there to meet them.

There is a need for more statistics – how many people are waiting for discharge but cannot be discharged and what are the reasons. It is hard to know the scale of the problem.

Table 6 feedback

People have been seen in the discharge lounge wearing pyjamas – were they being discharged or just watching the television?

Prescriptions for long-term conditions should be free or cheaper.

One person had always received a quick follow-up after being discharged to the care of their GP.

Another person had received excellent care when discharged to the heart failure specialist nurses; they had carried out monitoring of the patient's condition and medication making adjustments to the latter as necessary, although this was only during practice hours. Experience of the specialist nurses for ovarian cancer was similarly good.

There is a dearth of community nursing with huge caseloads. There is a move from qualified nurses to carers. Also practice nurse roles are not being filled with community nurses, just assistants. Wages of care assistants are low which may lead to strike action. This would result in untrained and inexperienced volunteer provision of care i.e. a risk to safeguarding and effective continuous treatment. When relying on volunteer organisations it is important to ensure they provide feedback.

One patient, on discharge from hospital, had been told the district nurse could not visit him as he could walk to his surgery.

People living alone are facing isolation so more home visits would be appreciated. Support from local charities such as Age UK can help.

There is little or no provision for people suffering mental health problems, particularly those with borderline conditions.

Community nursing – there should be a system which allows feedback when services are not followed up.

Appendix 7 – Discharge from hospital consultant to GP. Summary of information from workshop on 23rd July 2014

At the beginning of the workshop session there was a short talk by Dr Alastair Turnbull, Medical Director for York Hospital on discharge from consultant to GP

The management of long term care patients is being moved from hospitals to the primary care services and this is a fundamental change. It is not known whether this is the right thing to do, the best model or is cost effective as there is no evidence as yet.

The disadvantages of this system are that GPs now have to see more patients than previously, requiring more clinics, including evening opening hours. The advantages are that GPs can now make consultants aware of any concerns they have regarding specific patients.

A set of conditions and associated complications will be identified that specialist consultants must see. There will be a register of chronic conditions which is very different to the situation of a year ago.

These changes will free up appointments in outpatient services although this net gain has not happened yet.

A large number of patients that were due to or were on the list to be seen by consultants have been reviewed i.e. do they need to be seen by a consultant and/or do they fit within the criteria of the register. All lists have been checked with GPs and, at the moment, all seem to be correct.

Those patients no longer seen regularly will now see a GP therefore this will increase GPs' work load substantially. Patients were informed either by letter or at their final appointment with their consultant.

The local NHS Trust is supportive of all these changes and is working closely with the Commissioners.

No patient will be discharged to a GP if the consultant thinks this would be unsafe. The safety of patients will be protected but this is not about patient choice.

Table discussions about discharge from consultants to GPs

Table 1 feedback

MS Society:

- Phone call from a female MS patient, in pain and in tears, as she can no longer see her consultant and has to see her GP
- One patient visiting the clinic once per week has now been discharged to his GP

There are too many referrals to consultants in York and this costs too much. Patients are informed by letter or at the clinic and there is poor or no communication from the hospital. Why not let the voluntary sector help in sending information out to patients? There is no consultation with patients or the relevant voluntary groups. Recommended working with other neurological groups in partnership to provide information to all people affected with neurological diseases.

It takes two weeks to get an appointment with a GP with a further two weeks for the GP to send a letter to the consultant and then it is two to three months before the patient can see the consultant.

Some patients do not need to see the consultant for six months for example, but do need a means of seeing appropriate specialists when necessary.

All of this is putting a strain on GPs who are not specialists in neurological conditions and MS is a complex disease.

All of this is to do with finances.

MY Aware (Myasthenia Gravis):

Following lobbying by the chief executive of the organisation, the decision to refer patients to GPs has been overturned so patients are now seeing their consultants. This relates to approximately 80 individuals on the organisation database. There is an open door with their consultants for some patients.

Individual: A patient with four associated conditions is now being treated by her GP. Some expensive medications are required which the GP would not prescribe. The consultant said the patient must contact him if these medications were needed. The GP monitors what is needed and this is sent quarterly to the consultant and he then makes any decisions necessary.

Other feedback:

- It's difficult for GPs taking on this extra work without specialist knowledge
- When will there be enough evidence as to whether this system is working and cost effective
- Voluntary groups must work together to get information out to patients and collate the experiences of individuals and patients
- There have been too many referrals back to consultants in some cases which has led to this situation
- Budgets must be balanced; if the Commissioners don't provide funding then work will not be done

- There are problems with lack of transparency; again this is a lack of communication with voluntary groups
- This has not been discussed at the Vale of York Clinical Commissioning Group (VoYCCG) public meetings
- There are not enough medical and nursing staff in the community to deal with this extra work
- VoYCCG does not appreciate how much care is being done in the community by carers; there will be more stress put onto carers
- There is a lack of communication and consultation between VoYCCG, the hospital, voluntary groups and patients

Question 1: What are the VoYCCG going to do about this lack of communication and when will they listen to what patients and voluntary groups have to say?

Question 2: The MS Society York Branch would like to invite Sharron Hegarty (VoYCCG) to the MS cafe to talk to their members and all those affected by all these changes.

Table 2 feedback

It takes ten days for a GP to get a prescription from a consultant; the short prescription is not working. Consultants do not check for allergies to medications and no check for allergies given in hospital.

There is no tie-up between the GP and the consultant.

Do not do reviews of drugs at GPs. GPs are now overstretched leading to long waits for appointments. Once a patient is allocated to a consultant, GPs "back off". GPs are now their own bosses.

Question**:** How will GPs manage the extra load? How will they cope having to have more knowledge of different conditions?

Table 3 feedback

It is difficult to get GP appointments now and will they be for ten minutes or more?

One patient with diabetes did not receive a letter regarding their return to GP care.

Will practices identify the GP who is the expert in a particular field and will training be provided for them? Will patients be able to see the same GP?

Will GP practices be proactive and call patients in if they are on the list? How will patients know they are on the list?

Will there be an extension of the named GP principal i.e. for the elderly, to other areas?

At the time of booking an appointment the patient will have to say to the receptionist that they need an appointment with a particular GP.

Back Pain Clinic – there is a need for clarity for the rules; are they logical? Back pain is a chronic condition therefore will be referred to GPs. If the situation alters, how does a patient get back to see the consultant?

If a patient is referred back to a GP who then has to pay for further investigation? Will what happens be affected by cost?

What is to be done about priorities, set by NHS England, as public health is now with local authorities' control?

Table 4 feedback

York Rheumatoid Arthritis (RA) support group:

Members come with issues most of which are negative. In one week alone 60 people with RA or a related condition contacted RA Support even though they were not all members.

Some people keep consultant appointments for part of their care whilst other aspects of their care are done by their GP i.e. blood tests. This is disjointed and unsafe and another cutback in services. All patients had booklets for their blood results and this no longer happens. Many GPs did not fill in the booklets so patients were not getting their results, even when the results were abnormal, whilst other patients were told by their GPs that they do not need to know their results which is shocking. There is a need for consistency and guidelines.

GPs are being asked to be more than general practitioners. They are busy and if they cannot take on the extra work then it is not good enough to continue with this new scheme.

Annual reviews are not happening for RA.

Some people with MS have been discharged and they do not know why and do not know how to get back into the system.

There is a two week wait for non-urgent appointments with GPs.

Is any extra money being provided for primary care to cope with the extra patients?

Are there enough GPs being provided or any extra training for GPs?

GPs miss diagnoses of RA and there are concerns GPs will not pick up serious issues.

It is not a good use of consultant time to see a patient once per year; it should be about access when it is needed.

No shows for appointments needs to be addressed as there are very high non-attendance figures. How many appointments would be freed up is this was to be tackled?

Presentation and identification must be a priority as the costs are less to the NHS with early identification.

GPs have less specialist expertise compared to consultants. If GPs do not have the appropriate knowledge and expertise in long-term conditions in the first place how can they manage and support patients? They need increased training.

Patients must feel confident in the person managing their long term condition.

An example was given of a GP having to phone a rheumatology nurse specialist so would an answer be to have more specialist nurses?

MS patients:

- The way the letters were sent out was blunt
- It was not made clear how to opt back into the system
- The change was done too early, before GPs really knew what was happening

Improved communication is needed between patients and the health service and between all areas of the health service internally.

GPs need improved awareness, resources and better knowledge.

Question: Is any extra money being provided for primary care to cope with the extra patients?

Table 5 feedback

Most people did not realise this change has happened including someone whose wife may be affected – no information has been received by the patients and she has not been told she has been discharged to the care of her GP.

This change started one year ago so most people affected should have been informed but a few may still be outstanding.

Would people necessarily have understood the implications of the letter they received?

Physiotherapy now allows a maximum of six appointments then there is a need to re-refer a patient. This will not change but if a patient is discharged from a specialist clinic then access to an associated clinic e.g. the dietician, also ends. If a patient with a range of conditions and attending a number of clinics is in doubt, they should contact their consultants as each consultant will make an individual decision based on their specialist knowledge.

It is not certain if this affects paediatric clinics.

GPs may know very little about specific conditions.

Question 1: Is information on the discharge changes available on the Vale of York Clinical Commissioning Group (VoYCCG) and York Hospital websites plus an explanation as to why these changes have been made?

Question 2: Is information on what patients should do if they are unsure about or they disagree with a decision also available?

Question 3: Do GP practices have easily accessible records of which consultant lists patients are still on or where patients have been discharged to?

Question 4: What follow-up will be ongoing and how can patients access it?

Table 6 feedback

Person with diabetes has an “amazing” named nurse who always replies to phone calls and knows where to refer the patient to if there are any issues.

Another person with diabetes initially had some concerns but has since had no problems and has been able to get appointments as needed.

A third person was unclear as to whether she had been discharged from her consultant. She still attends hospital for blood tests but has not been told if going to the GP instead is an option.

One issue raised was that a GP does not have a diary system for booking appointments regularly e.g. at three monthly intervals. If a patient misses an appointment no one rings to check why the appointment has been missed so if a patient does not remember after a specified time to ring and book an appointment there is no safety mechanism.

If a letter is sent from the hospital to a GP, the GP does not always read it.

There is an issue as to whether GPs have enough knowledge to monitor complex conditions; they may not have enough experience to pick up on key signs of deterioration or change in a patient’s condition. Reassurance is required.

The changes will not work if the local GP is a single-handed practice of if a GP with the required specialism is not available.

There needs to be a link between the hospital and GPs to be able to tell a patient at discharge who their named GP will be at their practice and who has the correct specialism.

Positive aspects are that if the discharge can be done safely and competently, it is much easier for people to get to their GP’s or for potential home visits.

It is not possible to book ahead for GP appointments more than two weeks. There is already an issue with getting an appointment with a GP for “normal” appointments; sometimes it is only possible on the day of phoning.

There is a need to change how GPs book appointments, moving to a proactive approach from the GP for booking follow-up appointments.

At discharge there is a clear need for information as to whose care the patient will be under i.e. a named GP who has an appropriate specialism and how this will be followed up.

Encourage the provision of patient reference groups within GP practices to encourage dialogue.

We are losing small groups in rural areas as VoYCCG only wants to engage with larger groups so smaller groups are disbanding as they do not have the resources to join with others.

Question 1: Is anyone checking that GPs can handle this extra workload and are there extra resources for GPs?

Question 2: Worries that diabetes and asthma are quite common with very good treatment at GP practices but what about specialist nurses for neurological and other chronic conditions?

Question 3: Do GPs read letters sent from the hospital? They are usually just attached to patients' records.

Table 7 feedback

Rheumatoid Arthritis clinic – a patient was initially told he would see the consultant in three months; a letter was then received to say the patient would be contacted six weeks prior to the appointment and the appointment ended up being in six months.

In some aspects these changes will be useful as there are finite resources. Outpatients often do not turn up therefore it might be more manageable at GP practices as text reminders can be used.

GPs can still refer patients back to consultants if necessary.

GPs do not have specialist knowledge.

GPs do not always have continuity that the specialists have, patients often seeing different GPs.

There is concern over problems such as headaches, etc being discharged without full diagnosis and treatment.

One person had diabetes and had never had treatment at the hospital; the GP service has been adequate.

Following discharge, a patient still had his consultant's contact details and has been able to call him.

A GP has been consulting on an alternative treatment route (elective) and this has been useful.

Rheumatoid arthritis nursing team has no cover due to illness.

It is difficult to get advance appointments, e.g. six weeks ahead, with GPs relating to RA condition and this can cause problems scheduling care. If a patient is told to come back in a month, they need to remember in two weeks to contact the GP to book the appointment.

Transport can be a problem for single individuals trying to get to GP appointments.

It is usually possible to get GP appointments at the end of the surgery for acute problems.

GPs can phone the hospital for test results.

It is easy to consult GPs on changes in physiology rather than direction of condition.

The changes in discharge all sound good but there must be a mechanism for reporting and reviewing it if it appears to not be working correctly.

Much depends on GP practice staff; receptionists can act as “gatekeepers” and it can be difficult to get past them.

Elderly people being discharged from hospital may be frightened to be left at home alone. AGE UK can help with this via their volunteers.

Patients should not be discharged at 1am.

Practice nurses can often be the best people to see.

Discharge to the care of a GP can be a good experience as the GP will probably be known, it is more personal and local whereas treatment at the hospital can be faceless.

Once a GP is familiar with a patient’s case the situation can be good but convincing a new GP of a condition can be difficult. The patient has to get past the GP and misdiagnosis does happen. A patient diagnosed in India with an urgent gall bladder condition took three months to receive any treatment via their GP when they returned to the UK.

People receiving bad treatment at the hospital can be unwilling to complain.

It is most important to have continuity of treatment and provider, particularly.

The movement of patients “off” the consultant’s list onto a GP list – is this a possibility for Mental Health issues? I think this will be more difficult but may be necessary to move the consultant costs.

Appendix 8 - Discharge from Hospital Consultant to GP

Feedback from York Rheumatoid Arthritis Support Group Meeting 10th May 2014 plus direct feedback received at Healthwatch York

- If you cancel two appointments with a consultant you are referred back to the GP. This is very distressing – have to change appointments for work, told if you do it again you will be discharged. Sounds punitive. Fails to allow for the reality of our lives
- Appointment system – hospital should send text reminders to get on top of Did Not Attends. The system currently is penalising people who are not abusing the system by not letting people change
- GPs are not confident dealing with rheumatoid arthritis. They are not able to get hold of consultants or their secretaries. They know they are out of their depth but can't get any support
- People with rheumatoid arthritis become experts in their condition, but with some GPs it goes in one ear and out the other. They just don't understand
- GPs don't understand the safety issues. They don't interpret the blood tests right. But there are times when you need to change all medication immediately if you understand what you are looking for
- Training for GPs – they only get 40 minutes on Muscular Skeletal (MSK) issues, mainly on back pain. They can't be expected to know everything about rheumatoid arthritis
- Removal of blood monitoring books. This has been stopped due to funding issues at York Teaching Hospital. Now getting more regular tests because Leeds and York hospitals don't share results but under Leeds for some things and York for others. Lots of calls to York rheumatoid arthritis support group because of this issue. These books provide an extra safety net for people on a complicated mix of drugs
- Group believes that everyone wants them (blood books) back. They are now at GPs discretion – many GPs are saying "you don't need to know your results" but it is important for people with rheumatoid arthritis as they often know more about interpreting the results than their GP does. Goes against the principle of empowering patients to self-care. There has been an article from the National Rheumatoid Arthritis Society on this, advising those in Trusts without blood books to press for them
- It also ties up GP time – have to get an appointment to discuss the results, if they are willing to share them
- Blood books are useful guides to compare how you are doing and a helpful reminder of when blood tests are due. Can also take them to places such as the dentists

- Blood books are something that works well, so why stop it? Patients have offered solutions, such as they would pay per year to keep them up to date, but these solutions have not been adopted
- Always had a very good service from the urgent referrals eye clinic. The hard bit is getting the referral needed from your GP
- Changes in provision of Methotrexate. Previously this patient had to contact YH one month before her three month prescription ran out to request a repeat, which was completed by a rheumatologist. Has been informed she can no longer get this from the hospital and her GP would now issue it. Concerns are: a) Patients and RA Support Group were not consulted. b) She received no individual warning of the change. c) She has been left without medication as she still has to give GP one month's notice and it takes two weeks to get an appointment with GP. d) She does not believe GP has been made aware of this change. e) May not be able to get drug on repeat prescription as it is cytotoxic, meaning having to arrange further appointments around work commitments. f) Would have to have duplicate blood tests as GP and York Hospital do not share details and other medication requires her to still visit rheumatologist. g) Concerned about new users in terms of training for self-inject of drug, will GPs take over administration?
- Transfer of rheumatological care to GPs. One GP practice is now saying that a patient has to attend their practice specialist arthritis clinic despite this person having to see their rheumatologist every three months. Only the rheumatologist can provide biologic drugs and the hospital perform all necessary checks, monitoring and care. Concern over unnecessary attendance of another clinic. Wider concern about service users not being involved in discussions of transfer of care to GPs. Concern over whether all GPs will be providing specialist clinics or whether a two tier system will result in some Rheumatoid Arthritis patients receiving enhanced care from GPs and others not.
- Patient was informed she can only change appointments twice and then will be discharged. Concern is that if she changes an appointment with a different department within the trust this would be included in this total. She has regular appointments in different departments. Though she changes appointments when received / with reasonable notice, the system does not take into account patient circumstances such as work commitments, dependency on an assistant, illness and family circumstances. She receives new biologics medication that can only be prescribed by consulting rheumatologist so discharge would result in her being taken off essential medication.

Feedback received at Healthwatch York January to June 2014

Feedback reported to Healthwatch York through Myasthenia Gravis Support Group York

- Two people with Myasthenia Gravis have been told by consultants at York Hospital that they have been discharged back to GP. They were told this is necessary to save money and they don't need to return to hospital as their condition is stable. They are worried as have to wait two weeks for a GP appointment and feel GPs don't know enough about their condition.
- A Myasthenia Gravis patient was discharged from York Hospital care after being treated for past two years. If any problems occur the patient must now consult their GP. This also appears to be the case with other Myasthenia Gravis patients.
- A Myasthenia Gravis patient was told by his consultant that he is not happy discharging Myasthenia Gravis patients back to their GPs and has not discharged any of his patients. He told the patient it was just a money saving exercise.

Issues raised by people with neurological conditions

- Patient with severe Multiple Sclerosis (MS) to lower body, wears body jacket to keep spine straight, has had neurological physiotherapy for a long time but has now been discharged into the community and has to see GP to start process over again so is very upset.
- MS patient discharged by MS Nurse in July 2013; condition is now deteriorating with no medication available. Saw their GP in October 2013 and had an appointment with Neurologist in January.
- For people moving from Disability Living Allowance (DLA) to Personal Independence Payment (PIP), will there be any negative consequences for having been discharged from the care of a neurological consultant back to a GP?

Concerns from Headache Clinic Patients

- Patients at the headache clinic at York Hospital with chronic migraine are being discharged without any consultation with patient or their GP.
- A Headache Clinic Patient wishes to ensure York Hospital is aware of the impact of changes on migraine sufferers and is very anxious about the future of the service. They are particularly aware that GPs don't have the insight that specialist consultants are able to provide.
- Changes to the headache clinic at York Hospital are 'a matter of acute concern' to patient. Specialist advice from a consultant is not available elsewhere in region. Changes will place greater burden on GPs and

neurologists who do not have time or specialist knowledge to treat headache disorders.

Other concerns raised

- A patient with diabetes is worried about the approach being taken regarding diabetes care at York Hospital. A diabetes consultant at the hospital has said they have to remove approximately 30% of patients from his list by referring them back to GPs. This patient is very concerned as GPs are already overstretched, and they have to wait several weeks to get an appointment to see the doctor.
- A woman saw consultant at York Hospital about a wrist injury. She was told she could not be put on waiting list for after care as they can no longer add people to the list, but she would have to be referred back to GP. Neither consultant nor patient were happy with this situation.
- Received letter informing them that due to long standing financial problems NHS Vale of York Clinical Commissioning Group (CCG) has told the hospital to stop a significant proportion of follow up outpatient care that it currently provides. Felt letter didn't give a very good explanation of why they were someone who could be discharged back to the GP, or what had been put in place to help GPs deal with these extra cases.
- A patient has had six monthly hearing checks at York Hospital. They have now been told that these are not being done routinely anymore. If they need a check in future they will have to ask GP for a referral.

Contact us:

Post:	Freepost RTEG-BLES-RRYJ Healthwatch York 15 Priory Street York YO1 6ET
Phone:	01904 621133
Mobile:	07779 597361 – use this if you would like to leave us a text or voicemail message
E mail:	healthwatch@yorkcvs.org.uk
Twitter:	@healthwatchyork
Facebook:	Like us on Facebook
Web:	www.healthwatchyork.co.uk

York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York.
York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

This report is available to download from the Healthwatch York website: www.healthwatchyork.co.uk

Paper copies are available from the Healthwatch York office

If you would like this report in any other format, please contact the Healthwatch York office