

# People's experiences of hospital discharge



May 2018

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## Purpose of the evaluation and objectives

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Healthwatch Wakefield were commissioned to evaluate people's experiences of discharge from hospital into the care of services operating from the Connecting Care hubs in the community.

In particular we were asked to evaluate new initiatives such as Discharge to Assess<sup>1</sup>, early discharge to the care of the Adult Community Nursing Team and the Trusted Assessor initiative<sup>2</sup>.

The objectives of the evaluation were to understand from a patient perspective:

1. How well services are integrated to support hospital discharge;
2. Experience of discharge from hospital back into the community including any unintended consequences of early discharge initiatives;
3. What works well and not so well around discharge from hospital.

## Methodology

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Interviews were conducted by Healthwatch Wakefield staff with people who had recently been discharged from hospital. The approach was through mixed method interviews, combining a small number of consistent questions including the IntegRATE measure\*, with a semi-structured element to explore wider issues related to the discharge experience. These interviews were conducted in people's own homes, sometimes with another family member or carer present.

Sampling was purposive, with referrals being received through the Hospital to Home transport service delivered locally by Age UK Wakefield District.

\*IntegRATE is a new patient reported measure of integration in health care delivery, developed through iterative rounds of cognitive interviews with end users. IntegRATE comprises four items which map onto the unique domains of *information sharing, consistent advice, mutual respect and role clarity*, assessing aspects of health care delivery that are both meaningful to patients and readily modifiable. The instrument is brief and can be completed in less than one minute, maximising its suitability for use in routine performance monitoring in health care, as well as in research. The instrument is also sufficiently generic to allow completion by any individual who has recently interacted with two or more people while receiving care for a health issue, whether those people are members of an identified health care team within a single setting or members of a multi-site network of providers.<sup>3</sup>

The four IntegRATE questions are:

- How often did you have to explain something because people did not share information with each other?
- How often were you confused because people gave you conflicting information or advice?
- How often did you feel uncomfortable because people did not get along with each other?
- How often were you unclear whose job it was to deal with a specific question or concern?

Data was analysed using SmartSurvey software and nVivo qualitative analysis software.

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<sup>1</sup> <https://www.nhs.uk/NHSEngland/keogh-review/Documents/quick-guides/Quick-Guide-discharge-to-access.pdf>

<sup>2</sup> <https://www.england.nhs.uk/urgent-emergency-care/hospital-to-home/improving-hospital-discharge/trusted-assessor/>

<sup>3</sup> <https://www.ijic.org/articles/10.5334/ijic.1597/>

## Limitations

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As with similar evaluations of integrated care in Wakefield District, information governance – being able to share information – was the most significant limitation. It was not until near the end of the evaluation period that agreement was obtained to pass patient details to Healthwatch Wakefield in order to conduct interviews. Once this was achieved, it was then identified that the Connecting Care Patient Integrated Care records did not necessarily identify those patients that had recently been discharged from hospital. We received one referral through this process, and coincidentally had already interviewed this person.

The Discharge to Assess and Trusted Assessor initiatives took some time to be mobilised and we were unable to obtain any referrals through these teams.

In order to overcome these difficulties we took a pragmatic approach and requested referrals from the Hospital to Home transport service delivered by Age UK Wakefield District, who passed us information about people who had used their service. We spoke to sixteen people in total, some of whom had only experienced a straightforward normal discharge from hospital, rather than a discharge into ongoing community care or a discharge experience through a new initiative.

## Overall summary

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The integration of health and social care services to support discharge from hospital on the whole seems to work fairly well from the evidence of this sample.

The IntegRATE questions, measuring information sharing, consistent advice, mutual respect and role clarity, were mostly positive. This was reflected in other qualitative feedback around the overall experience of integration of care, with good examples being given of care packages being put in place and support being provided after discharge.

There were mixed experiences in relation to people's discharge from hospital, on the whole balanced fairly evenly between positive and negative.

Negative findings relate to delays in processes due to issues with staffing, medication and waiting for tests such as x-rays. Less positive experiences were also highlighted in relation to overall communication between different members of the healthcare team, the provision of medication on discharge and receipt of follow up appointments. Several respondents also highlighted that items of personal belongings had gone missing and not been found by the time that they were discharged.

Positive findings related to the compassion in the care that was received and the way people were treated by staff in general.

In addition, the availability and quality of support from the voluntary sector, in particular Age UK was consistently highlighted throughout the interviews.

## Detailed findings

We spoke to sixteen people, fifteen who had been discharged from Pinderfields Hospital and one from Wakefield Intermediate Care Unit (Queen Elizabeth House). They had all been discharged to their own homes, apart from one who had been discharged to a care home while a suitable care package was being arranged so he could be transferred back home. The people we interviewed had been discharged between August and December 2017.

### 1. How well services are integrated to support hospital discharge

The four IntegRATE questions are designed to establish how well services or healthcare professionals are working in a joined up way. Of the sixteen people interviewed, not everybody gave responses to the four questions, but overall the responses were positive.

Q.1 How often did you have to explain something because people did not share information with each other?				
			Response Percent	Response Total
1	Never		71.43%	10
2	A little		7.14%	1
3	A lot		21.43%	3

The majority of respondents had a positive experience. One respondent's family found that information about thickened fluids and walking aids were not transferred onto a written headboard when the patient was transferred between wards.

Q.2 How often were you confused because people gave you conflicting information or advice?				
			Response Percent	Response Total
1	Never		61.54%	8
2	A little		23.08%	3
3	A lot		15.38%	2

In answer to question two, feedback again was mostly positive. Where confusion had occurred this was sometimes felt to have been a result of the patient being in a confused state, rather than the information or advice given actually being conflicting. One respondent highlighted that they had had to make requests for the same information on several occasions:

“Well we had to chase up a few times but when we got the information it was concise.”

Q.3 How often did you feel uncomfortable because people did not get along with each other?				
			Response Percent	Response Total
1	Never		84.62%	11
2	A little		7.69%	1
3	A lot		7.69%	1

Most people who answered felt that this had not been a problem. One instance that was highlighted was not about staff, but more about the nurse and the patient not getting along:

“No, no they all seemed fine, I just had one nurse and she was a foreigner and when I first had the operation and I was getting into bed I could not lift this leg in and it was awful because I could just not lift it up at all, and I was supposed to do it myself, and I admit I was supposed to do it myself, and this nurse, I said ‘do you think you could just help me please?’ and she said ‘no, you have to do it yourself’ and she stood there and I just could not do it, so in the end I said to her get out of this room and don’t come back.”

Q.4 How often were you unclear whose job it was to deal with a specific question or concern?				
			Response Percent	Response Total
1	Never		60.00%	9
2	A little		33.33%	5
3	A lot		6.67%	1

For the final question responses were more mixed. Some respondents and their families highlighted that there had been long waits in getting concerns answered and that the workload of staff was a barrier to information being transferred between staff. There was one incident which is referred to elsewhere in the report (Home Care Packages) where not enough information was provided to a patient and their family about how to manage a catheter that had been inserted.

The interviews provided some good evidence of integrated working:

Interviewer: “Did you have any support when you came home?”

Interviewee: “The OT team came and assessed my home while I was in QE House and they organised a care plan before I was discharged. I was given aids, they were very good with me.”

Interviewer: “How did you get home?”

Interviewee: “Age UK brought me, they were fairly quick too.”

Interviewer: “That was good. So did you have a discharge letter and some medication when you were discharged?”

Interviewee: “Yes I had a discharge letter and medication.”

Interviewer: “So back to your discharge did somebody from the hospital contact your GP to let them know you had been into hospital?”

Interviewee: “Yeah I think they did because doctor rang me and know I had been in and when she rang me a few weeks ago over something and she knew I’d been in”.

However, there were some times when things did not work together so well for people, and communication was mentioned as a problem, with staff not necessarily being aware of decisions that had previously been made, both within the hospital itself and with other professionals from primary care and social care.

“One doctor did not know what the other was doing.”

“Me and my sister went to the hospital the first time she went in and I got a phone call off the social worker, ‘your mam can go home’, I said no she can’t she has got to have tests done, and they said ‘well I have asked and they have said she can have tests done while she is at home we

can send for her'; so, we went through, me and my sister, and we spoke to the doctor and he said 'oh no it is a misunderstanding, she is stopping in', so we went 'oh right', then me and my sister is on our way home and my uncle went to see her and they were getting her ready, they were sending her home."

"Communication was an issue, no one answered the phone and the ward and transport don't communicate. I do not know how long I am staying here. I am waiting for a care package and if I do not get discharged [soon] I will discharge myself. I don't like being in a care home with older people." (Patient discharged to a care home)

People described various levels of support that they had received in their own homes following their discharge. These included domiciliary care packages and various aids and adaptations for the home. The support of Age UK staff was highlighted in every interview and in some cases without this intervention people said they would not have been able to manage at home.

"I think that was Age UK that sorted that out. Yeah, and he said they will probably be more or less straight away, and I said 'yeah fine' so we went for that and they were here within about 10 minutes [...] and we had a few nurses coming round a few days after that."

"I am trying to get a walk in shower. [...] I think cos I told Age UK I'd feel better with one."

"Age UK are going to try and help us with moving as well, we need to get out of here. The chap said he will help us."

"The OT team came and assessed my home while I was in Queen Elizabeth House and they organised a care plan before I was discharged. I was given aids, they were very good with me."

One person mentioned having spoken to a social worker who had supported their discharge.

"They were going to put me on a ward but social care lady came and said they were willing to discharge me. [...] she said they were ready to discharge me but she needed some details to set things up and that I could only come home if I accepted what she was offering kind of thing. Carers twice a day for up to 10 days, it stopped after seven."

Different people highlighted that they had not been provided with enough information to manage their situation at home, or that services had been promised that had not materialised.

"The results of his urology investigation states he will continue to need the catheter. The district nurse has told him to 'do it' and he is not sure how long to do it, he thinks they should show you more and explain in more depth."

"I mean when he was in hospital they fitted him with a catheter and didn't tell us or show us how to work it, they just gave him bags and a leaflet. Well that's no good we didn't know what to do, we were just left. The nurse did not come out or anything. My daughter has to come over twice a week to do it, she doesn't mind but she works full time and doesn't drive."

Interviewer: "So you did not actually have physio but she just gave you a stick?"

Interviewee: "No and then she did say I will come one day and see how you can climb into the shower, she had a look at the shower and it's just step in she said she would come one day and see how I stepped in but she never did, did she?"

As well as providing transport and support for people once they arrived home, support from Age UK was also mentioned by several interviewees in relation to other issues, for example accessing more financial support.

“XXXX from Age UK sorted it out I think it was the end of September for the attendance allowance.”

## 2. Experience of discharge from hospital back into the community including any unintended consequences of early discharge initiatives

### Waiting to be discharged

Nearly half of the people interviewed felt that they did not have to wait at all to be discharged from hospital but others mentioned delays in leaving the hospital due to communication issues, waiting for medication, tests or doctor’s notes/signatures.

Did you feel you were discharged at the right time or did you have to wait?			Response Percent	Response Total
1	I had to wait too long		18.75%	3
2	I had to wait but not too long		31.25%	5
3	I did not have to wait at all		43.75%	7
4	Not sure or can't remember		6.25%	1

There was a mixture of experiences, some were positive:

“They discharged me at the right time.”

“I was ready to come home.”

“No, no the right time [for discharge] they had done everything they needed to, she had an x-ray, there was no reason to keep her in.”

Others were more negative:

“You are just sat there waiting for hours and hours and it has happened at least three times, we have waited all day thinking he was coming home and then then didn’t. One time one of the nurses said something about waiting for the doctor’s signature and the doctor hadn’t been and as my daughter was available she went and collected it eventually which I think was the next day.”

“They just kicked her out first time.”

“Basically the main thing is just waiting; the waiting is a problem which it is, isn’t it, in the NHS?”

“I had to wait but not too long, I think it was because it was a Monday. They told me I was discharged on Friday but I had to wait until after the weekend to go home.”

## Medication

Nearly all the people we spoke to had been prescribed medication as part of their discharge and people's experiences varied. Some felt that they had no problems with medication.

"Oh yes, I was given medication, and I had loads, in fact I have not taken any today, I have got loads."

"I have plenty, it's all here."

Some spoke of long waits for medication to be delivered from the hospital pharmacy.

"The pharmacy is too slow, I was waiting for my drugs for over two hours."

"Pharmacy wants a kick up the arse. They are always late, one day I waited all day till 8 pm for my prescription. They nearly cancelled my discharge and they had had 24 hours' notice."

A couple of people told us that they felt communication with the hospital about medication was not very satisfactory.

"When we went into the ward I had to tell them what medication she was on."

And another told us that their family member had not received his medication.

"He was discharged without [it]."

## Discharge Letters

People generally felt that discharge letters had been received as they should be.

"I think I did yes, I did."

"Yes love, and they sent a letter to my doctor."

"I think someone told my GP because when she rang me a few weeks ago over something she knew I'd been in."

## Follow up appointments

People generally remembered having follow up appointments, although this was not always a straightforward process and sometimes required chasing up or resulted in people not going to their follow up appointment due to delays.

"I think I did yes."

"Not straight away. It took the doctor to have to come back out again to refer back to the hospital because she was losing that much weight."

"I think I went to the hospital yes I went to the hospital for follow ups."

“Yes I go often, it’s not too bad usually in there.”

“I can’t believe it really because I was going in March I think and then it was changed to August so I can’t see the point in it really. I have said I will cancel it in August because it’s hard going to Pinderfields because even parking in the disabled if you can get in the disabled it’s a long way to walk.”

“Yes we got a follow up appointment I think it was for a fortnight and did they give us a letter at the time or was it a bit later on I think [...] he told us that he had made an appointment and we got a letter a few days later, that was it.”

### Support for family and friends

This was highlighted as an area where people felt things could be improved, with six people telling us their family and friends had not had enough or any support following their discharge from hospital.

Thinking about your family and friends who care for you, do you feel that they have had as much support as they need?				
			Response Percent	Response Total
1	Yes they have had as much support as they needed		6.67%	1
2	They have had some support but not as much as they needed		6.67%	1
3	No they have had little or no support		33.33%	5
4	They did not want/need support		6.67%	1
5	I am not sure		13.33%	2
6	Not applicable		33.33%	5

### Compassion in care

People mostly reported being treated with kindness and compassion:

Were you treated with kindness and compassion?				
			Response Percent	Response Total
1	Yes definitely		68.75%	11
2	Yes most of the time		25.00%	4
3	Not really		0.00%	0
4	No definitely not		0.00%	0
5	I am not sure/can’t remember		6.25%	1

Several participants noted instances where staff had gone over and above their role to help out and / or had shown compassion in the way they treated the participants.

“Oh definitely, if I wanted ice cream instead of what they were having they would go and get me some (laughs) and as you can I see I drink a lot a lot of tea and you know the little cups I used to say don’t bring me them little cups if you are gonna do fetch me half a dozen and they used to sneak me [some more].”

“...another time he left his glasses behind but they were very kind then and where I thought I was going to have to go through and fetch them they organised a young chap to bring them he brought them and he dropped them off for me and I thought that was really good so that is a bit of good with the bad and honestly the nurses were brilliantly honestly but they were run off their feet.”

A number of people commented that the staff who dealt with them in hospital were very busy but treated them very well.

“Sometimes I had trouble getting a message to the sister all the nurses are very busy, they are run off their feet.”

“...the nurses were brilliant honestly but they were run off their feet.”

“I think they [nursing staff] were jolly good. I was impressed with how I was treated.”

“Yes he was on ward 37 I think and his stay wasn’t too bad really, quite good I’d say, decent staff anyway.”

### **Lost property**

A few participants found that they lost personal belongings in the process of being in hospital.

“...and they also lost the top of his expensive razor I bought him that went missing...that was annoying...”

“One lady was discharged without some of her personal belongings which the family have tried to recover but without success, she has lost sentimental jewellery which was bought for her by her husband over 30 years ago and cannot be replaced.”

## Conclusion

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### 1. How well services are integrated to support hospital discharge

The overall findings in relation to the integration of support around discharge were positive, with only a few highlighted negative experiences. This indicates that generally the domains of *information sharing, consistent advice, mutual respect* and *role clarity* in relation to respondents' experiences were good. These findings are also supported by people's examples of integrated working which were generally positive. Having said this, there were instances where care was not integrated so well for individuals and when this happened it generated confusion and impacted upon the overall discharge experience.

Home care packages provided in the community were generally seen as good, although some people highlighted that they had not been provided with enough information to manage their situation at home, or that services had been promised that had not materialised.

Communication was highlighted as an issue, with staff not necessarily being aware of decisions that had previously been made, both within the hospital itself and with other professionals from primary care and social care.

### 2. Experience of discharge from hospital back into the community including any unintended consequences of early discharge initiatives

There was a mixture of experiences with some respondents experiencing delays in their discharge due to issues with staffing, medication and waiting for tests such as x-rays. Discharge letters and follow up appointments worked well for some and not for others. As previously stated, it was not possible to evaluate early discharge initiatives specifically.

### 3. What works well and not so well around discharge from hospital

Compassion in the care that was received and the way people were treated by staff came across as a very positive aspect of people's overall experiences. The availability and quality of support from the voluntary sector, in particular Age UK was consistently highlighted as a positive throughout the interviews. This support was focused around the provision of home care packages (including aids and adaptations, carers), financial support and transport home from hospital.

Less positive experiences were highlighted by interviewees in relation to overall communication between different members of the healthcare team, the provision of medication on discharge and receipt of follow up appointments. People reported that support for friends and family could be better. Several respondents also highlighted that items of personal belongings had gone missing and not been found by the time that they were discharged.

## Acknowledgements

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Healthwatch Wakefield would like to thank the patients and their families who participated in our interviews and provided valuable insight into their experiences during their stay and on discharge from hospital.

## Disclaimer

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Please note this report relates to discussions and observations made in specific interviews. It is not a representative portrayal of the experiences of patients and their families / carers, only an account of what was observed and contributed at the time.

## Appendix 1: Connecting Care Discharge Survey Questions

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1. Date survey conducted DD/MM/YYYY

2. Patient Number

3. Discharged from:

4. Discharged to:

5. Date and time of discharge

6. Did you get discharged at the right time or did you have to wait?

- I had to wait too long
- I had to wait but not too long
- I did not have to wait at all
- Not sure or can't remember

7. How often did you have to explain something because people did not share information with each other?

- Never
- A little
- A lot

8. How often were you confused because people gave you conflicting information or advice?

- Never
- A little
- A lot

9. How often did you feel uncomfortable because people did not get along with each other?

- Never
- A little
- A lot

10. How often were you unclear whose job it was to deal with a specific question or concern?

- Never
- A little
- A lot

11. Were you treated with kindness and compassion?

- Yes definitely
- Yes most of the time
- Not really

- No definitely not
- I am not sure/can't remember

12. Would you say you have as much social contact as you would like?

- Yes definitely
- I have some, its ok
- Not really
- No definitely not
- I am not sure

13. Would you say that you feel safe living at home?

- Yes definitely
- Yes to some extent
- Not really
- No definitely not, I would rather be loved after somewhere else
- I am not sure

14. Thinking about your family and friends who care for you, do you feel that they have had as much support as they need?

- Yes they have had as much support as they needed
- They have had some support but not as much as they needed
- No they have had little or no support
- They did not want/need support
- I am not sure
- Not applicable

15. Do you have any more comments about your discharge which could help us to improve them in the future?