People affected by dementia and carers' experience of hospital care in Sussex

Impact Awards 2024 WINNER healthwatch

Committed to quality

healthwatch Brighton and Hove

People affected by dementia and carers' experience of hospitals in Sussex – Summary

Introduction

To feed into the development of the NHS University Hospitals Sussex five-year Dementia and Delirium strategy, we were approached by the Head of Nursing for Dementia and Learning Disabilities (NHS University Hospitals Sussex) to gather people's views about their hospital experience.

This study explores people who are affected by dementia and/or their carers' experience of hospital attendance – either as an inpatient or an outpatient. Five carers of people affected by dementia gave valuable insights into their inpatient and outpatient care in the Royal Sussex County Hospital (RSCH) and the Princess Royal Hospital (PRH). The age of the people affected by dementia who spoke to us, ranged from 75 to 89, and the age of diagnosis ranged from 1 to 5 years prior to the conversation. Three of the five people affected by dementia were men.

Main findings

Overall, care received was considered good, as one person said, "7 out of 10".

Contrasting views:
Some made positive comments about the valuable time they spent with the consultant. However, others said that contact with the nurses was limited, and they rarely saw a doctor. There were also different views about whether sufficient adjustments had been made to the needs of people with dementia.

Positive comments:
A positive aspect of care was allowing the carer to accompany the service-user for procedures and to stay overnight if appropriate. A further common remark was having 'everyday' conversations with empathetic staff, just to acknowledge they were there and waiting. The food at the Royal Sussex was also complimented.

For those with a variety of outpatient appointments, the experience at the PRH was considered to be a better experience compared to the RSCH. Also, having experienced the Emergency Department at both the PRH and RSCH, PRH was found to be "calmer and less distressing".

Concerns:
In terms of concerns, there was insufficient reassurance as to why the service-user was in hospital, often without a careful explanation of what the care plan or procedure was. Some were not involved in the care decision.

Negative comments were made about the RSCH in that it was too cold and with a distressing atmosphere at times. The PRH was said to have had poor signage, particularly if the carer was not accompanying the person affected by dementia.

Being moved around the hospital was particularly distressing for those affected by dementia.

There was one notable incident of poor-quality care related to a radioactive scan (at the RSCH).

The long waits to be seen in the Emergency Department at the RSCH was also found to be difficult for patients affected with dementia. This was associated with confusion and agitated behaviour. Having a quiet, separate place to wait would have been preferable.

Suggestions for good practice

From a study involving five people it would be inappropriate to post a series of recommendations. However, four findings were consistently mentioned which may serve as examples of good practice:

- Having ‘everyday’, short, informal conversations between staff and carers/service-users appears to make a real difference to people’s experiences.

- The importance of carers accompanying the service-user at all possible opportunities including, for example, using the communication channel when being scanned to keep them calm.

- Avoid moving dementia patients to different places or wards as this can be confusing.

- Involve both carers and dementia patients in decisions about their care.

People affected by dementia and carers' experience of hospitals in Sussex– Main Report

1. Introduction and background

There are currently 944,000 people with dementia in the UK, more than ever before, and this number is projected to increase. More than one million people will have dementia by 2030, and this will increase to more than 1.6 million by 2050. The number of people with dementia is projected to increase rapidly over the next several decades, largely due to increases in life expectancy and population demographics. However, due to the gradual nature of dementia, the mild early-stage symptoms and the low diagnosis rate, it is difficult to know the exact number of people living with the condition.

In Sussex, there are a total number of 16,552 people living with a diagnosis of dementia (the 4th highest Integrated Care Board number in England). Although these have been formerly diagnosed, it is estimated that 27,028 people are living with dementia in Sussex, thus providing a diagnosis rate of 61.2%.

As a means to improve care and inform future commissioning, it is important to understand people's experiences of the various support services. In 2023, Healthwatch Brighton and Hove (HWBH) published a report exploring people's experiences of initial concerns over memory through to professional assessment (at Memory Assessment Services), diagnosis and post diagnosis support. We followed this up by with a short survey of people's experiences of Memory Assessment Services, at the time when some services were temporarily suspended in Sussex.

To extend this work, this report will feed into the development of the NHS University Hospitals Sussex five-year Dementia and Delirium strategy. This strategy incorporates wider stakeholder engagement including the contribution of this study into hospital experience.

This study explores people who are affected by dementia and/or their carers' experience of hospital attendance – either as an inpatient or an outpatient.

2. Methods

The names and contact details of people willing to participate in this study were provided from three support services in Sussex:

- Sage House (Chichester)
- Boundary Health Care
- Carers' Hub

A flyer (Appendix 1) was produced to generate people's interest in the study and provided details about who to contact to find out more about the study. The email address of the lead researcher was also provided. On this initial interest, prospective participants were sent a one-sided information sheet (Appendix 2) explaining the project purpose, what being involved would mean and how the findings would be used.

With the satisfactory agreement to have a phone of online conversation, a suitable time and date was agreed. At the start of the conversation, either the carer or person affected by dementia (or both) had to provide verbal consent to continue (Appendix 3). This included awareness of confidentiality, anonymity, safeguarding and consent for the conversation to be recorded. Participants were told that they could end the conversation at any time without giving an explanation.

The conversation was steered through a flexible and adaptable topic guide. This acted as an 'aide memoir' rather than a prescribed set of questions. The topic guide (Appendix 4) covered 6 main areas:

- Introduction, covering location, age of person affected by dementia, their dementia story since first suspecting memory issues and whether they were sharing experiences of as an inpatient or outpatient (and at which hospital).

- Hospital experience being 'dementia friendly' etc.

- Care and treatment received including respect and dignity, quality of care, compassion, patient centred, etc.

- Post care including clarity over hospital discharge, support for ongoing care, etc.

- Opportunities to provide feedback about the care received.

- Further comments about the key points about dementia care that the NHS should be aware of.

The notes from the conversations, supported by the recordings where possible, were entered into a Smart Survey document, at the individual level (i.e. one entry per participant). The results were analysed in a case study fashion, given that a total of five people shared their in-depth experiences.

3. Findings

A total of five conversations with carers (also with the person affected by dementia on one occasion) were held. They typically lasted between 45 minutes to 1 hour.

The age of the person affected by dementia ranged from 75 to 89, and the age of diagnosis ranged from 1 to 5 years prior to the conversation. Additional information about the sample is shown below:

Age at interview	Age at diagnosis	Gender	Ethnicity	Sexual orientation
75	74	Male	White-British	Heterosexual
89	84	Male	White-British	Heterosexual
87	82	Male	White-British	Heterosexual
75	70	Female	White-British	Heterosexual
84	81	Female	White-British	Heterosexual

Case study 1. Carer and male partner with dementia (aged 75, aged 74 at diagnosis) – East Sussex (not Brighton and Hove), White-British, heterosexual

This carer rated the inpatient care (five days in the Royal Sussex County Hospital/RSCH) her partner received as generally excellent, including positive interactions with the consultant and receptionist staff. Being able to accompany her partner during procedures was an important part of the care. There were some concerns raised over needing more interaction with staff and assurances about what was being planned as they were waiting. The overall environment was found to be cold, distressing and with poor signage.

The carer summed up her experience as *"7 out of 10"* with some mixed comments. The **care was generally considered as excellent** and some staff made light of the various tests and procedures which made both people feel relaxed. The receptionist in the department also took the initiative to talk to them both when they were waiting, especially as the service-user was not keen to stay overnight.

“The receptionist was, was there the whole time and she was perfectly pleasant. And very shortly after she stepped in and was very nice to him, which was good.”

During a lumbar puncture, the process went well with the carer **allowed to accompany the service-user**, and supported by the relaxed atmosphere of the staff:

“I think it was quite good [the carer accompanied the service-user for a procedure] because [the service-user] is looking at me, you know, so he, he, you know, I was able to defuse. So I think that was a good touch that they did that.”

“It was very difficult to get him into the room with a lumber punch. He did not want to go. He relented but you know, accused me of tricking him all the rest of it. Yeah. And he said, call us XXX, whatever it was. I've forgotten her name but that was quite nice., My consultant was Mr. so and so or Dr. so and so. Never have been on first name terms, but little touches like that.”

During a subsequent outpatient experience (at the Princess Royal Hospital/PRH), they were both particularly complementary about the **time spent with the consultant**:

“The actual appointment was wonderful. The doctor said oh, they haven't booked me another appointment after you, so let's spend some time over this. And it was well over an hour that he devoted to us and enabling us to fully understand what the condition was”.

The hospital **food** was also found to be excellent:

“Food was brought and he absolutely loved the hospital food. Must be one of the very few people that really go for the hospital food. Wonderful. He just said now life looked up when he was fed.”

Although the career and service-user were mostly positive, there were some concerns. The carer also felt there was **insufficient reassurance** as to why the service-user was in hospital and what procedures they were planning:

“I suppose standing at the deeper depth was the mentality, the mindset of somebody who is very concerned, worried, doesn't understand what process is. The fact is they didn't get it right in terms of him being scared and worried. And someone not being able to jolly him along and talking a little bit more about why he was there.”

The environment was also found to be too **cold**:

“Another weird thing was it was actually quite cold. It was November. Yeah. It was a big room and xxxx had in his anorak on the whole time he was there. And you think of hospital as being too hot in general. And I probably kept my coat on.”

When waiting, they found the **atmosphere** quite distressing:

“And during that time there's evidently a patient not far away who is screaming and in discomfort, mental discomfort of some sort. So that was pretty unnerving.”

From the outpatient experience at the PRH, the carer accompanied the service-user for a follow-up from the inpatient stay. The **poor signage** was found to be an issue:

“When we arrived at reception, they said, going down the corridor, turn left, you on the blue area, which for me is the person accompanying was very easy to follow. But I think had [the service-user] gone on his own, then it would have been nice had there been somebody there to say, ‘let me come with you to take you to where you've got to wait’”.

As for other case studies, a recurring theme was having **more ‘everyday’ conversations** just to acknowledge they were there and waiting:

“People, people went by. Medics went by. When I say medics or form of medics, anybody working there. They went by getting on with their job. But there wasn't that sort of relaxed smile of hi, you know, nice to see you, how are you?...I suppose my overall impression was that it would have been lovely if the people walking by had been a bit more smiling. Relaxed. ‘How are you?’ Yeah.”

When asked what could make the carer rate it 10 out of 10, they responded by saying having more interaction with **empathetic staff**:

“I suppose the main thing being a person to be there to watch and to step in and show empathy and understanding on occasions when it was obvious that [the service-user] was upset and concerned.”

Case study 2. Daughter of her father affected by dementia (aged 89, diagnosed at 84) – East Sussex (not Brighton and Hove), White-British, heterosexual

The daughter spoke about the distress seeing her father moved between hospitals and within the PRH which he felt was distressing. She also felt little empathy from the staff, and minimal recognition of her father’s needs.

The main topic of conversation was the inpatient care at PRH. The service-user had a prostrate operation at Montefiore Hospital, but various problems led to him being in hospital for longer than expected. At short notice he was transferred to the PRH. The daughter was asked to transfer him and took a letter for the nurse to read but *"the nurse in charge refused point blank to read the letter, which really, really annoyed me."*

The main concern was that he was **moved within PRH** which he found really distressing:

"I left him settled in a side ward up at the end which was perfect for him. He had a window next to him, he could look out, it wasn't busy. Ther was only one other person in that particular section. So, the next day I go in and he's been moved. So not only did he have the move from Montefiore to the urology ward, but then they moved him and they moved him right in the middle of the ward, right opposite the nursing station, it was the noisiest, busiest place."

This moved position was to help to treat his urine infection but was unsuitable given his Alzheimer's:

"He had a urine infection, and they wanted it sorted. But my impression was they took absolutely zero notice of his Alzheimer's."

The **nursing contact** was criticised by the daughter as not always being present:

"He kept saying no is no. I have a nurse, who are the nurses? And actually, it wasn't that easy for me to tell who the nurses were. So many people in and out and, and they were all hiding behind computer screens. They were barely ever coming to him as a person. They were nearly always stood at the side, you know, observing outside the ward or at the end of the bed behind a screen. There was so little personal contact. So, I basically, I just thought, I mean he's going to die here."

Overall, the patient's daughter felt his **Alzheimer's needs were not recognised**, despite the apparent staff training:

"There's no account for the dementia needs of people. They're just treated more as a kind of the medical condition, and they just sort of ignore the fact that this person has a particular other condition as well. I cannot tell you how many times. It's probably over 50 times that medical personnel have told me 'Oh, we've had the dementia training. We know about dementia', and then they just seem to ignore it."

The daughter also was critical of the **communication from the medical staff**, either rarely seeing a doctor, not receiving any details about his care and not being involved in care decisions:

"I barely saw the doctors because it was designed that visiting wasn't at the time when the doctors were going round. I needed to be there with the doctors so that I knew and I could kind of liaise. And because Dad wasn't responding and [the doctor] was on a schedule, he would just do things to Dad without his consent. Because Dad couldn't give his consent, they were not taking the time and trouble to actually even try and explain it in a way he could understand."

Case study 3. Carer of her husband affected by dementia (aged 87, diagnosed at 82) – East Sussex (not Brighton and Hove), White-British, heterosexual

The carer spoke about an outpatient experience at the RSCH, which was compared less favourably to their better experience at the PRH.

Concerns were raised about **poor quality of care** related to a radioactive scan. The carer describes this scan of her husband's prostrate as *"our first horrific hospital experience, which was at Brighton."*

She understood she could not go in the scanning room at that time, but did talk about how *"he had a sweet nurse that stayed with him and talked to him and relaxed him and she gave me a cup of tea."*

However, the carer was critical of the procedure by not putting him in a gown which meant the test had to be redone:

"But they needed to redo it. Right. Because they had not taken off his jumper and put him in a gown…and it was a terrifying experience for him, which completely traumatised him….they were negligent in not putting him in the gown…It's not acceptable to have an elderly man and not take his jumper off and put the gown on. I mean, he's had the same X-ray at Princess Royal and they put him in a gown."

The service-user had experienced more recent outpatient appointments, with the experience at the **PRH always considered to be a better experience compared to the RSCH**:

"Another one was when he had a sort of 20-minute pass out in church which was low blood pressure. So, on each occasion they have taken us straight through to a trolley, so we've never had to sit in the waiting room. I mean Princess Royal is better [than

RSCH]. They've taken us straight through to a trolley to a cubicle, which has been fantastic."

The PRH was also supportive of his after care, in one case paying for a taxi to take them home and also supplying him with cardboard urine boxes:

"They had to actually pay for us to have a taxi to come home because we'd gone in an ambulance and I didn't have my car and I didn't have any money. So they did pay for that…They had, like, these cardboard ones that you throw away because of his prostate cancer and anxiety and they actually gave us some to take home."

Finally, the carer talked about the **required adjustments** for people with dementia in a hospital environment and how more needs to be done:

"I think it's such a pity with Alzheimer's that the techniques used for young people with language difficulties and autism aren't also used for people with Alzheimer's because they would work, you know, say, for example, we have a wall diary as well as a big diary, so they need to make adjustments."

Case study 4. Carer of his female partner affected by dementia (aged 75, diagnosed at 70) – East Sussex (not Brighton and Hove), White-British, heterosexual

The carer's wife had additional health needs which means there have been several outpatient visits (mostly via an ambulance to the Emergency Department) and one inpatient stay. For many visits, the partner can be very uncooperative to tests and procedures. One wait in the Emergency Department at RSCH was 12 hours.

The carer found the nursing staff at the RSCH as very accommodating about him being **able to stay with his partner** which was beneficial given her dementia:

"The first time when we went to Brighton I was going home late at night, about 11 o'clock at night and coming in as early as I could in the morning. On subsequent visits, after that when they realised that how much better it was when I was there, I stayed over. So, they'd do things like if I was there for ages and first thing in the morning, they'd make sure I got a bit of breakfast or a cup of tea and making sure I had blankets. Small touches really, but very meaningful. Mostly slept in the chair… because some people say that's the most hardest thing is like when you have to leave the person with dementia in the hospital on their own, it can be quite distressing for them."

Similarly, the carer was able to be with her during a scan as the she found this particularly distressing:

“They’ve had CT scans, X rays, blood tests. I go with her and actually on the last occasion I walked down to the scanning room but on the last time they went to a CT scan she was so distressed they actually got me to come into the control room and speak to her there, using the microphone trying to get her calmed down.”

The carer also felt the staff were accommodating to the service-user’s needs by having **casual conversations**, which was thought to make the experience much better for the patient:

“They spend a little time chatting with her, talking that included them in the conversations in consultations, the staff seemed do quite well, I think they were pretty good especially I would say.“

However, the carer also said that the staff turnover made building a rapport with staff members more difficult:

“The other thing I would say it wasn't that bad to be honest but it was a little bit disorienting that what they do is that they shift the nursing staff from day to day each day, so each day you're getting different faces which meant you couldn't get that rapport going.”

One of their biggest concerns was waiting for a neurologist and an occupational therapist, with both delayed by a day. This wait led them to discharge themselves earlier. Waiting for information was an issue, with a **general lack of communication** from some staff:

“I think one of the biggest problems was lack of communication. Like you don't know whether scans could be taken place that day or after the weekend. So there's a lot of waiting around which is fine for me because I can just sit there but they feel anxious and want to know what's happening.”

In terms of improving the service, the carer spoke about simple changes that could make their experience better, in particular **staff being aware that they could not leave their partner** who may be disorientated in the environment:

“I think there should be more awareness of people like me who can't leave their partner’s side, especially when in A and E. So, they quite often come round with refreshments and staff would come around and they would get a drink or something like that and I wouldn't be offered generally which is fair enough, but I couldn't at that time leave. You can't just pop off and go and get a drink or anything or even go to the toilet.”

Overall, having experienced the Emergency Department at both the PRH and RSCH, the **PRH was found to be *"calmer and less distressing"***.

Case study 5 - Carer of his mother affected by dementia (aged 84, diagnosed at 81) – Brighton and Hove, White-British, heterosexual

This case study raises concerns over waiting in the Emergency Department which exacerbated the confusion for the person affected by dementia, the benefits of a quiet space, the quality of the hospital staff (including the 'small touches'), and accompanying the service-user during procedures.

The carer's mother and step-father had dementia (latter undiagnosed). The mother has live-in carers and has had several Emergency Department visits due to falling and broken bones. At a visit to the ED at RSCH, the **waiting is difficult** for her due to having to wait around feeling very confused and she can get bad tempered.

"It would be much better if they could deal with what needed to be done and going in immediately and then be out and that wasn't possible."

In relation, having a **quiet, separate place** to wait would have been preferable:

"I think if she'd have had a space, like an environment which was, you know, a quiet space, because obviously he's going into an outpatient place where people are going to have X-rays. It was very busy, and he was trying to walk through into areas of the hospital you're not allowed to go. Very, very confused and very distressed. Not just A&E but at the X-ray department."

In respect to the PRH, the carer talks about how staff were **mindful of her mother's dementia** and his presenting behaviour:

"They were very good with how they managed her. The staff, those in the area were very, very good. They didn't react. They were calm and nice and sweet with her. You know, she was being aggressive and threatening herself and they completely got it."

The carer describes the **staff empathy, respect and calmness** as:

"Brilliant. It just makes my heart ache looking at what they have to do. There was a woman with pretty bad dementia on her own in a bed in a ward next to us in the corridor next us who was desperately unhappy and kept trying to get out of bed. But when the doctor case was in the midst of all this, he came and he sat and it was like he had all the time in the world, you know. Just amazing what they managed to do. Sort of keeping calm in that situation."

Being able to **stay with thier parent** helped when there were procedures being done, for example:

“So she was admitted and he was, you know, upset and confusing stuff. So I went and sat in the room with her and I was know made to wear an apron.”

Also, a more personal touch from staff may have helped, including **careful explanation of what the care plan or procedure was**:

“Supposing somebody could have met us and said, ‘hello, you know, come this way’, you know, then she might. Because she might be more able to accept that, that sort of personal touch, and that recognition, you know, that they know who she is and then this is what we're doing. You're going to have this done and we're going to go along here, you know. it was all immediate, instead of sitting in a busy environment, lots of people around not understanding why she was there and being told to sit and wait.”

Conclusion

These five people gave valuable insights into their inpatient and outpatient care in the Royal Sussex County Hospital (RSCH) and the Princess Royal Hospital (PRH).

Overall, the care received was considered good, as one person said, “7 out of 10”. Interestingly, no one was given the opportunity to feedback about the care they received. There was a combination of contrasting comments, those more positive and those reporting concerns. The key observations were:

Contrasting comments:

Some made positive comments about the valuable time they spent with the consultant. However, others said that contact with the nurses was limited, and they rarely saw a doctor.

Carers felt that acknowledging the specific issues of caring for a person affected with dementia was not always implemented, despite the apparent staff training. One carer talked about the required adjustments for people with dementia in a hospital environment and how more needs to be done. However, another carer also said that staff at the PRH were mindful of her father’s dementia and his presenting behaviour.

Positive comments:

A positive aspect of care was allowing the carer to accompany the service-user for procedures and to stay overnight if appropriate. It was felt important that staff need to be aware that carers cannot leave their partner alone as they may become disorientated in the environment.

One of the most frequently mentioned positive aspects of the experience was having more 'everyday' conversations with empathetic staff, just to acknowledge they were there and waiting. Having these casual conversations was thought to make the experience much better for the patient.

The food at the RSCH was also complimented.

For those with a variety of outpatient appointments, the experience at the PRH was considered to be a better experience compared to the RSCH.

Also, having experienced the Emergency Department at both the PRH and RSCH, PRH was found to be "calmer and less distressing".

Concerns:

Occasionally, there was insufficient reassurance as to why the service-user was in hospital without a careful explanation of what the care plan or procedure was. Some were not involved in the care decision.

Negative comments made about the RSCH were that it was too cold and with a distressing atmosphere at times.

The PRH was said to have had poor signage, particularly if the carer was not accompanying the person affected by dementia.

Being moved around the hospital was distressing for those affected by dementia.

There was one notable incident of poor-quality care related to a radioactive scan (at the RSCH).

The long waits to be seen in the Emergency Department at the RSCH were difficult for patients affected with dementia. This was associated with confusion and agitated behaviour. Having a quiet, separate place to wait would have been preferable.

Suggestions for good practice

From a study involving five people it would be inappropriate to post a series of recommendations. However, four findings were consistently mentioned which may serve as examples of good practice:

- Having ‘everyday’, short, informal conversations between staff and carers/service-users appears to make a real difference to people’s experiences.
- The importance of carers accompanying the service-user at all possible opportunities including, for example, using the communication channel when being scanned to keep them calm.
- Avoid moving dementia patients to different places or wards as this can be confusing.
- Involve both carers and dementia patients in decisions about their care.

Appendix 1 – Flyer

NHS
Sussex

healthwatch
Brighton and Hove
Your health and social care champion

We want to hear from carers or people affected by dementia

Tell us about your experience of being a hospital inpatient or outpatient.

We are interested in your experience at your local Sussex hospital.

- Were you treated with dignity and respect?
- Were you involved in care options?
- Were you able to share feedback about your care?

For more information, please contact:
Lester Coleman
Head of Research, Healthwatch Brighton and Hove
lester@hwbh.co.uk / 01273 234 040
Project starting October 2024

www.healthwatchbrightonandhove.co.uk

Appendix 2 – Participant information

Sheet

Information sheet - Patient/carer experience of hospital outpatient or inpatient care regarding dementia

What is this project about?
We would like to hear people's experiences of being an inpatient or outpatient at a hospital for a dementia related condition. We want to hear about the care you received and whether you had the opportunity to share your experiences with anyone at the hospital (like a feedback form).

Your views will be important in shaping the latest dementia strategy produced by NHS Sussex.

We would like to speak to people with dementia and/or their family/carer(s).

Who is doing this project?
This study is being led by Healthwatch Brighton and Hove. Healthwatch is a consumer watchdog for health and social care services, is completely independent, and has expertise to hear from patients about their experiences of health and social care. We completed a study on dementia services last year. We share the experiences we hear with those who design services to help improve the patient experience.

Why are we doing this project?
We are doing this study as we believe that hearing from patients and carers about their experience is the best way to improve services. This evidence will be used to inform the latest dementia strategy, so hearing your views is very important.

What does the project involve?
To hear people's views and experiences, we will offer the choice of a conversation over the phone or via online video messaging (such as Teams or Zoom). The conversation may be around 45 minutes but could be longer depending on people's preference. The conversation will ask about your experience with dementia (or caring for a person with dementia) and then focus more on your inpatient/outpatient experience at a hospital.

Who is supporting this project?
Healthwatch Brighton and Hove are leading this project on behalf of NHS University Hospitals Sussex.

Confidentiality
All conversations will be strictly confidential and all names will be changed in any report produced. Also, prior to the conversation, people will go through an informed consent process to see if they are happy to continue.

How do I take part?
To take part in this study, or to find out more, please contact **Lester Coleman** (Head of Research) at Healthwatch Brighton and Hove by email (Lester@hwbh.co.uk). A member of the research team will then contact you to arrange a convenient time to have this conversation.

The project lead at the NHS is: Katy Mundy, katy.mundy1@nhs.net, Head of Nursing for Dementia and Learning Disabilities, NHS University Hospitals Sussex.

Appendix 3 – Informed Consent

healthwatch
Brighton and Hove

CONSENT TO PARTICIPATE IN AN INTERVIEW STUDY

Hospital inpatient and outpatient care for people affected by dementia

Phone or Teams: agree or disagree over the phone.

Face-to-Face: Please put your initials in the box alongside each statement to indicate that you agree with it and then put your name and the date at the bottom of the form. If you do not agree with any of the statements or do not wish to consent, you should not initial or sign the form.

Please initial box

1	I agree to participate in an interview to share views and experiences about my own, or the person I care for, views and experiences of hospital care (as an inpatient or outpatient).	
2	The researcher has explained to my satisfaction the purpose of the study and how the information will be used (Participation Information Sheet).	
3	I understand that everything I say will be treated in strict confidence and no information identifying me will be passed on to anyone other than members of the research team.	
4	I understand that my details will not be shared with anybody outside the research team; however, I know that the researcher is obliged to inform another professional if I disclose that I, or someone I know, is at risk of harm.	
5	I understand that I am free to withdraw from the study at any time, without giving an explanation. All data will be destroyed if you withdraw from the study.	
6	I agree to the discussion being digitally recorded for the purposes of this research study.	

Participant's name: …………………………………………..

Signature: ……………………………………. / Date: ………………………………………

Researcher's name: ……………………………………….

Signature: ……………………………………. / Date: …………………………………

Appendix 4 – Topic Guide

healthwatch
Brighton and Hove

Questions are a guide rather than set of specific questions. The conversation will flow so that these prompts will be raised when suitable.

1. Introduction

- Go through consent form
- Check who you are speaking to – carer / patient. Relationship with each other.
- Check town/city.
- How they found out - via Boundary Health Care (Eat Sx), Sage house (West Sx) or Carers Hub (B&H).
- Check ages, age when diagnosed.
- Brief story of diagnosis – first suspected, experience of MAS (time waiting, environment, knowing what to expect, the test, etc.), medication and medication reviews, follow-up support (professional and others in the community).

2. Experience as an inpatient or outpatient

- Check or inpatient or outpatient.
- Which hospital, what was the reason for hospital? Inpatient or outpatient? When?
- (If applicable), was the hospital involve in the initial diagnosis of dementia?
- What was good or not so good about this hospital experience? (general)
- When first attending hospital, were they screened for pain?
- Was the environment 'dementia friendly' e.g. notices, signposting?

3. Care and treatment in hospital

- 'This is me' form i.e. how were you treated in terms of:
  - ➢ respect and dignity,
  - ➢ quality of care,
  - ➢ compassion,
  - ➢ patient-centred,
  - ➢ people included/involved with care,
  - ➢ discharge process,
  - ➢ food (including finger food),
  - ➢ open visiting times,
  - ➢ carer's café.

- Were you provided any information about the illness or the care issue that necessitated hospital treatment?

- Did the hospital staff have a good understanding of dementia? For example, how they talked to you?

- Did they involve the person with dementia in any discussion? Eye contact etc.

- How was the environment - Did they move wards/location?

- End of life care for people with dementia (if applicable)

4. Post-care

- Was there clarity over hospital discharge, what (may) changed when leaving hospital (care package, care home, etc) and how were you involved in decision-making?

- If to a care home, was there follow-up support for the first week post discharge?

- As a carer, did the hospital experience lead to any more support for you? e.g. extra carer support, befriending groups, etc.?

- Were you given any support to help better care for the person affected by dementia?

5. Providing feedback about the care

- Were you given the opportunity to feedback on this hospital care? How?
- Do you think patient/carer feedback is important?
- How would you suggest ways to give feedback?
- What could encourage people to provide feedback?

6. Final/close

- Thoughts about the dementia strategy – what are the main things the NHS need to know about regarding dementia and caring the people with dementia?
- Any further comments.
- Check details for voucher.

Healthwatch Brighton and Hove
113 Queens Road, Brighton, BN1 3XG

t: 01273 23 40 40
Email info@healthwatchbrightonandhove.co.uk

healthwatch
Brighton and Hove