Let's Talk… Hospital Visiting
Engagement Report

October 2021

Contents

Key Findings

- Family members feel shut out of hospitals and care homes, unable to be involved in and oversee care of a loved one. This can have a negative effect on visitors' wellbeing.
- Visitors have appreciated other ways of seeing their loved ones, such as iPads and the 'Letters to Loved Ones' service, but that doesn't replace face-to-face contact. Especially in terms of a patients last days.
- Communication with health professionals was not always positive or regular. This can lead to the visitor feeling even more isolated from the patient.
- New visiting guidelines are not flexible enough for family members and carers who are working or have other commitments. Having only daytime visiting slots and one designated visitor can be a strain on friends and family, especially when the patient may be in hospital for many weeks.
- It has been well documented that visits from loved ones can be beneficial for the patient and this study shows it is also good for visitor peace of mind. Restrictions of face-to-face visiting can mean key parts of the patient story are missed or overlooked.

Recommendations

1. Continue to provide patients with the technology to digitally connect with their social networks outside of hospital.
2. Continue to provide the 'Letters to Loved Ones' service when restrictions are in place.
3. Improve procedures for providing regular updates to families. If this was initiated by the hospital it may reduce the amount of phone calls that the ward receives and make more time available for caring. It would reduce family members' frustration, mistrust, and sense of alienation.
4. Provide a more consistent and well communicated approach to visiting policies.
5. Where visiting is allowed, families should be offered a choice of slots within and outside of the working day.
6. Allow family members to be with loved ones during end-of-life care or when receiving serious diagnosis; during restrictions and when they are lifted.

Introduction

In June 2021 Healthwatch Rutland, in partnership with Healthwatch Leicester and Leicestershire, embarked on a project to investigate the public's experiences and opinions about the new ways of working in and accessing health and social care that have emerged during the COVID-19 pandemic. The aim is to understand the impact these changes have had on service users, whether the changes have been perceived as positive or negative and how people's health and wellbeing has been affected because of this.

The ***Let’s Talk*** project, will look at different themes each month and each Healthwatch intends to report individually on every subject. A final report will bring together findings across Leicester, Leicestershire, and Rutland at the end of the project in Spring 2022.

The themes we hope to address are:

- Access to GP practice appointments
- Visiting patients in hospital
- Regular NHS health checks and screening
- Emergency and urgent care
- How people have experienced changes in the delivery of social care
- Access to maternity and children’s services

This is the second report in the series and reflects public experiences and opinions about hospital visiting during and post COVID-19 lockdowns.

Context

Before the COVID-19 pandemic hospitals were open for access. People could walk into a hospital and ask questions at the front desk at any time, there were busy outpatient clinics attended often by patients and their supporters, regular visiting to inpatients and restaurants and shops. Procedures for accessing wards to visit a patient, or guidelines for attending appointments with patients were commonly known, or made available by posters in the hospitals, telephone enquiries, visitors’ and patients’ information leaflets, ward staff and hospital websites.

Since the emergence of COVID-19, hospitals were advised by NHS England to close their doors to visitors to help control the spread of Coronavirus among patients, staff and the public.

As lockdown restrictions have been lifted, visiting restrictions have varied across care settings, dependent on factors such as the local number of COVID-19 cases, government guidelines, assessments of patients’ clinical vulnerability or ward workload. These changes to hospital visiting have affected the patient and the patients’ loved ones (the visitor) and this report will explore some of the ‘visitors’ feelings in response to this.

Although the project was designed to talk about hospital visiting, participants talked about the changes to both hospital and care home visiting rules they encountered. These included:

- The inability to accompany a loved one being taken to hospital by ambulance
- Being unable to provide support at outpatient appointments
- Wards closed to visitors
- Needing to select just one person as a ‘designated visitor’
- Having to stay outside and talk to loved ones through windows
- The prerequisite to take lateral flow tests before entering care homes

Method

This *Let's Talk* project uses qualitative research methods, asking semi-structured questions in small discussion groups or individual interviews, with the main benefit being the collection of rich accounts of people's experiences and expectations. However, this means that a smaller number of the population are involved than when using quantitative methods such as closed questions in surveys.

Strict ethical guidelines were followed, to ensure participant wellbeing, anonymity and confidentiality, interviewer safety and research integrity. Face-to-face interviews were conducted in full compliance with Government COVID-19 advice.

Feedback was received from 8 people:

- 5 Face-to-face interviews
- 2 Telephone interviews
- 1 Email narrative

This report draws on the thematic analysis of the participants' own words as they talked about their experiences. Our findings of the most commonly expressed themes are presented. These are followed by case studies which provide a fuller picture of how these themes combined and cumulatively influenced visitors' experiences and their emotional responses.

Findings

1. Visitors being on the 'outside'

In terms of hospital visiting, before the pandemic visitors brought news and greetings from home and the outside world, offered treats and gifts, gave emotional support, provided clarity of information for the medical professionals, advocated on behalf of the patient and even helped with care tasks. Visitors were therefore actively involved in the patients' hospital 'journey'.

However, the pandemic restrictions disrupted these traditional roles and responsibilities. A predominant theme that emerged from the feedback was the sense of isolation felt by visitors – a metaphorical and physical sense of 'being on the outside'. This is despite the value placed on the collaborative approach to care reflected in the NHS core values: 'We put patients first in everything we do, by reaching out to staff, patients, carers, families and communities'[1] and the acknowledged detrimental effect on patients and visitors of visiting restrictions[2].

This concept of 'being on the outside' was furthered by:

- Physically being outside of the care facility and being unable to see your loved one:

"My wife has been going in and getting her treatment and I have to sit in the car and wait for her. I understand the reason behind it, but it is not nice. I want to support my wife. It upset me [….] When my wife got her cancer diagnosis, I wasn't allowed to be with her."

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[1] See, https://eput.nhs.uk/about-us/nhs-constitution/nhs-core-values/ NHS core values

[2] See, for example, https://www.royalvoluntaryservice.org.uk/news-and-events/news/lack-of-visitors-has-detrimental-effect-on-patient-recovery

- Poor communication of new visiting rules left people feeling uncertain and more isolated:

“I didn't get any communication from the hospital regarding visiting I just kept watching the news and checking the website.”

“We had a call from the grumpy doctor saying that there were processes in place and we must follow them and should not call. He was not very pleasant. We told him that was all well and good if the relatives were informed of the process from the offset, so they knew what to expect and that the process actually worked!”

- Not being able to be with your loved one leads the family to feel like they were not part of the collaborative care:

“Before we were discharged in the April, we saw a Neurologist who hadn’t seen him for a year. He just took one look at him and said, “end of life.” Just like that. It broke the children’s hearts – they couldn’t come to the hospital.”

“I did feel a bit out of it sometimes, although they did give me a call to say my husband was out of theatre.”

- The sense of the loved one ‘being on the outside’ was heightened if the patient was taken away in an ambulance alone:

“I was panicky and stressed and it was very upsetting not being with him.”

“My husband was taken to Peterborough by ambulance after calling 111 [….] It was just so hard to not go with him. To see him go off in an ambulance.”

In such stressful situations, the care shown by the paramedics was appreciated:

“The paramedics came out and they were some lovely ambulance drivers, they really helped.”

- The visitor has an emotional pull to see a loved one, which was brought into conflict by the reality of restricted visiting:

“One day we begged to see mum as it was my mum and dad’s wedding anniversary, so we wanted to drop something off. Nothing was allowed but finally a carer said they would bring my mum to a window to see us. But I don’t know if that was worse, seeing her like that.”

COVID-19 has thrown hospital visitors, patients and staff into a new set of rules, which are ever-changing and not easily understood by, or well-communicated to, the public. The following sections examine how visitors experienced these new rules.

2. Communication with hospital professionals

Communication with hospital professionals was a dominant theme arising from participants’ feedback. As Moi Alis (2017) states, ‘Good communication is critical to good healthcare’[3]. Eight people spoke to us and mentioned communication with health professionals twenty-nine times. Twenty-three of these were negative comments, five were positive and one was both positive and negative. We explored this theme further:

Problems with communication seem to have been exacerbated by the added workload pressures caused by COVID-19. These pressures might arise from: staff shortages due to isolating, shielding and sickness; staff being moved to unfamiliar work areas; and more acutely unwell patients. Participants understood this:

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[3] Retrieved from: https://www.nursingtimes.net/opinion/comment-communication-an-essential-skill-in-healthcare-01-12-2017/

“The doctor said earlier we can call anytime but it is really busy and it may be an effort. It is! They are obviously overworked.”

This meant that family members were unable to have face-to-face communication, but were often denied the updates they so anxiously awaited:

“There wasn’t any feedback from the ward. If I rang up, they didn’t always know what was going on and it was always someone different. They didn’t ring me.”

As hospital visitors were often unable to see the patient face–to–face, communication with medical staff became even more crucial. It is important to note that inadequate communication can have lifelong effects on patients’ families, as one participant’s words demonstrate:

“By the Saturday, I rang and rang the ward to see how she was. I rang about thirty times and no one answered and nobody rang us back. On the Sunday, they rang us and told us that she had passed away.’ [….] We had made it clear that if mum was looking worse, they could ring me […], but no-one ever rang. We missed out on the opportunity to be with her. When other family members died, we were able to gather together in a side room.”

This is a sad example of a communication breakdown, with the family wanting to be present when their loved one passed away. This situation may not have been avoidable, but the family may have benefited from better communication regarding their loved one.

However, despite all the added strains on the hospital professionals, examples of good care were still recognised:

“The doctors we have spoken to still have such compassion - which is amazing!”

The benefits of effective communication were clearly noticeable:

“We have visited the hospital to drop off what my dad asked for. The receptionist was truly lovely, and the young girl was a volunteer. She took the time to ask us about our experience with contacting Dad. We explained it was difficult and she gave us a website that has been set up to email loved ones. I have just sent the email and some photos. The thought that we can do that, and it will be passed on means so much! I am going to contact the hospital as these special people deserve credit.”

The ‘Letters to Loved Ones’ service was a new development during COVID-19 so people could keep in touch with friends or relatives by typing an email or leaving a voice message to be delivered to the patient. This scheme provided crucial contact that the visitor and patient craved at this time, whilst helping to reduce some of the workload for the busy medical professionals.

The differences in communication between hospitals was also noted. One person commented about the difference between when her father was in Peterborough City Hospital (PCH) and Addenbrookes Hospital and demonstrates how effective communication instils trust:

“They have actually taken the time to call us and even ask us how we are feeling, which has never happened once in Peterborough. I feel a bit more positive now that Dad has moved to Addenbrookes.”

As the COVID-19 infection rates came down, rules were changed. Newer rules included visitors being assigned set times on specific days or just one family member being the ‘designated visitor’. Hospital staff were not always available to chat to patient’s families at these times.

[Visiting time of 1-2pm] *“It would have been better if we could’ve visited in the evenings. Hardly anyone had visitors and there was never a doctor around or anyone medical to chat things through with. I don’t know whether staff were on their lunch break.”*

COVID-19 is beyond anyone’s experience and it has severely challenged the health service. So, whilst acknowledging the pressures, it is important to emphasise that good communication for both patient and family is central to good health care.

3. Communication between the visitor and patient

With the introduction of Covid-19 restrictions, patients and their loved ones used their mobile phones, tablet computers or laptops to communicate with each other. People had both positive and negative opinions about this.

Positive:

- You can speak to your loved one at any time:

“He did have a phone so I could speak to him anytime. I guess it would be more difficult if he didn’t have a phone.”

Negative:

- The patient is not always heard or understood:

“I have spoken to him several times today, but he is not too easy to understand now”

“I think with the hearing problem, the oxygen and the fact that he is so weak it doesn't make him easy to understand.”

- Patients and/or visitors might not have access to, or be able to use, technology:

“As we had just moved house [when her husband had his accident and went into hospital] his phone had died, as we couldn’t find the charger, I couldn’t contact him.”

- Talking to the patient on the phone, rather than face-to-face means there is no opportunistic and unplanned visitor contact with the hospital professionals:

“As his wife I didn’t see any medical staff and we also didn’t get any follow up.”

- Promised video meetings either did not happen or bring their own stresses as the following extract demonstrates:

“In that whole time, we were offered two Skype calls so that we could see him, the first time was by Peterborough hospital. […] My sister travelled here because her computer was broken. We had not seen Dad for some time so both had sleepless nights. We waited at the time we were told and heard nothing. My husband eventually called them and was told that the call could not go ahead because they could not find an I Pad! The second time we were offered a virtual visit was by Addenbrookes. We were called just as the meeting was due to start and told to head over to the hospital. In theory a virtual visit should work really well and should be easy. The reality is something very different in a very busy overstretched ward. In the 5 weeks and 1 day that Dad was in hospital we only got to see him in person in his final hours, I found it a real shock to see him, being told what is happening to your loved one in a five-minute daily call and seeing it with your own eyes is something completely different. It is something that still haunts me.”

Whilst ‘remote visiting’ may be considered better than nothing, it is important not to overlook the practical and emotional impacts the participants described.

4. The impact of restricted visiting on families and carers

The timed visiting slots during the working day has caused practical problems and distress for families and carers. Working family members are not always able to get time off, or work flexibly, to make regular visits to a loved one during business hours. The rigidity of the new system is a practical and emotional strain on the visitor:

"We were only allowed one person to be designated to go in. I was due to go on holiday, but they wouldn't let anyone go in my place. […] In Peterborough Hospital they had an odd and even bed system where the odd beds were allowed visitors at one time and the evens another time. It was quite difficult as we live in Rutland, so we had an hours' drive to the hospital, then visiting was 1-2pm then an hour back. I was working at the time, so I needed to take 3 hours out of my day. It was really hard juggling work and seeing mum and having to ask for time off…. It was a relief when they did lockdown for a while as it meant I wasn't allowed to go, so I didn't have to try to juggle their visiting timings. It would have been better if we could've visited in the evenings. It was very hard being the only visitor. I wanted to support mum and emotionally that was hard, but then I also had to be the one talking to the doctor and trying to find answers, then also feedback to the family and try and answer their questions. It was all a lot. When previous family members were ill, we all supported each other […] It was so hard, with the new visiting rules, on me. It was such a pressure for about 10 weeks of juggling visiting alone."

It is interesting to note the expressed sense of relief when the ward locked down - not because the participant did not want to visit but because the visiting had become such a physical, mental and emotional strain.

However, another person found the new system worked well as the hospital seemed more ordered and less busy.

"I was very satisfied with the system. I think it was all for the better having restricted visiting."

The participant above also demonstrates the positive impact of modern, welcoming facilities and environments on visitors' and patients' experience:

"111 sent an ambulance and they took my husband to Peterborough which I was a bit dubious about as we have never been. We already go to Leicester, but I was delighted in the new modern hospital, with new facilities. I was anxious as I didn't know Peterborough hospital, but we struck lucky. If we had a choice, we would go to Peterborough again."

5. Case Studies

Due to the qualitative nature of this study, we received some emotive data that raises some interesting points. Three longer stories have been added to give a greater sense of the dominant themes described in this report and introduces some of the equally important minor themes. Names have been changed for anonymity.

5.1 Isabel’s Story - Prioritisation of COVID-19

> *“My mum had cancer for many years. She was in the late stages, and she went into hospital at the end of February. It was the first few weeks of COVID-19, and everything was kicking off. I was going in quite regularly and being asked to wear an apron and a mask. You could tell that things were changing. In March they said that I couldn’t go and see her. I thought we only had a few weeks left for mum to live but I was told not to visit and there were no iPads - no, nothing. […] Everyone was so busy preparing for COVID. They seemed to be trying to get people out of the Oncology Ward to make room for COVID patients. The whole communication was so tricky. Trying to speak to the ward was difficult with the emerging pandemic. I could FaceTime mum on her own phone, but she had often had lots of drugs, so she didn't always make sense. I often captured screenshots of my mum's face as I thought it might be the last time I might see her. Communication with the ward was hard. I got lots of mixed messages from the different people that I would speak to.*
>
> *It seemed like they didn't really want mum on the ward. They wanted to ‘clear the decks.’ My mum said that she was the only person on the ward. There was nobody around, no other patients. […] There was talk of mum going to Stamford Hospital but then they got her a place at Tixover Care Home. Before she had needed treatment and now it was palliative care. It was all a real muddle trying to get things sorted [..]*
>
> *We couldn’t visit her at the care home. We were told to just drop stuff at the door, and they seemed so unfriendly and uncaring, but they had a lot on. [Difficulties at the care home and the two-week room isolation caused problems.] These difficulties at the care home went on for days and after a week mum said that she couldn’t cope with the situation anymore and she wanted to leave. I think being in quarantine in the care home pushed my mum over the edge.”*

This case study shows the impact on a family that has struggled with cancer for many years and how the end of that journey was impacted by COVID-19 regulations. The clear sense of the hospital wanting to ‘clear the decks’ seems to deny the very specific and sensitive care required at the end of life and the difficulties that occur when such care is not given the proper priority. This is a very emotive story. However, there were some positives to the hospital being cleared of other patients.

“The care seemed good in the hospital. Mum never complained, as the ward was empty it felt like mum had 100% attention. They were lovely caring staff.”

5.2 Sarah’s Story - The visitor knowing the patient

> *“Peterborough decided mum should go for respite at a care home (Oak House in Greetham) they were very good, and we could speak to mum through her window when we wanted. We felt that she still wasn’t right, so we told the care home, and the Doctor from Empingham came out. He thought she had an infection in her hip so prescribed antibiotics.*
>
> *She went downhill really quickly, considering a few weeks ago she was living and managing in her own home. The paramedics were called. She had to sit in A and E from 3:30pm to 11:30pm. She was confused and scared, but I wasn’t allowed to be with her. The Doctor rang and said it was dementia, but it wasn’t dementia. She had been fine until very recently and gone downhill fast after the operation. She stayed in hospital for about three weeks [….] At one point when I rang the ward to ask about mum, they said she was having a ‘good day,’ but she wasn’t. She was hardly responsive and lying-in bed. This was not my mum and definitely not on a good day! I said she has had rapid decline, which is why she came in and this is not normal.”*

One of the important roles of the visitor is to be able to offer care professionals further insight into the patient’s background, usual demeanour, preferences, and habits. This can often be a vital part of the collaborative care the NHS values. Restricted visiting could lead to valuable parts of the patient story being missed as there is nobody there to explain and advocate for the patient. It is clear in this case study that there are several times when the visitor’s insight could have helped the medical professionals. Without such insight from loved ones, there could be wrong diagnoses and delays in receiving treatment as demonstrated in Sarah’s story when confusion was attributed to dementia rather than infection.

5.3 Jean’s Story -The highs and lows of being unable to visit your loved one in person

Jean is a Rutland resident, and the following case study is from emails to a friend during her father’s last illness before he passed away after being in hospital for many weeks.

> *[Day 5] ‘We spoke to a very kind doctor yesterday who gave us lots of information and answered any questions we had. Today it is a different story. We haven't got a clue! I know that they are very busy, but we are unable to visit and gauge what is going on for ourselves. It is very difficult. I know no news is good news. We have been promised so many call backs that just do not materialise, I have lost faith. We don't seem to be getting information from the doctors. Given that he is in intensive care, and we cannot see him, I think they should at least agree to update us in full daily.*
>
> *[Day 10] Just had a text from Dad and have managed a quick call with him. He says that he is breathing a bit better today and hopes that he is turning a corner […] it is lovely to have some more positive news! Fingers crossed!*
>
> *[Day 12] It was so lovely to have a little chat with Dad this morning. It has lifted my spirits and I feel much more positive again.*
>
> *[Day 20] We are still waiting for news; the days seem to get longer and longer! They said that they wanted to set up a video call for Thursday so that the doctors could talk to us. Unfortunately, the call didn't happen.*
>
> *[Day 36] Dad has taken a big step backwards […] I have spoken to my sister, and we have both decided to let him go without any suffering. The waiting for the phone to ring is terrible. […] The waiting has been horrendous.*
>
> *[Day 40] We have a Skype call arranged from Dad's bedside at 3.30pm. It will be the first time that I have seen my dad since he was admitted. I am getting myself all worked up about it. I did last time and then it didn't happen. I want to see Dad desperately but feel really worried about seeing him looking so ill and I suppose not knowing exactly what to expect.’*

This feedback shows the emotional highs and lows of the visitor waiting for contact with their loved one, the patient. These emotional difficulties are intensified in this case by the length of stay and the inability to witness the steady decline in the patient’s condition. It highlights that for every patient in hospital there is a much wider support network of family and friends who may be struggling with the situation and this may affect their physical and mental wellbeing.

Conclusion

This report highlights the emotions and complexities involved for patients’ loved ones as they navigate the new hospital visiting system. Whilst the reason behind these restrictions is understood, the impact on patients and their significant others cannot be overlooked - especially in terms of end-of-life care, new serious diagnosis or when the patient is taken by emergency ambulance to hospital. Negative experiences for the visitor, especially at these times, can have long lasting effects.

Amongst the negative experiences expressed there was also positive appreciation for the care providers.

Here, Healthwatch Rutland has attempted to represent, for health care commissioners and providers, the visitors’ opinions, experiences and how they have been impacted by the inability to see their loved one.

We suggest that new ways of hospital visiting could work better if communication with the public was improved.

Acknowledgements

We are incredibly grateful to all those who took the time to share their views and experiences with us. Some of the feedback was of a sensitive nature so we appreciate you entrusting us with your stories. Thank you!

About Healthwatch Rutland

Healthwatch Rutland is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people’s needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised, and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch Rutland and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

Find out more at www.healthwatchrutland.co.uk

About Connected Together

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Northamptonshire.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures

Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

Find out more at www.connectedtogether.co.uk

Appendix - Question script for interviews

1. How did you find hospital visiting in the pandemic?
2. Were you made aware of the visiting process and any restrictions?
3. Were any special arrangements needed?
4. How involved did you feel in the care and treatment received by your loved one?
5. How satisfied were you with your “visits”?
6. What single change would improve your experience of keeping in touch with your loved one in hospital?

Contact us

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