

Experiences of out of hours Palliative Care in Shropshire, Telford & Wrekin

Survey Report

Engagement period:
July - November 2020

Publication date:
21 January 2021

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About Healthwatch



Healthwatch Shropshire and Healthwatch Telford & Wrekin are the independent health and social care champions for local people

We work to make your voice count when it comes to shaping and improving services. We use a variety of methods to find out what people like about services, and what could be improved and we share these views with those with the power to make change happen. Our reports go to:

- the organisations who provide services
- the commissioners who pay for services (e.g. Shropshire, Telford & Wrekin Clinical Commissioning Group, Shropshire and Telford & Wrekin Councils)
- service regulators (the Care Quality Commission, NHS England)
- our national body Healthwatch England to let them know how local services are working.



We are not experts in health and social care and surveys are just one of the methods we use to put a spotlight on services and ask people to share their views with us. Usually our surveys are publicised and promoted through our engagement activities (e.g. talks and stands at events) as well as through online publicity and local press releases. Due to the pandemic we were unable to use face to face engagement for this topic.

Please note

Our survey was time limited but we continue to want to hear from people who are willing to share their experiences with us and we will share them with the providers, commissioners and regulators.

The context

Since July 2018 all out of hours calls have been directed to NHS 111. This service is provided by West Midlands Ambulance Service.

In early March 2020 due to the Covid-19 pandemic the number of calls to NHS 111 grew which led to some delays in calls from patients being answered. For patients at the end of their lives with distressing symptoms, any delay is unacceptable.

ShropDoc were aware of the difficulties being experienced by these patients, their families/carers and the professionals who care for them because 15% of home visits out-of-hours are for palliative care. To offer additional support at this time ShropDoc introduced a dedicated Palliative Care Helpline. The aim of this survey was to understand the experience of patients on a palliative care pathway, and those supporting them, in getting help when they needed it from NHS 111 and ShropDoc during the pandemic.

The survey ran from July to November 2020 and follows on from engagement work focused on End of Life services in Shropshire in 2019. [Experiences of End of Life and Palliative Care Services in Shropshire Report](#)

The World Health Organization (WHO) defines palliative care as follows¹:

‘Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.’

¹ <https://cks.nice.org.uk/topics/palliative-care-general-issues/background-information/definition/>

What we did

We decided to ask those on a palliative care pathway and those supporting them to share their experiences through an online survey or by contacting us by phone.² This was publicised across both council areas through our media, stakeholders and community contacts across Shropshire asking people to contact us and share their experiences.

We consulted with local doctors and service managers to ensure the questions we were asking were relevant and that the answers would be useful.



The people we heard from

Who contacted us

We heard from 27 people.

Are you:	No.	%
Receiving palliative care	1	3%
A family member, friend or carer of somebody receiving palliative care	9	33%
Other	17	63%
Total	27	100%

N.B. Those in the 'other' category were all healthcare professionals.

² A full list of the survey questions can be found in Appendix A

Description given for 'other':	No.
Community Nurse	4
District Nurse	4
Healthcare Professional	2
HCP working within palliative care	1
Hospice Outreach Nurse	1
Nurse	1
Outreach nurse	1
Professional group	1
Registered nurse supporting patients at EOL	1
Urgent Care Practitioner who regularly carries out home visits for palliative patients.	1
Total	17

Age of patient:	No.	%
45 - 54	1	4%
55 - 64	1	4%
65 - 74	7	26%
75 - 84	6	22%
85+	1	4%
Blank	11	41%
Total	27	100%

Which council area does the patient live in?	No.	%
Shropshire Council	14	52%
Telford & Wrekin Council	4	15%
Powys County Council	5	19%
Other (The person covers both Shropshire and Telford & Wrekin)	1	4%
Blank	3	11%
Total	27	100%

Experiences people shared

We asked people to describe their latest contact with NHS 111, ShropDoc and any other organisation providing out of hours palliative care support. They were also given the option to describe a second experience with any of these; three people chose to describe a second experience, two about NHS 111 and one about ShropDoc. All the experiences have been analysed together.

The respondents shared 51 experiences:

Experiences	No.	%
ShropDoc Palliative Care helpline	26	51%
NHS 111	24	47%
Other	1	2%
Total	51	100%

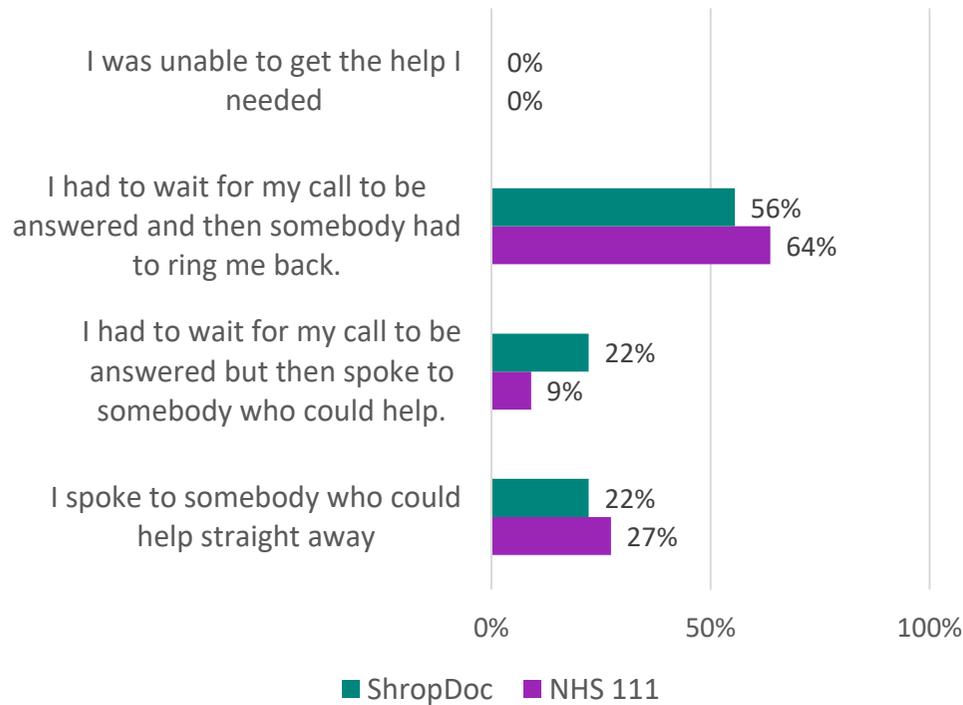
N.B. It was unclear which organisation was being referred to under 'other' and therefore does not feature in the analysis.

What people told us

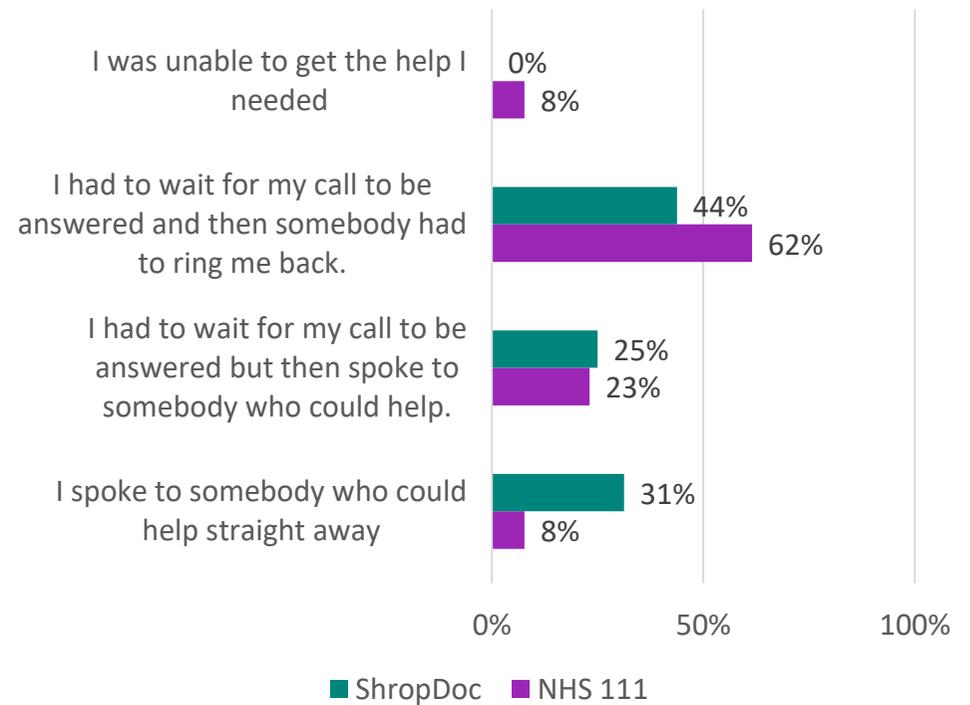
Although healthcare professionals will be contacting the services with regard to a patient's treatment and support we felt we should look at the experiences of the two groups, patients/carers and healthcare professionals, separately.

Please choose an option that best matches your contact experience

Patient / Carer responses

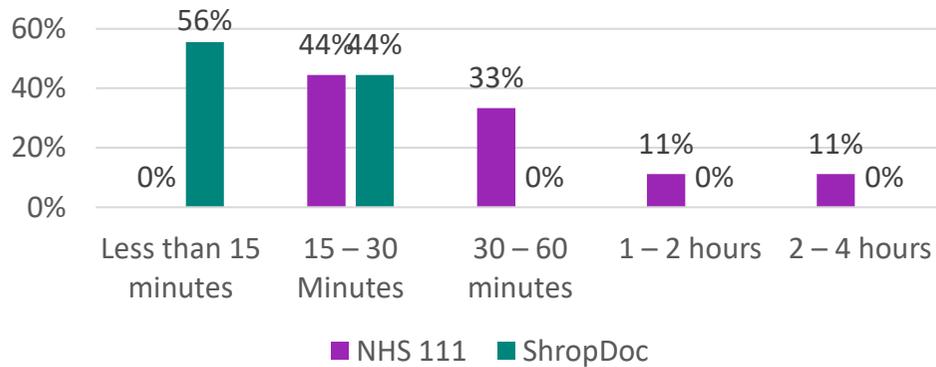


Professional responses

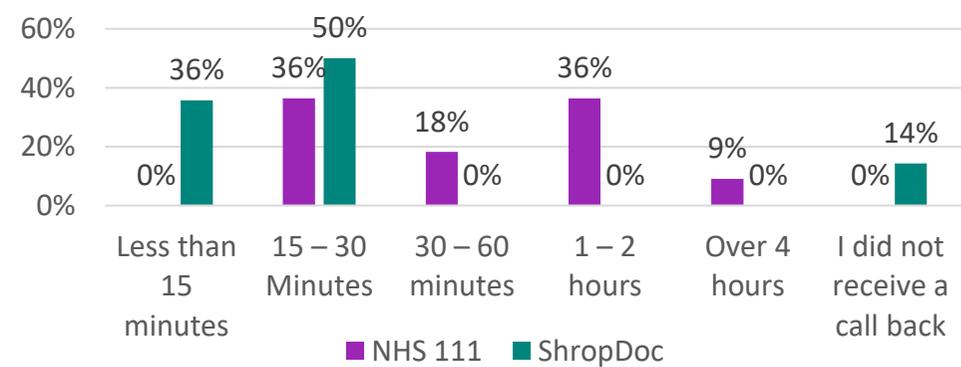


If you received a call back, how long did you have to wait?

Patient / Carer responses

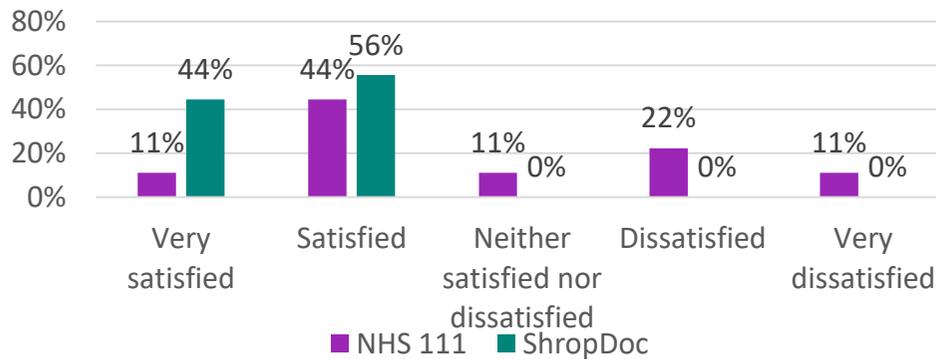


Professional responses

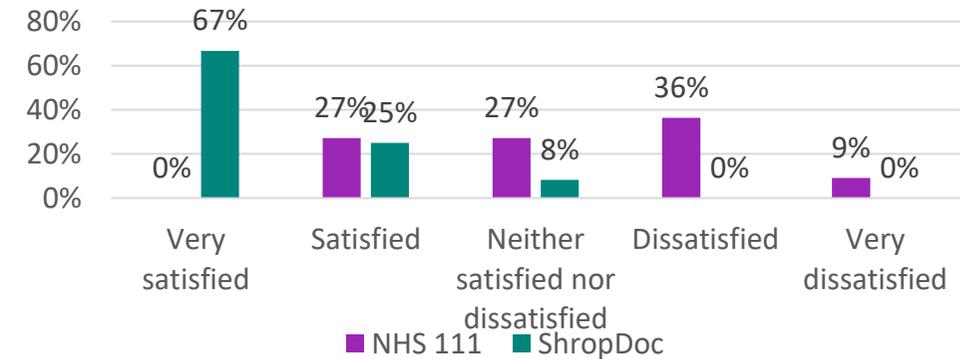


How did you feel about this wait?

Patient / Carer responses

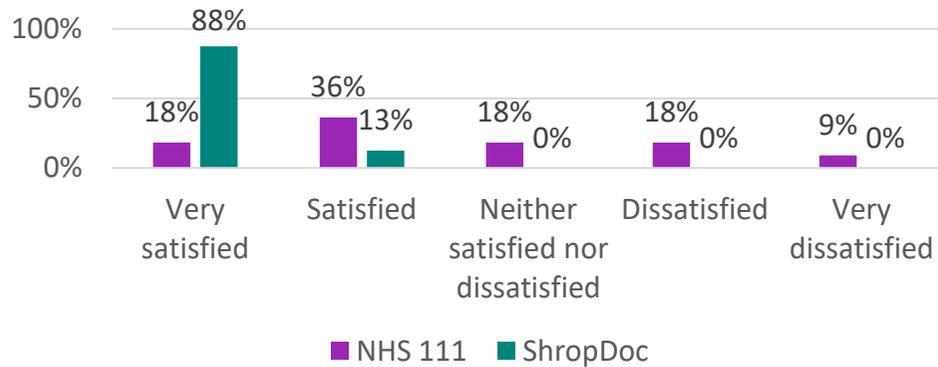


Professional responses

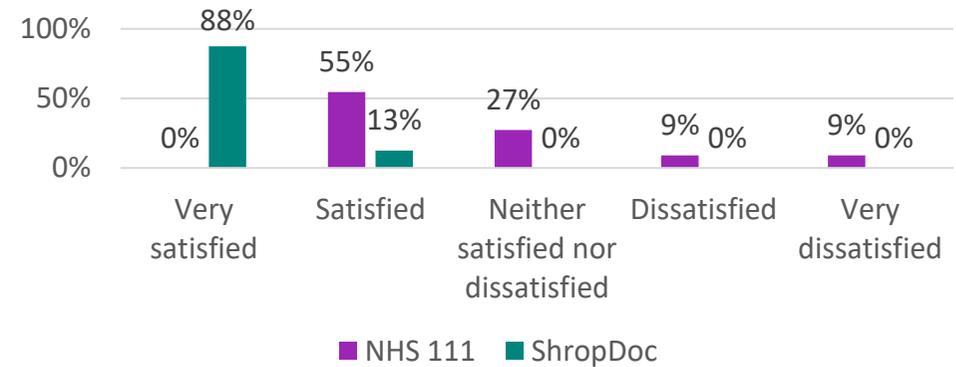


How satisfied were you with the service provided by the member of staff helping you?

Patient / Carer responses

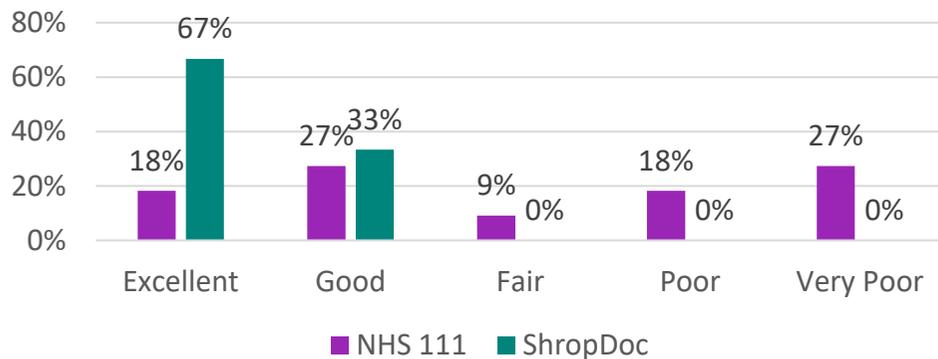


Professional responses

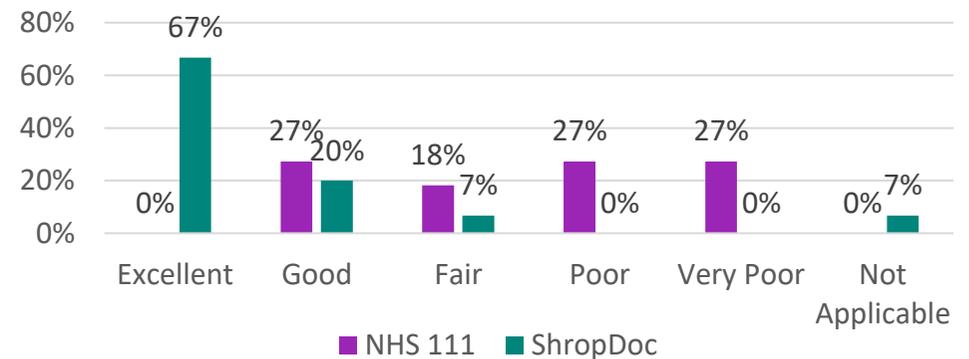


How would you describe the member of staff's understanding of the local area and local services?

Patient / Carer responses

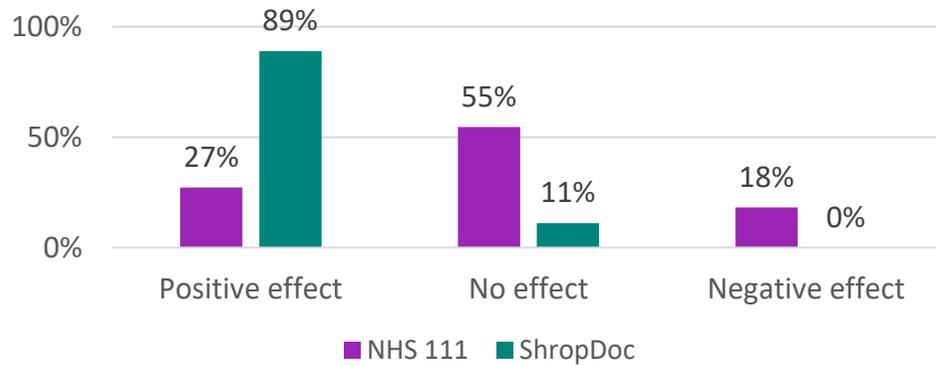


Professional responses

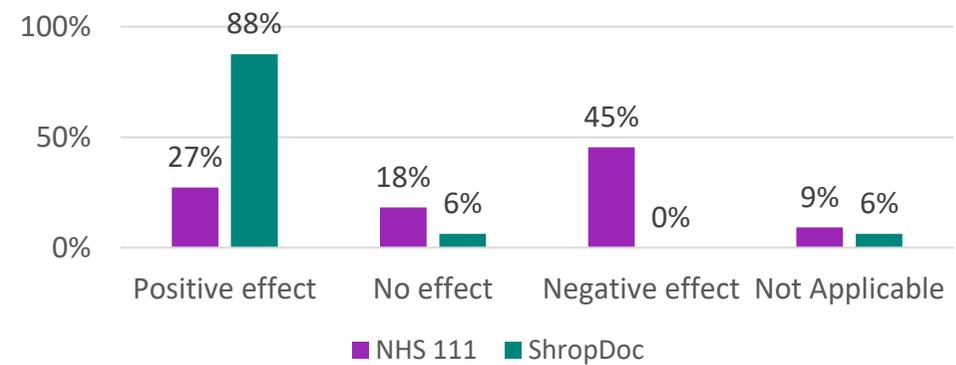


What effect did their understanding of the local area and services have on the care you received?

Patient / Carer responses

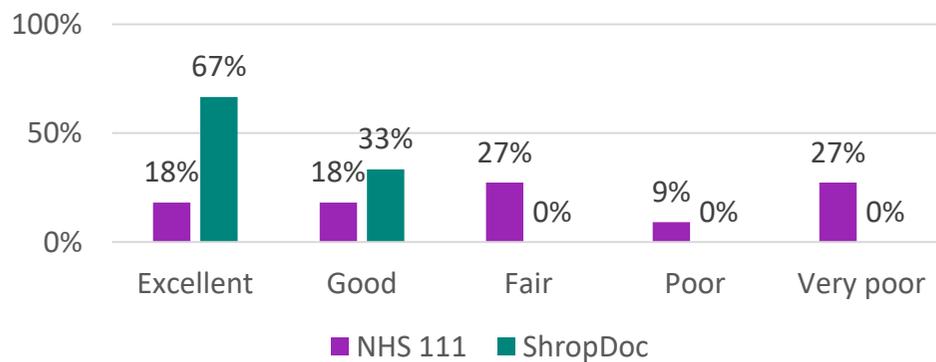


Professional responses

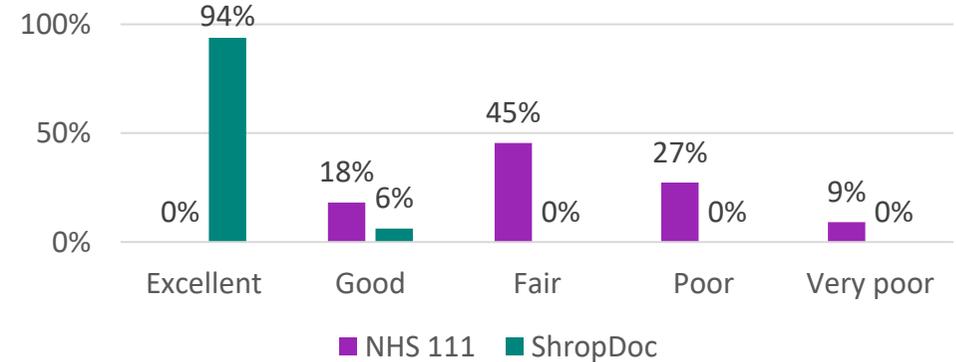


How would you rate your overall experience?

Patient / Carer responses



Professional responses



Is there anything else you would like to tell us about your experience?

NHS 111 Experiences

Patient / Carers:

- ‘It took a long time to get through, then a long wait for a return call. The call taker did her best but she was a bit clueless, very anxious about using 111 in the future’
- ‘The call handler left me on hold for ages then told me someone would have to ring me back. They only work through care pathways and if the patient doesn't fit into the pathway they cannot help or advise’
- ‘An ambulance was called and attended. Paramedics wanted to take my wife to hospital. This was refused as prior year she had been taken into RSH Friday am to return Friday pm. She did not return. I had to discharge her the following Monday as ward could not find the file relating to her. Hospital refused ambulance service and I had to use our motor van which has a bed facility. Refusal was based on prior experience. Paramedics bullied me for 15 minutes and made it clear that whatever went wrong "would be my fault". Then departed, wife remained at home in my care. GP was disappointed with the first result of extended stay that I deemed unnecessary in the RSH and then the later attempts by paramedics to take her to hospital again. I was told "be it on your own head and sign this to show that you refuse advice and that will absolve us when things go wrong". Nothing went wrong and she remains at home. GP later prepared a RESPITE form with the instruction that my wife should not be removed from home care for hospital attention’
- ‘The lady on the phone was very helpful and went through the process they have to go through, and she then told us that a clinical colleague would call back to help’
- ‘111 option was ambulance again. This was declined based on prior experience. I waited and contacted GP who gave palliative care contact and GP made hospice contact for me and they have since visited. Hospital experience was diabolical. My wife was not got out of bed from Friday to Monday when I removed her. She was very stiff, the excuse was that "OT had been unable to visit and they, nurses, could do nothing without OT agreement. Let the nurses decide and get on with proper nursing not arm's length. My wife was SRN in 3 major hospitals prior to a health visitor

training. She would be appalled at division of responsibility that impacted patient care. I do not want paramedics here again based on prior experience.'

- 'Very long winded. I find 111 works very remotely and do not understand the area I live in. I would like ShropDoc back with our own GPS PLEASE.'

Professionals:

- 'Powys has poor timely access to out of hours Doctor - Impacts care patients received- through no fault of theirs. Doctors should be more local.'
- 'I rang for my daughter and they reported they would call back, they then passed onto the OOH local ShropDoc but when I had not had a phone call for a few hours I rang back and the referral had been lost we then had to travel 20 miles to ShropDoc instead of 7 due to the late time/lost referral.'
- 'I called 111 for a family member who does not live in Shropshire. Even calling as a clinician, I felt frustrated by the poor service. It was embarrassing.'
- 'Phone answered by call handler with no clinical knowledge. Wait times are too long, holding the clinician up from visiting other patients.'
- 'Before palliative care line set up often wanted to send an ambulance following expected death had occurred.'
- 'Often long waiting times to be contacted, triage is often not effective as 111 make several calls before we can speak with a local GP who can assist. Sometimes I have had to call 111 several times as no one has phoned me back. Call backs were of varying times. Please keep the specialist palliative line.'
- 'Clinician rang back anywhere between 20 minutes but I have experienced waiting for call-backs for more than an hour.'

ShropDoc Palliative Care Line Experiences

Patient / Carers:

- 'This service has taken a lot of stress off our minds. We have had to use 111 in the past and it was atrocious and very stressful, lots of questions, no urgency in organising a call back. This service was quick, no silly questions

and quick prompt return call. As a family we feel much calmer about getting help when our nurse is off duty.'

- 'Understanding, respectful, caring'
- 'I am a district nurse, have used the palliative care line many times during COVID-19, and I have nothing but praise for the staff, call staff and Doctors to drivers have all been extremely helpful when I have help or advice with end of life patients, even delivered medications and paperwork required. This helped the patient gain the medication required asap and eased a possible stressful time. If this direct line could continue it would be extremely helpful for us as staff in the community but it is also benefiting the patients we all care for the best we possibly can.'
- 'Palliative care call was close to 08:00. It was suggested I wait for the GP. GP advised and gave me hospice contact of [staff member], she has subsequently visited. My wife has had intensive care for 3yr 3 months. She requires more assistance, as yet I am able to manage with am and pm carer. It is good to know that should the instance or time come when more care is needed or there is a night-time or weekend crisis then assistance can be available.'
- 'Patient needed the support of syringe driver. Out of hours help invaluable'

Professionals:

- 'This process is more efficient and effective when dealing with palliative care patients in the community. There was minimal delay in treatment and the fact the care is streamlined reduced the second guessing of the urgency by a call handler'
- 'As a District Nurse, I have found this service invaluable to supporting families and patients to be cared for at home. To have a direct line when caring for a palliative patient has been time saving and of a huge comfort to the patients and their relatives. There have been occasions where the DN may have had to phone ShropDoc previously for the patient but now the relatives can do this and a care plan can be put in place quickly. I think if this service was to cease it would have a detrimental effect to palliative patients being cared for in the community.'
- 'The patient was not end of life palliative, however, had persistent hiccoughs following chemotherapy and the advice given was very helpful.'

- ‘The feedback from relatives has been very positive. They have used it frequently and have felt well supported and advice has been excellent. Timely response to call.’
- ‘Not specific to one particular patient, but generally I have found the palliative patients on my caseload have been so reassured to have a direct line to ShropDoc, significantly reducing their anxiety out of hours/weekends. The patients that have used this line have all reported prompt responses and praised the service.’
- ‘I use this helpline as a clinician. I recommend the helpline to palliative patients and families instead of 111. Without exception the feedback is positive. Not having to answer the lengthy and irrelevant 111 triage questions, not having an ambulance sent inappropriately and speaking to knowledgeable clinicians are the most common feedback points that I am told by families of palliative patients. They are relieved to be able to speak to someone in Shropshire who understands their problems and concerns and can arrange appropriate and timely help. Occasionally I use the helpline to call a colleague at ShropDoc if I need to discuss a patient’s treatment or other options. Sometimes I also triage the initial calls that come through on the helpline.’
- ‘Excellent service compared with the 111 service which introduces a lengthy wait time.’
- ‘As a professional this has reduced waiting time for end of life patients in gaining symptom control as previously there was incident going through 111 it could take all day. Patient care for this group of patients is paramount we only have one chance to get it right for the patient/family.’
- ‘I have accessed this service regularly as a community staff nurse looking after patients who are receiving palliative care at home. It is great to be able to access locally based clinicians who understand the locality of the area we work in and the challenges this sometimes causes. It is good to not have to go through endless, sometimes inappropriate, questions with 111. I have no hesitation in asking families / carers / friends to call this service if there are any concerns or issues with a patient. It removes the distress and hassle that some relatives have gone through when accessing 111.’

- ‘Good outcome due to Doctor’s extensive knowledge. This resulted in a quick response to patients’ condition.’
 - ‘Immediate answer to phone call. Helpful and relevant information from call handler, who arranged for a ShropDoc professional to review the patient within the next hour. Excellent service.’
 - ‘The palliative care line used is responsive and assists in the speedy delivery of care to patients who are EOL. Having had to use 111 in the past this specialist line improves patient care and safety.’
-

Key Findings

In most aspects both patients/carers and professionals had more positive experiences of the additional support provided by the dedicated ShropDoc Palliative Care Helpline when compared with the NHS 111 service.

Getting a quick response when help is needed

- Patients/carers reported higher levels of being able to speak to somebody who could help when they first rang ShropDoc, 44% of calls, as opposed to 36% of NHS 111 calls. The difference between the services for professional experiences was greater with 56% of calls to ShropDoc leading to them speaking to somebody who could help against 31% of calls to NHS 111.
- 48% of all ShropDoc contacts and 63% of all NHS 111 contacts needed a call back. ShropDoc called back 100% of patient/carers and 86% of professionals within 30 minutes. NHS 111 responded within 30 minutes to 44% of patient/carers and 36% of professional calls.
- 95% of callers to ShropDoc reported being either ‘very satisfied’ or ‘satisfied’ and 40% of callers to NHS 111.

NHS 111:

- 'It took a long time to get through, then a long wait for a return call.'
- 'Very long winded'
- 'Wait times are too long, holding the clinician up from visiting other patients'

ShropDoc:

- 'This service was quick, no silly questions and quick, prompt return call.'
- 'The patients that have used this line have all reported prompt responses and praised the service'

Quality of Service

- All Patients/carers and professionals were 'very satisfied' or 'satisfied' with the service provided during their contacts with ShropDoc as opposed to just over half with their contacts with NHS 111.
- Patients/carers contacting ShropDoc described the staff's understanding of the local area as 'excellent' or 'good' in 100% of their contacts and felt that this had a positive impact on their care in 89% of contacts. Professionals had a similar view, described as 'excellent' or 'good' in 87% of contacts and a positive impact in 88% of contacts.
- There was a significant difference in the way patients/carers and professionals felt about the NHS 111 staff's local knowledge and the impact on care it had. Patients/carers thought the local knowledge was 'excellent' or 'good' in 45% of contacts while professionals thought it was in 27% of contacts. Patient/carers thought that the lack of understanding had a negative impact in 18% of contacts while professionals thought it had a negative impact in 45% of contacts.

NHS 111:

- ‘The lady on the phone was very helpful and went through the process they have to go through, and she then told us that a clinical colleague would call back to help.’
- ‘I find 111 works very remotely and do not understand the area I live in’

ShropDoc:

- ‘I am a district nurse, have used the palliative care line many times during COVID-19, and I have nothing but praise for the staff, call staff and Doctors to drivers have all been extremely helpful’
- ‘The feedback from relatives has been very positive. they have used it frequently and have felt well supported and advice has been excellent.’

Overall experience

- Patient/Carers rated their experience as ‘excellent’ or ‘good’ in 100% of contacts with ShropDoc as opposed to 36% of NHS 111 contacts.
- Professionals rated their experience as ‘excellent’ or ‘good’ in 100% of contacts with ShropDoc as opposed to 18% of NHS 111 contacts.

Service provider response

Both ShropDoc and the West Midlands Ambulance Service have been invited to provide a response to this report. Due to the pressure both services are under because of the pandemic these have not yet been received but will added as soon as they are available.

Acknowledgements

Healthwatch Shropshire & Healthwatch Telford & Wrekin would like to thank the organisations who helped to promote this survey. We particularly thank all those people receiving services who have shared their experiences with us.

Get in Touch

Please contact Healthwatch to share your views and experiences of this service or any other health and social care service in Shropshire, Telford & Wrekin. We gather comments anonymously and share them with service commissioners and providers to highlight areas of good practice and identify areas for improvement.

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Appendix A - Survey Questions

Section 1 - Please tell us a little about yourself or the person on whose behalf you are filling out this survey.

Are you:

- Receiving palliative care
- A family member, friend or carer of somebody receiving palliative care
- Other: Please describe

Age of patient:

- Under 18
- 18 - 24
- 25 - 34
- 35 - 44
- 45 - 54
- 55 - 64
- 65 - 74
- 75 - 84
- 85+

Condition for which you, or the person on whose behalf you are responding, are receiving palliative care:

- Free Text

Which council area does the patient live in?

- Shropshire Council
- Telford & Wrekin Council
- Powys County Council
- Other: Please describe

Section 2 - Please tell us a bit about the services you have used to access care.

Before hearing about this survey which out of hours services were you aware of?

- ShropDoc Palliative Care Helpline
- NHS 111
- Other: Please Specify

For each experience the questions were:

How did you find out about this service?

- Free Text

Thinking about the last time you contacted them about the palliative care condition, please choose an option that best matches your experience:

- I spoke to somebody who could help straight away
- I had to wait for my call to be answered but then spoke to somebody who could help.
- I had to wait for my call to be answered and then somebody had to ring me back.
- I was unable to get the help I needed

Please tell us more (if unable to get the help needed)

- Free Text

If you received a call back, how long did you have to wait?

- Less than 15 minutes
- 15 - 30 Minutes
- 30 - 60 minutes
- 1 - 2 hours
- 2 - 4 hours
- Over 4 hours
- I did not receive a call back

How did you feel about this wait?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- Not Applicable

How satisfied were you with the service provided by the member of staff helping you?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied

How would you describe the member of staff's understanding of the local area and local services?

- Excellent
- Good
- Fair
- Poor
- Very Poor
- Not Applicable

What effect did their understanding of the local area and services have on the care you received?

- Positive effect
- No effect
- Negative effect
- Not Applicable

How would you rate your overall experience?

- Excellent
- Good
- Fair
- Poor
- Very poor

Is there anything else you would like to tell us about your experience?

- Free Text