Healthwatch B&NES Community Pot
Final project report 2018-19

If you have any questions about this report, please contact Alex Francis,
Team Manager Healthwatch B&NES
T: 0117 9589 347 or **E:** alexfrancis@thecareforum.org.uk

The deadline for report submissions is 4pm (midday) on Monday 30 September 2019

***NOTE**: The text boxes will expand as you type.*

SECTION A: YOUR ORGANISATION

1. Name of Organisation	West of England Rural Network - WERN
2. Full Address of Organisation (for correspondence)	Unit 2, The Barn, Lady Farm, Chelwood, Bristol, BS40 4NN

3. Contact details

Main Contact for reporting	
Name	Denise Perrin
Position	Project Manager
Telephone	01275 333701
Mobile	07973 148699
Email	denise@wern.org.uk

SECTION B: THE PROJECT

4. Focus of project

- Please state clearly what issue(s) your project looked at.
- Were these the issues that you had planned to focus on?
- If not, please explain what the project focused on and how and why the focus changed.

The project focussed on engaging with rural residents who are isolated by geography or circumstance. These included older people, carers, younger adults, single parents and mothers with young children. The only group that we did not find people willing to engage with the process were young people in their early twenties. Those we spoke to were reluctant to disclose their thoughts and experiences in any formal way. Some gave off the record comments which will be included later in this report and anonymous contributions.

The aim was to hear the voices of those who are rarely asked their opinion but have a lot to tell us about their experiences of health and social care. From our existing knowledge we planned five topics to focus on:
1) Rural Transport
2) Difficulties finding care providers who will deliver to rural areas
3) The escalating cost of care in premium rate rural postcodes

4) Communications between medical providers, GPs and patients
5) Difficult appointment times that don't account for distance to travel

We did focus on these topics, but also found that additional topics emerged as we talked to people, so these were incorporated in discussions and will be referred to in Section 6.

We were very determined that during the 8 month consultation period people would understand the ongoing important role of Healthwatch and that our collaboration would continue after this campaign, allowing everyone a future space to place their ideas, comments and observations.

5. What did you do?

- Using your Memorandum of Understanding for reference, please tell us what progress was made against each of the activities that were due to be delivered through this project - including numerical data for outputs where agreed.
- Please include details of any factors that contributed to or impeded the achievement of the agreed outputs.
- If the agreed outputs were not achieved, please explain the reasons why and any actions that were taken to try to address this.

***NB** – Please include any photos, video links, examples of surveys, media and communications used etc to illustrate what you did in the box below or attach them as an appendix.*

We talked to a total of 211 people over 13 separate occasions. Four of these were focussed one to one sessions with people who wanted to contribute but were unable to do so in a group setting; seven were during community group sessions of between 14 and 20 people and two were at larger groups of around 45 people.

The framework for each conversation was:
1) **context** of the campaign
2) **your view is important** to a wider understanding
3) our **listening is the start of a process** well established by Healthwatch
4) we have **useful information to share** that may be relevant to your situation
5) our conversation can also lead to **referrals for other support**

We offered people a simple format questionnaire (see appendix 1) to ascertain which of the eight services people had used within the last 12 months. They could tick a box and add comments which were later compiled. A total of 107 forms were completed. Couples tended to share one copy although everyone was invited to provide their individual experience. People were also encouraged to award a Gold Star for excellent service across the same service groups. A total of 175 gold stars were awarded and are analysed later in this report. This questionnaire provided the best feedback for the larger groups and suited those who were less vocal but had something to share.

Each group session included a discussion with opportunities for people to share their individual experiences within small group of four to six people. These facilitated sessions

allowed conversations to widen out and respond to topics that were relevant to those in the room. New topics emerged and we allowed time for these to be fleshed out within the context it was raised. We also had good opportunities to correct any misconceptions and where possible offer accurate information (e.g.: 111 service can be accessed by anyone over the age of five), pick up on individual complaints (and explain that these would be directed at advocacy services), recognise unmet needs (which were directed at our Village Agent service) and tell people about services that were directly relevant to a topic discussed (e.g. new provider of Non Emergency Patient Transport since June).

The groups/events we held or attended were:

March – Goldies Singing Group, Timsbury (20 people)
March – Pensford Healthwatch event (12 people)
April – Monday Club, Chew Magna (18 people)
April/May – Individuals (4)
May – West Harptree Lunch Club (16 people)
May – Wellness Wednesday (20 people)
June – High Littleton WI (42 people)
June – Timsbury Toddlers (20 people)
July – Chew Magna Toddlers (20 people)
August – Wellness Wednesday Open Day (45 people)

We also interviewed some participants on camera, particularly where they had direct experience of one of our focus themes to expand upon. To gain insight into the largest topic of rural medical transport and early morning appointment times, we interviewed attendees of Wellness Wednesdays on camera. We also interviewed a lady who had been frustrated by the lack of communication between services, which was another of our focus topics.

We created four short videos from all the interviews. One has been available online during the whole project period and was shown in March at the Chew Valley Forum where we presented our campaign to an audience of 50 people – Parish Councillors, local residents, statutory service providers and members of the public). https://youtu.be/YdegjDXqtHE

Three were used as topic teasers at our largest event held in August. These proved to be successful with those who could relate immediately with the words of others. All of the videos have been combined into a single film which is now available online or on DVD to be made available with our public report.

Video 1 transport https://youtu.be/PO5RjaYbsd8

Video 2- Patient Transport and Appointment times https://youtu.be/Md33Fjm588g

Video 3 – Olive's Story – Communication and patient notes, https://youtu.be/PICXPajHGpo

Combined and final video. https://youtu.be/oubjpKl5yzk

6. What did you find out?

- Please outline the key findings from your project, considering:
  - key themes from the feedback that you received

- themes related to any particular health and social care services that participants said that they used
- what participants said worked well (with regards to health and social care)
- where participants felt things could be improved (with regards to health and social care)
- any conclusions or recommendations that your organisation would like to make based upon the feedback that you have received (please try to make these SMART – if you would like to discuss these further please do not hesitate to get in touch with us)

***NB** – Please include any relevant survey data, tables/ graphs, case studies etc to illustrate what you learnt in the box below or attach them as an appendix.*

Please also see more details in appendix 2- Case Studies and stories. Also video links supplied. The main five topics we originally planned plus three more.

1) Rural Transport was one of the most talked-about themes at all the sessions we facilitated. There was great appreciation for the Chew Valley Community Car Scheme and many people commented that they didn't know what they would do without it. However, much frustration was shown about the stress, logistics and cost of organising transport to appointments if the Car Scheme was unable to help. This is very much a rural problem and there is a belief amongst those affected that people in cities and those who make the appointments just don't understand the implications or the stress that trying to arrange transport can cause. We filmed some of our Wellness Wednesday participants on what is a very emotive subject. They shared comments about very high taxi costs to attend hospital appointments - £60-£80 per appointment; bus journey that could take four hours to travel just eight miles because of the lack of direct bus services. Non Emergency Patient Transport and the lack of information and understanding of eligibility voiced many times as surgeries do not supply any information about this. Very few of our older people being able to access internet for information. Also view videos : **Video 1 transport** https://youtu.be/PO5RjaYbsd8

2) Difficulties finding care providers who will deliver to rural areas
3) The escalating cost of care in premium rate rural postcodes

Care provision and the cost of care in rural areas showed itself to be a worry for participants; even if they had no concerns right now they worried how it might affect them in the future. Many of our participants were also unpaid Carers and had concerns about how they would be supported as the needs increased and pressure would inevitable fall on them. The overriding fear is about having the funds when they became unable to cope and was echoed through our people living alone. "Asset rich but cash poor" explained one man of him and his cohort of local friends. As Village Agents we now see an increasing number of people who are living very frugally, almost to the point of self neglect, heating off during extreme weather and not eating as well and they should. We have conversations about their "rainy day" funds but they tell us that those had diminished significantly (they used to be able to live off the interest of their savings) and as they hear about the increasing cost of outside help, they live in fear of having to ask for help.

See also Case Studies - Appendix 2.

4) Communications between medical providers, GPs and patients
This was a topic that provoked much discussion. It transpired that many of these problems seem to occur when patients receive treatment from services outside B&NES. Letters not being received, test results not being transferred, the lack of sharing information between different consultants...all these left people feeling frustrated and annoyed that they had to give the same information time and time again or undertake the same assessments at each different provider. This places a huge responsibility on the patient to hold all the current information about their medical status; and impractical (for those with memory issues) and risky (for anyone who doesn't fully understand what they are going through). We talk to people who have no accurate recollection of whom they have seen and exactly what for but they had an appointment somewhere. Yet everyone is told that "Tell your story once" was a CCG promise and fundamental to the outcome of Your Care, Your Way.

There seemed to be a common perception that "Bristol hospitals don't speak to Bath" or vice versa. The frustration was almost always directed at "the system" rather than at individuals. Olive's Story, available as a video, was shocking in the lapse of information exchange. She was told to get to her GP as soon as possible after an examination during an appointment at the Bristol Eye Hospital indicated that she may have had a stroke. Not only did she return home to have difficulty getting an emergency appointment, there was no forwarded information at all from the Eye Hospital or South Bristol Hospital where she was sent for immediate investigation.

See Case Study and video - Olive's Story. **Video 3** https://youtu.be/PICXPajHGpo

5) Difficult appointment times that don't account for distance to travel
Although some people told us that they do routinely ring the booking number on receipt of a letter and reschedule early morning appointments, the majority do not. Fear of losing that vital slot, having awaited it for months or weeks, was the first reason. Those having ongoing treatments or regular check-ups "knew the system" and felt more confident of negotiating times.

Difficulty with early morning appointment times is largely linked to transport but distance is also a factor. Logistics are difficult for those in rural areas to make an early appointment if they don't have their own transport and have to rely on friends or community transport. Bus services are limited and even more so before 9am. People told us that their bus pass was valid from 9.30am onwards, if they could get a lift to a decent bus route. 9am appointments at the RUH require at least two hours for people to get to the city, through rush hour traffic or to Odd Down Park and Ride (the nearest P&R at Newbridge does not have a direct shuttle bus), parked and then to the correct location. Volunteers of the Chew Valley Car Scheme encounter people being unwell on the journey because they haven't eaten breakfast or taken medication because of the early start. Early morning requests are less easy to fulfil by that service.

We were told that late arrival for an appointment usually meant being turned away whereas Patient Transport later arrivals were given a more sympathetic response. The general

feeling was that service providers should be able to consider the postcode of patients before making an appropriate appointment time. We are aware that the 3 Valleys PCN is now trying to get more consultations within GP's surgeries which will help a lot.

See (Pat & Edith) Case Study : **Video 2- Patient Transport and Appointment times** https://youtu.be/Md33Fjm588g

With both transport and appointment times, it became clear from talking to people that the emotional impact of organising and worrying about how to get to a medical appointment often supersedes any worries the patient has about their health condition.

Three further topics emerged as being very important to voice.

6) Cross Border complications: The Chew Valley sits close to the borders of Mendip District, Bristol and North Somerset, with patients living in these local authority areas but registered with B&NES based GPs. Logistical problems arise on discharge from hospital where care might be required. Virgin Care District Nurses and Reablement Teams often provide bridging care until a solution can be found. Patients are in the middle of complex arrangements and keeping up to date is a challenge. Bristol hospital do not supply B&NES community health teams with up to date discharge information (there is no Green List) so forward planning and keeping care packages on hold is very tricky.

It's not unusual for an individual to find themselves in limbo because each authority refers them back to the other for information. At Chew Magna Parent and Toddler Group, whilst most were complementary about the support they had been given by midwives and health visitors, those living in border villages felt very isolated. One lady living across the border in Winford told us that local weigh-in sessions were disappointing for their lack of bringing local Mums together for peer support – a missed opportunity. The only other sessions are in Weston super Mare, impossible for her to attend.

7) **Patient Choice** also came up in conversations. Many feel there isn't really a choice, largely due to the transport problems already mentioned; you will choose the easiest place to get to rather than your best choice. There is also the need for information about each of the medical facilities. People said that the most useful way of finding out about different hospitals or services is often through talking to people who have had the experience, or who are knowledgeable about what is on offer. Community groups getting together to enable these conversations to happen was recognised as being very important, and projects such as our Wellness Wednesdays offer this opportunity and allow people to freely discuss their situation.

8) Information in a format appropriate to each patient's needs. There seems to be a mixture of too much information but less clarity about the most important fact within that information. Letter from Consultants or instruction to attend an appointment are often the reason why people will call a Village Agent. They might be in fear or panic or just not understanding the content. "Do I have to do something?" when it's mostly confirmation of a diagnosis or investigation route. Letters that include leaflets and further reading are also confusing and often overwhelming. If an investigatory appointment is looming, important information such as "Do not eat for (specified period)" or "take specific actions before attending" are lost in these confusions. Ideally, patients will have someone with them at

important medical meetings but that is not always possible.

People told us that this important topic is one for further discussion because no one system will fit all.

Olive's Story (used as illustration in topic 4 – Communication between services) also contained a shocking lack of process when she attended a routine appointment at the Bristol Eye Hospital. She had been many times before and maybe many years ago, someone did go through all the warning and side effects with her. At that time informed consent was given and she has continued to sign the form at each visit. Inevitable, with macular degeneration, she is unable to read the form but still signs consent. After one examination revealed a suspected stroke, she did ask for clarification and was reminded of the potential risks of the procedure.

Olive is due an operation for cataract and was given good information of which some was in larger print but she felt this was not sufficient. Being very able online, she contacted the RNIB who sent excellent larger print information and an audio file on CD. It does feel that patients with impairments should have vital information available and for someone to check that they are indeed informed.

9) **Peer support** at all ages is a key ingredient in reducing the stress for patients.

An example of this happened when we talked to individuals from the Chew Valley Parkinson's UK group who regularly attend our Wellness Wednesday sessions. This led to a request for more information about home delivered services. Through this project, a participant had told us about the excellent service offered by The Outside Clinic for home hearing and sight tests. We arranged for one of their representatives to attend our final event and spend an hour exclusively with that group. During that chat one individual was referred to Paulton Hospital for lip reading sessions. Their peer support conversation allowed the group to voice their concern about multiple cancelled appointments for vital 6 month check-ins with the specialist nurse at the RUH. GPs rely on this system to cover symptoms and solutions that fall outside of their expertise but their cancellation meant this isolating disease was becoming more of an ordeal to manage. We were able to relate these problems to Healthwatch and appreciated Pat Foster's attendance at this session. Since this session we have heard that Chew Medical Practice are hosting Parkinson's outreach appointments.

The need for peer support was also very evident at the Parent and Toddler groups we attended, along with a frustration about not being taken seriously or listened to. Although most were happy with the service they received, several said that when they were particularly concerned about something, they felt patronised and told "all babies cry at night". One Timsbury mum had a battle to get the right treatment for her baby who had infant food intolerance. Desperation led to her researching her own solutions, getting a private food allergy test done and presenting those finding to the GP. She now talks to the Todder group and supports other young Mums who feel they are not being taken seriously when you express real fears and actual symptoms. It became clear to us that these peer support groups are vital for young parents whether they are getting on fine or struggling most of the time. One lady suggested that these groups should be supported more by the

NHS information services.

Our survey results:
Our survey was offered as an icebreaker and engagement tool but nearly half the people we spoke to followed up with a written response.

The results of our survey allowed us to capture some quantitative data and give a snapshot of services used by the participants in this project. 107 surveys were completed. These show that the most used service (in the last 12 months) was GP Surgeries (102 users) followed by Pharmacies (78 users), Hospitals (75 users), Dentists (67 users), Opticians (54 users), Community Health & Social Care (39 users), Emergency Care (34 users) and Care Homes (18 users).

Participants were encouraged to award Gold Stars where they felt the service had been particularly good. Of 175 Gold Stars awarded, the top three recipients were GP Surgeries followed by Hospitals and Community Pharmacies.

Gold Stars Awarded	
GP surgeries	**57**
Hospitals	**27**
Community Pharmacies	**26**
Dentists	**19**
Community Health and Social Care	**18**
Emergency	**18**
Optician	**8**
Care Homes	**2**

See Appendix 3 for analysis of % of Gold Stars awarded relating to numbers of service users.

Young people engagement- This was our area of disappointment because we had good contact for school leavers who are now in their 20s. We tried a number of routes to engage with individuals and their friends and non wishes to go on the record. They voiced their anxieties about being in between a school experience, where they widely told nobody anything and living at home with their parents. They did accept help when it became clear they were unwell but would not make appointment and seek wider help unless things were desperate. All their information was researched online and this is where they might feel most reassured. Mental health has always been a concern in the Chew Valley but most of our late teens to early 20s had experience of a suicide of a pupil at their school. Chew Valley School has a good history of supporting their young community at such times. Winston's Wish continues to be an organisation that we refer younger people to. Support for those with extra needs has historically been hard to find and parents tell us that their lives have been overshadowed by a constant need to be vigilant with each step in childhood development being a major battle.

7. Demographic information

- Using your Memorandum of Understanding for reference, please report who you engaged with through this project, including any agreed questions such as:
  - postcode
  - age range
  - disability
  - carer etc
- Did you identify any differences or themes in the experiences of different demographic or protected characteristics groups (i.e. that might suggest barriers to and/or potential inequalities in access to health and social care services)

At the community groups that we visited (Parkinson's Group, West Harptree Lunch Club, Chew Magna Monday Club and Toddler Group in Chew Magna and Timsbury) it was not practicable to collect individual postcodes but we know from long association with the groups that the participants come from a wide surrounding area for each meeting. Of the 23 B&NES Parishes that our Village Agent service covers all were represented with others coming from rural villages in North Somerset and Mendip. Keynsham was also represented and a few people came out from Bath for our events.

Postcodes we covered are: BS39, BS40, BA2, BA3, BS14 and BS31.

We covered four main age brackets:

25-44 in our conversations at the two Toddler Groups
45-64 at High Littleton WI and Golden Oldies
65-74 and 75+ at all other groups

Our engagement with those aged 75 plus is particularly noteworthy as this is a demographic which can sometimes struggle to be heard. Many of our participants are in their late eighties, the oldest person we spoke to is 97.

We also spoke to 12 couples where one was the unpaid Carer for their partner.

Long term health conditions include: Heart and blood pressure conditions, COPD, Hearing and Sight loss, Parkinson's. Alzheimer's, Memory loss. Stroke. Post Cancer complications, Lymphoedema, Arthritis, Osteoporosis, Depression, Mental Health difficulties.

8. Outcomes – please tell us how this project has impacted those people who took part?

NB - *If you have any testimonials or quotes that you would like to share to demonstrate the outcomes that your project achieved, please include them in the box below or attach them as an appendix.*

Mrs T – Thank you for this event today. I learnt a lot as well so it was well worth coming.
Mrs C – That was a fascinating afternoon. I had no idea that people are struggling so much with transport. It's going to be terrible when I have to give up driving. I think I might

volunteer to drive for the car scheme.
Mr W – You are talking to the converted here. How about tell all those people who make the decisions! (he went away reassured that all our finding will go to those who make the decisions).
Anon – Nobody has asked for my opinion before. That was the best part of today, being able to tell someone what has been happening.
Anon – We are very lucky in this area with our GPs considering all the pressures they are under these days. It felt good to award them a Gold Star. Tell them they are very good.
Mrs L – I live in a bit of a bubble with my husband. Different people coming and going. I gave my Gold Start to the Community Matron because she has been such a huge support. That was a small way to say thank you.
Jenny (Parkinson's Group organiser)- Thank you for today. We try to provide support and understanding for each other but today showed us that we are not so alone and we can talk to people like you to get our concerns heard. Pat Foster was very helpful too so please tell her how much we appreciated her coming today.
Toddler Group leader (Chew Magna). We love to help the Mums get together and that peer support is so essential. Thank you for making time to listen, that is very important too as it gets so isolated, even for this age group.

9. Considerations

Did you have to take any steps when designing and conducting the project to ensure the safety and wellbeing of your participants? If yes, please explain what these steps were and how you overcame them. Example areas include: Data Protection, Ethical considerations, safeguarding etc.

The open and public nature of this project brings in some people who we might have concerns about. In one case we spent one to one time with that individual and continue to help him through a complaints process that might be passed to medical negligence solicitors. Once again, this is about poor exchange of information between two hospitals and his GP.

Some of our participants were unable to attend a group session due to their health conditions. In these cases we visited them in their own home to allow them to take part and gain an insight into their unique circumstances.

Larger group sessions were opportunities for Pat Foster to join us. Both of these events were the richer for her being able to address points as they were raised. People told us that her attendance added weight to the process of listening.

Videos were produced with subtitles. Permissions were gained on camera which is standard industry practice and have been retained.

10. Next steps…

What action do you think needs to be taken now to share the feedback/ conclusions/ recommendations from your project and help to improve people's experiences of health and social care services in B&NES?

- Please refer to your Memorandum of Understanding for any actions that had been agreed between your organisation and Healthwatch B&NES.
- Please let us know if your organisation is planning to carry out further work in this area.
- Please let us know if there is anything further that could be done in partnership with Healthwatch B&NES. We are very happy to work with you to escalate feedback, best practice and concerns where required. If it would be useful to talk about this in more detail please do get in touch
  E: alexfrancis@thecareforum.org.uk or **T:** 0117 9589 347

Care provision in rural areas- As a Village Agent service that supports vulnerable, isolated and under the radar people, we are concerned on a number of counts: Care assessments are difficult to arrange with long waiting lists. Self funders are draining their resources more quickly than ever before as they pay well above urban rates for care. Longer term, what happens when the money runs out? Especially for those who pay for residential care, also at premium rates. We would like to see more proactive consultations that get out into the community to find out more, where there is potential for local micro care and if anything can be achieved with some better creative and strategic thinking.

The consultation B&NES Council - Care and Support Charging and Financial Assessment Framework has just opened and will be assisting as many people as possible to contribute to that process and hosting sessions in Compton Martin and Timsbury.

Communication and patient records between medical facilities - We mostly operate in the North East of B&NES but with Patient Choice and being referred to specialist centres of excellence that can mean people using medical facilities in North Somerset, Bristol, Somerset and Wiltshire. We are aware that the NHS have an aspiration of centrally stored patient records and B&NES CCG "Tell your story once" was a big part of the Your Care, Your Way consultation. The reality is that information flow is far from perfect and in some cases, causing distress with potential high risks to patients. We have concerns that some consultations start without up to date notes and patients are asked to fill in the gap themselves. For confused and now angry patients, this undermines trust and confidence.

Of all the topics discussed, patient notes and clear communication before and after appointments is the most important of all. Whilst we can support people with many of the logistics, we have no answer for the poor exchange of information and no amount of public engagement can solve this.

We will continue to have conversations with the people we meet daily. There is more awareness of Healthwatch and people are more likely to voice their fear, opinions and ideas than before this project. Our videos will be available for the rest of 2019. We intend to publish our report which we will make available at our next public event on 30th October.

11. Working with Healthwatch B&NES

This is the first time that we have run a small grant scheme for VCSE organisations. We very much hope to be able to continue this funding stream and build relationships with partners across B&NES. We would therefore be very grateful for your thoughts on which elements of this process have worked well and if there was anything that you think we could improve on or do differently next time.

The grant application process was quite straight forward but might intimidate those smaller community groups who could offer good insights into their world of experience. It would be good to find a way in which to support the less heard groups, maybe with mentoring support to apply and then for the final report.

SECTION C: WHAT NEXT?

Please ensure that you have completed **all** sections of this report. Once complete, please submit this report electronically along with any accompanying documents) to Alex Francis
E: alexfrancis@thecareforum.org.uk

The deadline for report submissions is 4pm (midday) on Monday 30 September 2019

We aim to hold an event for all grant recipients to discuss the findings of their projects with one another and the Healthwatch B&NES Executive Board. Details of this event will be shared in due course.

NB - The financial report is a separate document. This also needs to be submitted by 4pm on Monday 30 September 2019.