

Healthwatch B&NES Community Pot Final project report 2019-20

If you have any questions about this report, please contact Vanessa Scott,
Portfolio Manager Healthwatch B&NES
T: 07754780487 or E: vanessascott@thecareforum.org.uk

The deadline for report submissions is 12.00 (midday) on Friday 29 January 2021

NOTE: The text boxes will expand as you type.

SECTION A: YOUR ORGANISATION

1. Name of Organisation	Action for M.E.
2. Full Address of Organisation (for correspondence)	42 Temple Street, Keynsham, Bristol BS31 1EH

3. Contact details

Main Contact for reporting	
Name	Ruth Richardson
Position	Operations Director
Telephone	0117 927 9551
Mobile	07719 315207
Email	ruth@actionforme.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.

Our project looked at addressing health and social inequalities for adults with M.E. by:

- Facilitating self-advocacy workshops to develop self-advocacy skills and collate data about people's experiences of health and social care services in B&NES.
- Providing direct, one-to-one casework/issues-based advocacy to adults with M.E. to help them redress barriers to accessing health and social care services and support
- Use the views, wishes, feelings and experiences of people participating in the workshops and advocacy, alongside data from Action for M.E.'s 'Big Survey' (2019) with over 4,000 people in the UK to feedback to commissioners and service providers, to create systemic impact/influence from service provision

These were the issues we had planned to focus on.

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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.*

Project out puts:

1) Action for ME will work with 41 beneficiaries

Since June 2020, Action for M.E. has had contact with nearly 30 individuals living in BANES via our Crisis, Support and Advocacy services, and online enquiries. Twenty one beneficiaries from BANES attended advocacy workshops and/or one to one advocacy casework during the duration of the project (extended to February 2021 due to lower than anticipated uptake of the advocacy service and workshops).

2) Deliver two self-advocacy workshops for 24 people through one face to face and one online

Our original plan to deliver one face to face and one online workshop had to be adapted in response to Covid-19 lockdown restrictions and, since June 2020, we have delivered four online self-advocacy workshops. Given the low uptake of referrals to one to one advocacy work, we agreed with Healthwatch to extend the project for a further 2 months and delivered a further 2 workshops during this time. We had 19 patients and carers from BANES register to attend these workshops, although just less than 50% (9) were able to attend on the day. We hypothesise this is due to the fluctuating nature of M.E. which means it is often difficult for people with M.E. to plan ahead or anticipate whether they will have energy to engage in a future activity.

Despite our marketing material clearly stating that these workshops were for BANES residents, and 'boosting' our social media posts within the BANES area using the underspend from the venues budget, we did have an additional 16 people register, and 5 attend, from surrounding areas.

Following the interest expressed from people with M.E. living outside the BANES area, evidenced through workshop registrations and requests on social media, we have since run a further national self-advocacy workshop (developed from the BANES Healthwatch model) which attracted nearly 65 registrations, with over 20 people attending on the day.

Some attendees of the workshop shared their experience on Facebook following the sessions, with one person commenting: This was interesting and helpful. I wish the advocacy service had been available to support when I went through process of ill-health retirement 20 years ago. Very pleased it's there for people now !

3) 15 people will receive one to one, direct advocacy support

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During the funded period we have offered direct advocacy support to 2 people with M.E. living in BANES on 3 separate issues.

We have attempted to increase referrals by targeted promotion of the advocacy service to patients via: BANES Healthwatch networks; 3 local M.E. support groups; BANES GPs (via BSW CCG); BANES Carers Centre; and Bath Centre for Fatigue Services at the RUH. We sent information on our advocacy service to 60 Action for M.E. supporters living in BANES. We shared Facebook posts related to the workshops, which reached received 86 likes, 37 comments and 22 shares. All workshop attendees were informed of the availability of one to one advocacy support but there was not take up from workshop participants. We also included an article in Interaction (our regular magazine to over 4,300 people living with M.E.) in Autumn 2020 and supplied articles to Bath Chronicle and The Somerset Guardian regarding the project which were published in July 2020 (in advance of the first advocacy workshop).

- 4) Data will be collected on severity of illness, health inequalities and barriers to services experienced to be provided to Healthwatch, service providers and commissioners through a specific report correlating data from Action for ME's 2019 Big Survey**

Please see attached report.

- 5) Action for ME will increase biomedical research by providing information and support to raise awareness of existing research and increase participation of B&NES residents with ME**

All workshop participants were provided with details of the DecodeME, the world's largest DNA study of ME that is co-led by Action for M.E. The study aims to better understand the disease and ultimately find treatments through DNA analysis of 20,000 saliva samples provided by people with ME in the UK. Recruitment for the study will launch later this year and we have already received 23,000 expressions of interest from people who have said they are willing to take part in the study to increase biomedical research into the condition.

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.

- 6) The issues identified by patients and any plans to address them will be shared with Healthwatch so that they can be shared with Healthwatch England. - These will primarily be shared as key themes**

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through the final community pot project report. However concerns will to be brought to Healthwatch sooner where required, as outlined above.

See individual feedback below and attached report.

- M.E. is an invisible illness, people see us and think we're ok
- Medical professionals who don't understand or have experience of M.E.
- 'Brain fog' during an appointment, especially if we are attending alone
- Having the energy to fight or to advocate
- The emotional fall out
- Anxiety and other peoples perceptions
- Anger – having to retire due to ill health
- It's a multi faceted illness with many co-morbidities
- Bullying – at school and University by students and teachers
- Schools have no systems, no support during school – could leave with no grades
- Other health conditions and overlaps, find it hard to work with all different departments and keep them up to date
- The lack of understanding and bullying that I experienced at work
- Medical professionals don't talk to each other and this hinders our progress
- Having to prioritise other things sometimes
- Financial barrier – having to work to earn a living instead of taking care of myself
- bullying . It's only with hindsight that I can see some of the professionals I depended on to help me through were well out of order - and I'm sure at least one of them is still in the same post... I think it's a big issue and one where there needs to be support and follow up for M.E sufferers . We need to limit the damage from some of the professionals who have so much power over us

7) Action for ME will share their findings in a written report which will be submitted to Healthwatch B&NES: - Findings from the project will be shared with B&NES Council and BaNES Clinical Commissioning Group. - The report will be shared with Action for ME members via their website and social media. - The report will also be shared with appropriate boards and committees in B&NES and used as evidence to contribute as appropriate to the development of service improvements. - Action for ME and Healthwatch B&NES will work together, as appropriate, in order to ensure the findings from this project are widely disseminated and escalated where required. - Healthwatch may ask Action for ME to share further data/ intelligence where required to contribute towards the Joint Strategic Needs Assessment.

See attached Action for M.E. report.

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

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- 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)

8) Action for ME will record the following information about the projects participants Demographics to be recorded for:

- age range, gender, postcode, disability/condition and ethnicity.

Postcode	Ethnic Group	Age Range	Main Disability	Gender	Service User Group
BA2 2LT	White - British	45 To 54	M.E./CFS	Female	Adult With M.E.
BA1 7TZ	White - British	45 To 54		Female	Carer
BA2 5LX	White - British	55 To 64	M.E./CFS	Female	Adult With M.E.
BA2 2PL	White - British	25 To 34	M.E./CFS	Female	Adult With M.E.
	White - Other				
	White				
BA2 2TP	Background	45 To 54	M.E./CFS	Female	Adult With M.E.
	White - Other				
	White				
BA1 7PL	Background	45 To 54	M.E./CFS	Female	Adult With M.E.
BA2	White - British	Unknown	M.E./CFS	Female	Adult With M.E.
BA8 0HJ	White - British	45 To 54		Female	Carer
BAXXX	Unknown	Unknown	Unknown	Unknown	Unknown

- Which health and social care services they have used.

Health and Social Care services accessed by participants in the last 12 months



- What their experiences were of the self-advocacy workshops including what worked well, what they think could be better, and why.

100% of BANES workshop participants told us, following the workshop:

- they felt better informed
- they had increased self-advocacy skills
- they were satisfied with the service received from Action for M.E.

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Feedback on what worked well included:

- “It was really interesting and also to know you have rights.”
- “Well structured and paced effectively”
- “The zoom format worked well. Good to hear from other people's experiences”
- “small group meant it wasn't overwhelming or confusing which was more accessible”
- “Great to be able to access it from home- I'd never used Zoom before but it was easy to deal with”
- “Anna was very calm and patient and asked at regular intervals if we needed a break”
- “It helped to focus my foggy brain when I could see comments being written as well as the rest of the presentation . Anna talked us through all the points clearly . I like the "Right , Preference " idea . That will help me when I feel overwhelmed about the way forward in a situation . Also the "Control , influence , can't control" is a great way to get a foggy brain to focus , as is the "Action Plan"
- “Useful information and very clear presentation”
- “Great ladies who ran the course. Made us all feel welcome and part of the group.”
- “The organisers were very professional and committed”
- “Thanks for sending the information from the workshop through so promptly. I was able to look through it while the thoughts about it were still fresh in my mind. I feel I have a useful tool to support me with any issues that might pop up in the future.”

We asked participants for feedback on what they found most useful from the workshops and they shared the following:

- “Planning goals, thinking about what's achievable if you plan.”
- “Concise pointers about where to look for help. I'm pretty new to this.”
- “responding to each other e.g. filling out the grid and having access to the resources afterwards”

We received limited responses to our question “what could we have done better”, these were:

“You did great. A few more people would have been good, but that's probably out of your control!”
“Would be nice to get to know others in the group briefly, or have cameras on so its easier to chat and respond to one another, however of course this is difficult and should not be enforced!”

- What barriers they have faced in accessing the Action for ME workshop and/or online workshop and how these could be overcome.

100% told us they experienced no difficulties accessing the online workshop and would prefer to access future workshops online than in a face to face group meeting.

One participant shared “Even in non-covid times this is a good format due to no travel”, although another commented “Online very helpful as already stated, but human interaction brings other advantages”.

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.

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100% of BANES workshop participants told us, following the workshop:

- they felt better informed
- they had increased self-advocacy skills
- they were satisfied with the service received from Action for M.E.

One workshop participant shared:

“I wish I'd had access to what my rights were when I got M.E in the 90s , and how to get help to make my employer take their duty of care seriously . It would have been helpful to have had this advocacy support during the long and painful process of getting ill-health retirement , accessing benefits and facing benefits tribunals . It's taken a long time but at last M.E sufferers will be able to get the support they deserve!”

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.

We had planned to deliver online and one face to face workshop, however given the ongoing changes to Covid restrictions and the positive feedback received from the first online workshop, we chose to continue with online delivery to ensure the safety of all participants. Sign up was via an online survey and participants were then sent a secure Zoom link and password by email to join the online session. Consent to process data was given at point of registration.

No safeguarding concerns were raised during the online workshops or in delivery of one to one advocacy support.

10. Next steps...

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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: vanessascott@thecareforum.org.uk or T: 07754780487

We have been pleased to have had the opportunity to pilot online self-advocacy workshops through Healthwatch BANES funding. Despite many people signing up and then not attending the workshop, the feedback we have received has shown that the workshops are of value to people with M.E. and their Carers looking to increase their self-advocacy skills.

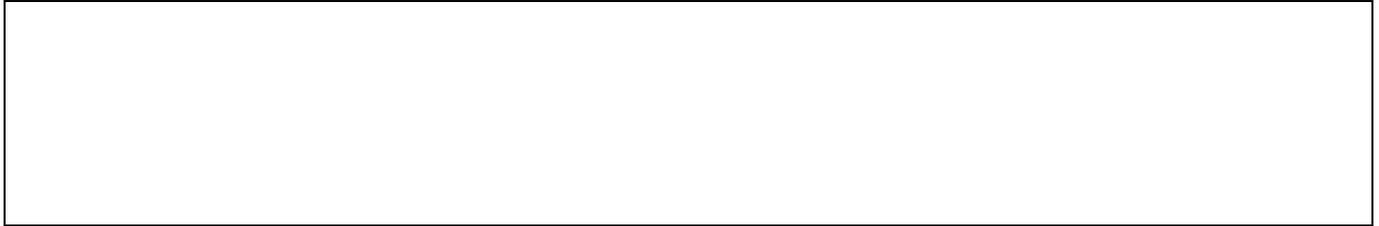
As a result of piloting the workshop approach, we have now mainstreamed this into our wider service delivery and are committed to delivering a minimum of 5 self-advocacy workshops annually. These workshops will be available to anyone in the UK, as we received many requests from out of are people wishing to take part during the BANES pilot.

11. Working with Healthwatch B&NES

This is the second 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.

We appreciate the flexibility in extending the grant timescales to enable us to deliver two further workshops during the project.

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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 Vanessa Scott
E: vanessascott@thecareforum.org.uk

The deadline for report submissions is 4pm (midday) on Friday 29 January 2021

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 12.00 (midday) on Friday 29 January 2021.