

Patient, Carer and Public Involvement in the time of Covid

Impact Report 2020-21

Background

Wessex Voices has, since 2014, worked to bring about cultural change in NHS England and Improvement's (NHSEI) approach to patient, carer and public involvement (PPI). This unique model involves a partnership with five local Healthwatch, independent consumer champions of health and social care, allowing us to engage people earlier in creating better services and health outcomes. Wessex Voices is hosted by Help & Care, a Dorset-based charity with more than 20 years of experience in patient and public involvement and community development.

In 2020/21, we worked primarily with the NHSEI Primary Care, Public Health and Wessex Cancer Alliance (WCA), as well as the emerging Integrated Care Systems based in Dorset and Hampshire and the Isle of Wight. By securing additional resource from WCA we went from providing part-time support to full-time support in August 2020.

Our approach is to:

- Focus on what is important to people and what is and isn't working for them
- Support NHSEI with their PPI assurance role
- Walk with NHS colleagues, providing practical advice, guidance and support so they can see how it can be done
- Reconnect NHS colleagues back to their values, local people and their communities so patients are at the centre of services
- Spread good practice and prevent the reinvention of wheels
- Share existing intelligence to stop people having to repeat themselves
- Translate 'health speak' so people can understand what it means for them
- Act as a critical friend and help provide solutions
- Facilitate an understanding of, and links with, local authorities and the voluntary sector

- Provide capacity for Healthwatch to work system(s)-wide and share their collective intelligence and approaches
- Work in a flexible, responsive and agile way

2020 has been a year like no other. Covid-19, as for many others, has had a dramatic effect on how we work and what would have been our work programme. This is especially because of its impact on our NHS partners' existing priorities and because we were unable to work in our usual way, face to face with people.

We had also hoped to use this year to work with colleagues to realign our work with the new NHSEI South East footprint, and the emerging new responsibilities of the Integrated Care Systems in this geography. The pandemic understandably made this difficult to achieve. However, we have flexed and adapted and continued to deliver valuable work making a significant impact, as set out below.

2020-2021 progress and impact

Impact: There has been a notable increased visibility of PPI in relation to WCA projects. There is also growing confidence in the team that we can and will do this, with the support of Wessex Voices. This change has been supported by:

- Wessex Voices representation on the Alliance Board
- Board discussions about a clear [Communications and Patient, Carer and Public Involvement strategy](#) and work programme, co-produced by Wessex Voices and Copia Productions with Alliance colleagues, partners and people
- The set up of a Patient, Carer and Public Involvement Network of patients, carers and the public (21 people); holding our first public information session (with 15 people); and launching our [‘Get involved’ webpages](#) and newsletter (to over 120 recipients)

- The launch of the Empowering Engagement Programme with 13 Alliance colleagues and partners.

Impact: More patients, carers and the public are now involved in WCA work from an earlier stage; [patient insight](#) is more readily available to the Alliance in ‘real time’, to inform their work, for example the recovery of services. We are also better networked with other organisations doing PPI. This has been supported by:

- Our development of patient and carer engagement for [Right by You](#), working with Macmillan’s Cancer Support Engagement Lead. As well as the original engagement supported by Wessex Voices and Healthwatch Dorset and Southampton (150 survey responses and 76 interviews), 10 people have joined the Advisory Group.
- Supporting the Alliance to gain £20,000 of additional funding, and partnering with Healthwatch Dorset, to support the [‘Our Cancer, Our Way’](#) coproduction with children, teenagers, young people and their families in the development of networked cancer services for them. Four young expert advisers have shaped the project from the outset and we have developed creative and flexible engagement mechanisms.
- Undertaking [41 interviews](#) with the first patients to experience the Rapid Investigation Service; and listening to people with learning disabilities and their carers about how the service can be developed to meet their needs.
- Supporting the relaunch of the [Communities Against Cancer](#), aimed at raising awareness of cancer and healthy lifestyles with seldom-reached communities
- Working with Dorset Race Equality Council to involve [Black men in a prostate cancer awareness campaign](#)
- Collating and sharing people’s insight, for example, into their [experiences of Covid and the impact on accessing cancer services](#) to inform the recovery of cancer services and Right by You; and the [‘Making the Right Decision: What matters to women in their first breast screening’](#) report (142 responses).

- Sharing feedback and helpful guidance from other organisations about people’s experiences of virtual appointments in ‘real time’ as this switch to remote consultations was having a significant impact on patients and NHS staff
- Continuing to provide advice and guidance to Alliance colleagues around their approach to health inequalities and PPI, for example, in relation to Academic Health Science Network (AHSN) and Alliance innovation bids
- Building relationships with ICS engagement colleagues to support the involvement of seldom-reached groups in Dorset and Hampshire/Isle of Wight.

“Wessex Voices has been integral to help me ensure we are considering patient and public engagement (PPE) right from the start of a new innovation programme. Sue has provided the crucial roles of facilitating connections with patient experience colleagues as well as offering advice and guidance around approaches so the programme can best ensure PPE. Most recently, Sue has helped the programme team to develop a new project PPE strategy and her support led to the organisation and delivery of a successful patient participation group to support this project planning.” **Anna Wykes, Programme Manager, Cancer Care, Wessex Academic Health Science Network & Wessex Cancer Alliance**

“Wessex Voices has been integral to developing, launching and improving the Rapid Investigation Service non-specific symptom pathway for suspected cancer patients. Wessex Voices has helped ensure a patient focus from the very initial stages of the programme. They supported the service to undertake a robust equality impact assessment and initial public view seeking prior to launch and fulfil an essential role as our critical friend, consistently and effectively evoking the patient voice. Sue and colleagues have enabled us to undertake robust, deep dive patient feedback, which we would not have been in a position to undertake independently. This has already resulted in direct and tangible improvements to our service including our written information for patients, how we welcome patients into our service, and then subsequently support them during their time with us.

They have also supported us to reach out effectively to seldom-heard groups, allowing us to consider how we can ensure we are providing an equitable service and can be responsive to individual patient need. I look forward to continuing to work with Wessex Voices as we move on to develop other patient pathways knowing that they will help me ensure the patient voice is always central and meaningfully heard as part of the RIS programme work.” **Kelly Spiller, Rapid Investigation Service Programme Manager**

“As a new member of the team and new to this type of post I have found Wessex Voices support incredibly helpful for a number of reasons. Firstly I think advocating engagement and ensuring this is evident within our plans and the ‘how we do things’ culture of the Alliance is so powerful. I personally have found the way you offer support really valuable: you challenge really constructively and have recognised the huge learning curve I am on, but have supported and nudged, rather than point out all the things I need to learn! I have found the support offered useful, practical and particularly the EEP has helped with relationship building and networking whilst focusing on engagement as a common purpose. The contribution and expertise offered to different aspects of my work programme has been really impactful - the innovations teams springs to mind immediately as engagement was overwhelmingly the thing most teams asked for support with. The way you structured your support enabled teams to benefit from your time and expertise - and allowed them to think about existing insights, resources available and the purpose of the work they were doing - as a consequence I feel their work will be more focused and impactful.” **Steph Heath, Programme Manager (Personalised Care)**

Impact: There have been other increased opportunities for patients and the public to have their voices heard and influence service design and delivery through meaningful and timely engagement. Colleagues have developed their

understanding of and skills in effective engagement. This change has been supported by:

- Supporting the recommissioning of the NHSEI South East primary care interpretation service. We spoke to 33 people who access interpreting services, either community languages or BSL, to ensure the service specification meets their needs. Online surveys and a BSL video were made available. Given the Covid restrictions we reached out through community organisations and offered online interviews supported by both BSL and language interpreters.

Recommendations included:

- Interpreting services must be known about and accessible
 - Interpreters need to behave in a professional way
 - Those requiring an interpreter should be offered choice to respond to cultural sensitivities
 - Support should be offered to those who might like to access interpreting services via technology
- The delivery of a **Leading System Wide Patient and Public Involvement programme**. Although affected by the pandemic, with the programme pausing midway, those involved gained significantly from the programme. Here are quotes from participants about what they gained and learnt:

“Time and planning is needed for meaningful engagement. Interview techniques and language (even using ‘positive’ words such as ‘and’ rather than ‘but’) are important to meaningful engagement and winning people’s confidence and trust. Meaningful PPI can empower people to lead healthy lives; deliver a quality of care of which we can be proud. Communication and engagement needs to be built at the start of projects and become part of our culture.” Mark Wingham, Hampshire and Isle of Wight CCGs

“Build PPI into the start of any project. Use meaningful language. Be patient. Small changes do make a big difference.”

Priya Mistry, Hampshire and Isle of Wight CCGs

“The PPI programme of study days was overshadowed by the Covid-19 Pandemic and the impact this has had on the daily working and personal lives of all those taking part in the programme. Despite this, the ‘in person’ workshops provided the opportunity for networking across participants and colleagues from Wessex Voices and local Healthwatch organisations across HIOW, which then continued when the programme was delivered online. For me, a clearer understanding of the roles of colleagues in different parts of the system will help me to plan and develop patient and public participation involvement for future commissioning projects.”

Louise Wells, Hampshire and Isle of Wight CCGs

- Publishing, widely promoting and running training sessions on [our PPI Toolkit](#), offering a suite of resources to support people to carry out effective engagement. While supporting people with the practicalities of planning and delivering engagement, the Toolkit also encourages the cultural shift that informs and underpins effective engagement.
- Commissioned by NHSEI South East, speaking to women in disadvantaged areas about the barriers to accessing perinatal mental health support. With the expansion of these services, the aim is to understand and remove barriers to access. The results will report in autumn 2021.
- Acting in our role as a voice between local Healthwatch and NHSEI we have raised systemic issues with dentistry both during and since the pandemic. Local Healthwatch have received a significant amount of feedback in relation to access to NHS dentistry and together we have raised, with NHS England, the

serious concerns about the lack of NHS funded dentists and treatment, the inability to afford private treatment, and the resulting inequality.

2021/22 PPI priorities

Changes in our funding means that our focus for 2021/22 will be on our work with the WCA and with the Hampshire and Isle of Wight Integrated Care System, reflected in the following priorities:

1. To continue to build practical foundations to make WCA's PPI easier for the team by:
 - Diversifying our Public, Patient and Carer Involvement Network and supporting our volunteers
 - Setting up a PPI Accountability Group made up of a diverse range of patients, carers and voluntary sector organisations
 - Recruiting patient representatives that will sit on the Alliance Board as the patient voice
 - Producing the regular 'Get Involved' Newsletter to publicise opportunities for people to get involved in Alliance projects
 - Sharing intelligence and making recommendations with key stakeholders, e.g. around inequalities around access to services
 - Providing advice, guidance and training to Alliance team and partners

2. Leading on the coordination of WCA PPI with those who experience health inequalities by:
 - Linking with ICS health inequalities leads, WCA's Clinical Lead for Black, Asian and minority ethnic communities and Communities against Cancer
 - Developing relationships with seldom reached groups, individuals, community, voluntary and faith sector organisations

- Sharing and making recommendations based on people's insight to address these inequalities
3. Develop a series of conversations with people across Wessex and beyond who are less likely to go to their GP with signs and symptoms or screening to improve early diagnosis of cancer. The focus will be on:
 - Breast screening across the South East
 - Bowel screening in areas of deprivation in Wessex
 - Prostate cancer for Black men
 4. Supporting the commissioning of social research into local Black, Asian and minority ethnic people's experience of cancer care and work with the Alliance to develop a strategy to respond to the findings
 5. Continuing to lead the Rapid Investigation Service evaluation; engagement with seldom-heard groups; and the breast pilot to inform further service development
 6. Continuing to support the coproduction and evaluation of Right by You.
 7. Complete the project - Our Cancer Our Way - identifying what needs to change in cancer services for children, teenagers and young adults, from a patient and parent's perspective. Having secured further funding from the National Experience of Care team, we will develop coproduction approaches to implement the identified improvements and embed coproduction models into services - Our Cancer Our Way - Always.
 8. Complete the perinatal mental health project - Opening the Door. Speaking to women from deprived areas we will identify barriers to seeking and accessing mental health support during and after pregnancy, so that the newly expanded

services can apply this learning.

9. Create a sustainable and effective model for our project that fits within and supports new NHS structures including:

- the development of Hampshire and Isle of Wight ICS with its new teams, new roles and responsibilities
- the need for local Healthwatch to engage at this system level
- the changing NHS commissioning responsibilities
the new geography of NHSEI

Conclusion

Our approach remains focused on supporting colleagues in the NHS and ICS, to build their skills and confidence in PPI, with a view to transforming the culture and enabling this to become ‘everyone’s business, every day’. Following our early successes, we need to be able to clearly measure the change we are supporting to bring about. Particularly with such an ambitious agenda to involve people who experience health inequalities. Our additional capacity for the coming year aims to enhance and demonstrate the impact people’s voices can have on the transformation of local cancer services and support.

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