

# Patient, Carer and Public Involvement in the time of Covid

## Impact Report for our work with the Wessex Cancer Alliance

2020-2021

## Background

Wessex Voices has worked with Wessex Cancer Alliance (WCA) to deliver a comprehensive patient, carer and public involvement (PPI) programme that has supported the transformation of cancer services and support since 2014. Until 2020, this was on a part-time basis and is part of our successful Wessex Voices project, which exists to bring about cultural change in NHS organisations' approaches to patient, carer and public involvement.

The unique Wessex Voices model involving our partnership with five local Healthwatch, independent consumer champions, means we engage people earlier in creating better services and health outcomes. Our approach is to:

- Focus on what is important to people and what is and isn't working for them
- Support NHS England and Improvement 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 having to people 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

Since August, we have been providing full-time support to the Alliance through the role of a Patient and Public Involvement Programme Manager and our current Memorandum of Agreement will run until July 2023. Within the coming year, we have ambitions to extend our support with additional team members who will lead on communications and volunteer support, and community engagement focused on health inequalities.

## Patient, carer and public involvement outcomes:

WCA has recently published its final draft of its [Communications and PPI Strategy](#), which sets out its vision and outcomes for the coming three years. Wessex Voices will support its delivery of the following:

### Vision

All Alliance communications and involvement will be:

- Meaningful and impactful to those involved in these activities
- Accessible and inclusive
- Proactive, well planned and coordinated across all systems and activities
- Supported, valued and joined up across a wider set of stakeholders

### Strategy outcomes

The outcomes that the strategy will deliver are:

- There will be a culture of understanding around communications, sharing of information and PPI within the Alliance team and our systems
- The team will undertake more meaningful PPI (as reported by those involved). This will shape and influence their workstreams
- Public and patients will receive timely updates and messages about cancer that will be informed by insight and reports we and others gather

- Alliance stakeholders will be involved and informed of Alliance communications at the right time, in the right way for them (via website, social media and other communication channels)
- Proactive media coverage will be part of business as usual
- People (patients, carers and the public), specifically those communities who experience worse health outcomes, will be more aware of how they can be involved and influence improvements in cancer services across Wessex
- That the way communications and involvement is collectively carried out across organisations and systems will be better coordinated, planned and executed, and the way we share intelligence is much more effective.

## 2020-2021 Progress and impact

2020 has been a year like no other. Covid19, as for many others, has had a dramatic effect on how we work. This is especially because of its impact on our NHS partners and because we were unable to work in our usual way, face to face with people. We have flexed and adapted and delivered the following:

**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
- Set-up of a Patient, Carer and Public Involvement Network (21 people); holding our first public information session (for 15 people); and launching our [‘Get involved’ webpages](#) and newsletter (to over 120 recipients)
- The launch of 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, to inform their work, for example to support the recovery of services; and we are 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), 13 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 and young people and their families in the development of networked cancer services for them. Five young advisers are shaping the project from the outset. (See appendix A)
- 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).
- Continuing to provide [advice and guidance](#) to Alliance colleagues around their approach to health inequalities and PPI, for example, in relation to 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.

## Alliance Team views about Wessex Voices support

*“Wessex Voices continue to be key in a number of workstreams helping Wessex Cancer Alliance to engage with communities, listen to and act on people’s experiences of accessing cancer services. With their access and links to various communities they have facilitated work with people we just wouldn’t be able to engage with.”*

**Nicola Duffield, Programme Manager (Prevention & Earlier Diagnosis)**

*“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)***

## 2021/22 PPI priorities

1. To continue to build practical foundations to make WCA's PPI easier 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
  - Discussing an approach to patient representation 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,
  - 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, Communities against Cancer, Macmillan's Engagement lead and others
  - 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 this pilot service
6. Continuing to support '[Our Cancer Our Way](#)', coproduction with children and young people and their families, for new service specifications and into the future
7. Continuing to support the coproduction and evaluation of Right by You
8. Ongoing PPI advice and guidance to support significant change in cancer services

## Conclusion

Our approach remains focused on supporting WCA and its partners 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.

## Contact details

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