

# Quarterly Report for Wessex Cancer Alliance

Patient and Public Involvement Steering Group  
and Network

October 2024 to December 2024

## Introduction

Wessex Cancer Alliance has commissioned the Involving People (IP) team at Help & Care to involve volunteers with lived experience in the work of the Alliance. Through a Steering Group (SG) and broader Network, the Alliance is able to involve people in all their work programmes in inclusive and meaningful ways.

The Steering Group acts as a critical friend to ensure patient and public involvement is effective, holding the Alliance to account in fulfilling its responsibilities in relation to public and patient involvement.

The Network enables us to invite more people with lived experience to be involved in a range of opportunities identified by the Alliance.

This report looks back on the previous quarter's work.

## Activities and outcomes

### **1. Build a robust, confident, independent forum for people who live across Wessex to have the opportunity to voice observations, participate in and contribute to service development and hold the alliance to account for the quality, influence and impact of PPI involvement on the Alliances work**

The Steering Group (SG) met in October 2024. The meeting first heard from Steering Group volunteers about their activity over the previous quarter including:

- Research and Innovation Day – several volunteers attended, and the event was described as “thought provoking and at times frustrating” (because things don’t move fast enough). The event included discussions about the gap between developing innovations and releasing them, and the lack of diversity in trials. There has though been some success in targeting lung cancer screening to communities where take up tends to be lower. One of the attendees commented on how few professionals there on the day actually to “meet the people they are doing things for”. All the SG volunteers who attended felt both able to voice their opinions and that their input was valued.
- Metastatic Breast Cancer Conference – this was a patient led conference aimed at improving services. There were discussions about clinical trials (and the lack of a national register), early detection tests, capturing data to enable funding to be targeted, and how to better link primary to secondary care. The Alliance promised to follow up the issue of the lack of a national register as this severely hinders people’s ability to take part.
- Clinical Strategy – the Steering Group chair fed back on the Alliance Board discussion. With the Strategy almost complete the SG will shortly see how their input has influenced the document. (Scheduled for the January away day)

- National PPV forum representation – a SG member has joined this forum and fed back on the induction session, which had been quite overwhelming. Further sessions are planned and will be reported back.
- Quality improvement – 2 SG volunteers are involved in planning and delivering the patient participation part of the Quality Improvement (QI) training for Cancer Nurse Specialists and Cancer Support Workers across Wessex. They have ensured the programme is more focussed on patient participation and how professionals can think about involving people at an earlier stage in their projects to allow them to be part of the process and provide feedback. Meeting in advance with the Head of People Participation for Academy of Research & Improvement at HIOW HealthCare NHS Foundation Trust, our volunteers discuss and review the content and contribute thoughts and ideas. They know patients often add information or a new perspective that can make a real difference and appreciate being asked to be involved.

*“We have seen some brilliant projects being developed. Before the course, some colleagues had not considered involving people in the services they are developing. Now they are, with our support to build their confidence to do so.”*

***Eileen Stonock, Steering Group chair***

*“We have been delighted to see the variety of projects that have been included so far which could really improve services for patients. A lot of thought and care has been demonstrated and we look forward to discovering how the data collected will be used.”*

***Sarah Rowcliffe, Steering Group member***

- National Cancer Patient Experience survey – the Alliance reported on the results of the recent survey and fed back the actions taken as a result of the previous survey.
- Updates from WCA including the “Know the Signs” cancer awareness campaign.

The SG also agreed to meet bi-monthly in future, given the number of issues to discuss and the information the Alliance wants to report on. This will start in 2025.

The value put on the Steering Group by the Alliance, and individual volunteers, is noted in a quote below from the Managing Director:

*“Your name (and others) in our steering group, is now referenced as common parlance. People pause for thought, “I can hear .....’s question here”. Or “How will this feel different for patients in the ward tomorrow”.*

*You are influencing our thinking, and collectively very much holding us to account. Exactly as I hoped you would.*

*I am very grateful and feel fortunate to have such a group of people to give up so much time and thought into how we can work together to get things better”*

**2. Oversee, manage, develop and facilitate the membership of the SG (12 – 20 people) and wider network ensuring it is fit for purpose, sustainable, that those with lived experience feel able to contribute in a meaningful way and that membership is rewarding**

The number of SG volunteers remains at 9 with strong links (being reviewed on an ongoing basis) to programme leads.

During the quarter we have welcomed 3 additional Network members taking the total number to 39 (including the 9 SG members).

During the quarter we offered several opportunities for involvement to both Steering Group and Network members with invitations to get involved in the following:

<b>Source</b>	<b>Opportunity</b>
WCA	Valuing Cancer Support in the Community event – SG invited and 3 SG members took part.
	An invitation to join the newly established Readers Panel – a total of 9 people have joined, 4 from the Steering Group, 3 from the Network and 2 from Healthwatch
	A draft text message to be used after a “clear” lung cancer check was sent to the Readers Panel for their views. 6 responded and the text message has been changed considerably as a result.
NHSE	An invitation to participate in the Covid enquiry – to SG and Network.

Note that we don’t always know how many people respond to these invitations, but we record what we are aware of.

**3. Work with people and communities to ensure people from a range of backgrounds and with different lived experiences can participate in the SG and network, including providing tailored support where that enables participation**

**4. Work collaboratively with community organisations and networks to carry out targeted and inclusive recruitment for both the SG and network, linking with other initiatives such as community research projects**

We continue to try to extend the network. Connections have been made through a range of organisations who can help to invite people to get involved. Dorset Race Equality Council, Healthwatch Dorset, Dorset County Hospital, Hampshire and Isle of Wight Community Research project, Community Action Hampshire/Communities against Cancer, Community Action Network (Bournemouth, Christchurch and Poole), Portsmouth Hospitals Inclusion Lead and WCA’s Involvement and Inclusion Lead, are all working with us to promote the Network. Cancer Nurse Specialists have been asked to advise people of the opportunities. People interested in the opportunity have begun to come forward.

We have a long list of other people and organisations we are in contact with to assist with this so our efforts will continue through the year. We circulate flyers and posters in a targeted way, always on the lookout for new contacts and opportunities.

**5. Develop the SG as part of the overall governance approach of the WCA, including identifying where further development/training might be required, clearly communicating the purpose of the SG internally and externally and agreeing the role descriptions with and for members**

Our volunteer chair (Eileen Stonock) reports regularly to the WCA Board. A report was provided to the December meeting.

Clear role descriptions are in place for all Steering Group members.

The Alliance website has a page dedicated to 'Get Involved', where all relevant information about the SG and Network sits and is regularly updated. [Get involved - Welcome to Wessex Cancer Alliance.](#)

Communications about the Steering Group and Network (external and internal) does need to be further developed. However, a new quarterly newsletter is now produced by the Alliance, with IP input. This is sent to all network members in addition to other organisations who are in turn invited to promote the network.

To enable a clear understanding of where the Steering Group and Network sits in relation to the Alliance, a member of the Steering Group has drafted a simple organogram which will be finalised and made available to all.

**6. Develop the network's role and purpose through regularly connecting with members, offering opportunities for involvement and articulating the impact of the group.**

During this quarter the Network has been offered 2 opportunities by the Alliance (See Table above, at 2.).

Offers are usually sent via email and our Volunteer lead also keeps in regular contact with the network members via email, phone or Teams, thanking people for their input, encouraging involvement, checking if people want to remain involved, checking if there are any issues for anyone, solving problems. From April 2025 the aim is to streamline this reporting and information gathering using the Volunteer app. as new volunteers join.

**7. Ensure provision of appropriate training sometimes for the whole group and sometimes tailored to the individual needs of steering group members.**

**8. To ensure volunteers receive support for their role in line with their needs.**

In terms of training at present there is no formal approach beyond our "induction" where people are provided with necessary policies and background information. Volunteers are also sent opportunities such as the National Peer Leadership Scheme, in which several have shown an interest.

Volunteers do receive general ongoing support from the Involving People volunteer lead and clinical support is in place for volunteers who want some support before or after an involvement opportunity.

At the away day in January 2025 SG members needs will be discussed in detail and a more comprehensive offer put in place.

Help & Care again received it's Investing in Volunteers recognition during this quarter, with some Steering Group members being interviewed by the assessors. This reflects well on the work of IP in supporting Steering Group and Network volunteers.

### **9. Provide volunteer management services including governance, expenses, communications and training**

During the quarter we ran the October Steering Group meeting and prepared for the January face to face workshop. This involves collating the agenda in collaboration with the chair and WCA staff, planning and holding a pre meet with the Chair, ensuring all reports are available and circulated in advance, writing up minutes, circulating to all, and chasing follow up actions.

Volunteer expenses continue to be approved and paid swiftly.

### **10. Provide communication support for recruitment, the sharing of impacts of the work and public facing quarterly and annual reports on the work of the SG and network**

Quarterly reports are now produced (this full written report accompanied by a summary infographic) and scheduled through the year, including impacts where tracked.

### **11. Work with WCA leads to maintain an up-to-date web page for the SG on the relevant WCA website**

While WCA is responsible for its own website, IP provides relevant information to ensure it is up to date, e.g. minutes of all meetings and governance documents.

We work collaboratively with the Alliance and volunteers to ensure the Involvement pages of the Alliance website (and the Cancer Matters Wessex website) meet everyone's needs and contain the information that is most important in an accessible and well-structured way.

### **12. Some quotes from our SG members**

Here are some quotes from our SG volunteers about their involvement with the Alliance

*"It's very rewarding to be involved in shaping the same healthcare system of which you are a patient, ensuring better services for future generations".*

*“Volunteering for me is to use my ability, experience and knowledge to make things better for everyone I get involved with and to make things better for the next generation, especially as it’s been a 31 year journey”.*

*“Volunteering makes everything I went through fighting cancer for 18 months have a purpose and a meaning and helps what was the most horrendous time in mine and my family's life seem a great deal more positive. I also enjoy the way I can effect change with real meaning as what I have experienced resonates with others and hopefully facilitates change for the better for others. That is a very powerful feeling”.*

## An update on areas for further focus 2024/25

The following were identified through the 2023/24 Impact Report. Here is a quick summary of progress:

Action	Progress	To do
Improving the mechanisms we use to record and measure impact	We now use the “PPIE Tracker” to record known impacts – from volunteers, or WCA staff.	Build in a mechanism for programme leads. Capture at monitoring meetings.
Broadening our reach – especially growing the network in terms of numbers and diversity	Flyers and posters printed and circulated to a range of partners/colleagues who can promote to their contacts.  The Alliance has written to all cancer support groups inviting them to “join” the network and forward to their members.  The quarterly newsletter promotes the Network and invites involvement.	Consider separate approach for LD groups.
Further matching of volunteers to programme leads.  Identify a Children, Teenagers and Young Adults programme link	Steering Group has received presentations on each programme and requested volunteers.  WCA CTYA leads in post.	Continue to encourage volunteers to come forward.  Invite relevant Volunteers to be the CTYA links.
Providing a programme of involvement opportunities in	Action for WCA.	

advance where possible		
Developing a training approach and offer	A discussion is planned for the Jan 25 away day, with a paper setting out options and seeking volunteers views.	An offer will be designed in line with away day conclusions.
Improving our communications, internally and externally	Quarterly newsletter now produced by WCA with IP input	
Providing training and support on our new system - Volunteero - to improve volunteer communications, management and reporting	Existing volunteers are being encouraged to use the app. and support will be provided at the Jan 25 away day.	Volunteero to be requirement for new volunteers.  Volunteero to be default from April 25.

And two issues that were raised at the December 2023 Steering Group away day:

Ensure patient stories at Board (with care)	WCA action	We now have a video of a volunteer talking about the impact of patient experience – this can be shown at Board and more produced featuring other volunteers.
Ensure some contact with and feedback from clinicians re the impact of SG ideas/ recommendations/ ideas	Chair of WCA Board attended last Steering Group  Edit invited to February meeting	Ongoing contact to be facilitated.