

Annual Report for Wessex Cancer Alliance

Patient and Public Involvement Steering Group
and Network

April 2023 to March 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 year's work, identifying successes and also where we need to put more focus. We view reporting in this way as a learning, exercise, reflecting our collaborative relationship with the Alliance.

Looking back on 2023/24

The section is set out using the outcomes we agreed to deliver in collaboration with the Alliance.

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 four times throughout 2023/24 with growing representation and input from the volunteer members. We have developed, and begun to use, a template that guides Programme Leads to succinctly present their projects and plans for patient and public involvement to the SG. This better enables the SG to advise on how to develop and improve involvement mechanisms, in its role as “critical friend”, “holding the Alliance to account”.

Here is a quote from one member:

“I feel that being part of the steering group as a patient with lived experience of blood cancer, has afforded me a purpose, a meaning to the 16mths I spent in isolation fighting Leukaemia. I hope that it will afford me the opportunity to affect change for the better for other patients and their carers suffering similar battles.”

We have also reviewed the Terms of Reference for the Steering Group and role descriptions for the volunteers on the SG and more broadly in the Network. This ensures clarity about roles, responsibilities, and expectations.

Agendas for meetings are carefully planned in advance to maximise involvement.

Discussion topics have included:

- Priorities for the Alliance 5-year plan
- National Cancer Patients Experience Survey results

- Genomics Strategy
- Multi Cancer Blood Test
- Data provided on the Alliance website

Members have made significant contributions to all these discussions. Considering the 5-year plan the key messages included:

- the need to achieve consistency in cancer care
- the need for primary and secondary care to communicate well
- not enough people fully understand their treatment (the NPECS shows 60%)
- patient experience insight matters – alongside statistics
- the need to truly personalise care, and for ongoing support for people post discharge

A major achievement in the year is that one of the SG lived experience members, Eileen Stonock, has been confirmed as the chair of the group. This means the group is truly volunteer led, provides more independence, and enables formal lived experience representation at the WCA Board. Here are her thoughts:

“I felt prepared, welcomed and included. Following discussion I was invited to and now meet monthly with the Hampshire and Isle of Wight ICB exploring further cancer focus”

Oversee, manage, develop and facilitate the membership of the SG (10 – 12 people) and wider network (20 – 30 people) ensuring 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 volunteers on the SG representing a range of lived experience is 13. At meetings they contribute to discussions very effectively. Many are also linked to specific work programmes where they get involved in a particular piece of work, supported by the relevant programme lead. Programmes where we currently have a volunteer linked to the programme lead includes:

- Early Diagnosis
- Faster Diagnosis
- Treatment
- Personalised Care
- Workforce

This allows for a more detailed understanding of and input to the work, and also enables the co design of patient and public involvement with programme leads. We will be looking for a Children, Teenager and Young Adult - CTYA - link this year.

Programme leads have commented as follows about the benefits and impact of this input:

“Grateful for your support, honesty and wisdom, your guidance has been invaluable. This is what brings about change”.

“Your support, encouragement and challenge has been so helpful – always ensuring the person affected by cancer is central to all we do”.

And a volunteer commented as follows:

“Linked to the Personalised Care and Workforce programmes I am able to utilise my skills, knowledge and lived experience. I feel strongly that public and patient involvement, reflective of our community is essential, keeping discussions focused and grounded in reality.....”

In November 2023 we held a face-to-face event and invited all volunteers on the Steering Group and Network. This was an opportunity for all members to discuss how the group works and any improvements to be made. Those at the event said many positive things about their work with us, and a few suggestions were made, which either have or will be implemented:

- The value of patient stories at WCA Board meetings and the need to ensure this happens frequently
- The group wanting to have more contact with clinicians to understand and hear evidence of the impact of patient involvement
- The need to broaden the diversity of the group

There are 23 Network members although only a proportion of these people are in regular contact with us.

We regularly ask volunteers to feed back to us, via a standard and simple report, about their involvement – how much they enjoy it and feel they are having an impact. We get a limited response to this but keep trying. Here is one quote:

“Feedback given is that what I have contributed to does make a difference”

During the year we have offered 24 opportunities for involvement (2 of these not directly from the Alliance). In response we have had 55 expressions of interest from 15 people

There was involvement in the following pieces of work, where the impact of involvement has been documented:

- Genomics Strategy – patient involvement. As a result, “patients’ priorities are upfront and central in the strategy.”
- Personalised Care Transformation Project. This informed the service specification.
- Primary care conference. Volunteers provided “hard hitting stories that framed the conversations”
- Drop-in sessions on the N CPES results and 5-year strategy. Provided a focus on “what is important to patients”
- FIT workshop focus group. Volunteer feedback “has changed the instruction form for the better. Language and images clearer/simpler”
- Assistive and Supportive Workforce conference. Volunteer input “informed and framed discussions for the day”
- Frailty. Volunteer input “encouraged their Steering Group to think about intersectionality and not to speak in jargon.”

- Self-referral service for testicular cancer lumps video. As a result, the “video is clearer/improved”

There has also been involvement in the following pieces of work where impact has not yet been measured:

- Bowel cancer awareness talk
- Wessex Cancer strategy away day
- Workshop about advice and signposting
- Blood based test for prostate cancer
- Prostrate cancer focus group
- Prehabilitation and Rehabilitation focus group
- Oncology remote monitoring at home
- CAN – EMPOWER – the development of a digital resource to manage psychological problems and wellbeing
- Acute oncology steering group and survey development
- Endometrial cancer focus group

Some opportunities were circulated which did not come from the Alliance but other partners wanting to use our network, e.g. the future of how clinical trials are run.

Some other opportunities were offered but not taken up:

- National Cancer Programme Patient and Public Involvement Partner Forum
- NHSE Bus-ting Cancer bus tour Portsmouth

Volunteer members have provided us with some feedback about their involvement:

“Enjoyed involvement and learned a lot”

“Had opportunity to ask questions and give points of view which were fed back at the end which was very worthwhile”

“Great opportunity to link up and listen to people”

“I hope I assisted them in “focusing” their minds for the day”

“Great opportunity to see these videos and leaflet and promotional materials. As many opinions as possible the better”

Here is a quote from one SG member about the contribution of other volunteers at a conference:

“..... and presented on the day and their honesty was brilliant and very powerful and added such context to the day and to the training. Saying what it was like for them at each point in the pathway was moving and powerful.”

IP have purchased and will soon be using volunteer software – Volunteero – which should make it much easier for this form of reporting – with volunteers having access via an app to all the information they need and a facility to report back within the app. At present we hear very little once people have expressed interest in getting involved in an opportunity. There is also a balance to be achieved –

volunteers want to volunteer, and not necessarily spend a lot of time feeding back about their input!

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

Our volunteers are fantastic, offering their time and lived experience to benefit the work of the Alliance and improve cancer care for all. Through close contact with our volunteers, including a welcome call when people first get involved, we build relationships with them and aim to communicate with them in the way that best suits them, involve them in things that interest them, and provide the support they need, individually, to do their work with us. We realise there is a need for good communication between IP and the Alliance about any specific needs or support, which sometimes become known through the work, rather than by asking a direct question when people join.

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 do know that our volunteer base is not as diverse as we would like – we have more women than men, volunteers tend to be at the “older” end of the age spectrum, there is little ethnic diversity and we have fewer people from Dorset compared to Hampshire. So, we need to encourage more people to join us. We have produced a flyer that provides basic information and contact details to encourage people to approach us. But to be successful in attracting interest we need to go TO people. We have connected with Action Hampshire to see how we can invite more people in through their broad networks with many groups. We have also connected with Dorset Race Equality Council and will work with them to help us broaden our reach. We have also engaged with those involved in our Community Research cancer work – people with disabilities, neurodiverse and trans +. A comprehensive plan will aid this work in 24/25.

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

With a volunteer chair (Eileen Stonock) in place this now enables regular reporting up to the WCA Board. A first report was provided at the March meeting, and these will continue through 24/25.

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](#)

Training and communications (external and internal) needs to be further developed.

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

Provide training and support as required on how to be an expert patient or patient contributor rather than a patient representative with modules both for members and WCA colleagues.

As mentioned above the Network has been offered approximately 2 opportunities per month by the Alliance. 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.

In terms of training at present there is no formal approach beyond our "induction" where people are provided with necessary policies and background information. This is an area for development.

Produce volunteer management services including governance, expenses, communications and training

Involving People (IP) arranges and supports all the SG meetings. Pre meetings take place with the Chair who contributes ideas for the agenda. These meetings also ensure she is well prepared and has all the required information in advance. The agenda and papers are sent out a week in advance of each meeting, allowing everyone an opportunity to prepare well in advance of the meeting. Minutes are produced swiftly, drafts circulated and once finalised sent to all shortly after each meeting. Dates of the meetings are provided for the full year ahead.

We have coordinated the review of the terms of reference and role descriptions, which are now approved. A full suite of governance documents and forms are available for all volunteers including contact details, photo consent, Volunteer Agreement, and appropriate policies.

We are responsible for volunteer expenses, with volunteers using and submitting a simple claim form. We have a swift system for approval and payment.

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

Our quarterly and annual reports to the Alliance provide information and feedback on the SG and network that the Alliance uses in its own publications and communication channels. Although these were not in place at the beginning of 2023/24, these have more recently been produced and this will continue in advance of WCA Board meetings in 2024/25.

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 website meets everyone's needs and contains the information that is most important.

Volunteers were also asked through the year to comment directly on the [Cancer Matters Wessex](#) webpages in terms of content and structure, and their feedback was taken on board.

Areas for further focus 2024/25

While the above report shows there has been significant progress and success during 2023/24, it has also highlighted where further work needs to be done – both by IP and the Alliance. Here are the main areas for further focus during 2024/25:

- Improving the mechanisms we use to record and measure impact
- Broadening our reach – especially growing the network in terms of numbers and diversity
- Further matching of volunteers to programme leads
- Providing a programme of involvement opportunities in advance where possible
- Developing a training approach and offer
- Improving our communications, internally and externally
- Providing training and support on our new system - Volunteero - to improve volunteer communications, management and reporting
- Identifying a Children, Teenagers and Young Adults programme link