

VOICE Annual Report 2018-2019

Looking back over the year to June 2018 it is evident that Voice has had a busy year finalising the work that supported the 3 year Macmillan Patient Partnership Initiative Programme and undertaking new activities and implementing a new service. A celebration event was held at Wimbledon Lawn Tennis Association to mark the end of the very successful PPI programme at which many senior members of the Trust, Macmillan Cancer Support staff and Voice members, enjoyed very good speakers and refreshments.

The introduction of new **GDPR legislation in 2018** meant that the Voice membership had to be re-registered to comply with the law.

Beverley Van der Molen, the PPI project manager and our guiding light for the previous three years, retired in December. By then Beverley had completed an overhaul of the structure and administration to give Voice a much stronger and well documented basis, which also meant our membership complied with the law.



This work was done with the help of the committee, reviewing and rewriting the terms of reference and developing a user friendly joining form, as well as introducing different membership options. The good news is that the format and functionality of the group has been strengthened and the membership has grown to nearly 100.

Sue Fox was voted to stand for another year as Chair and the group was delighted that Bruce Johnston agreed to be elected as the Vice Chair. The resulting changes needed to the bank account signatories proved very difficult but lessons were learnt and eventually Bruce Johnston's perseverance and patience achieved the necessary changes.



A **voice banner** has been produced which is very useful whenever Voice is represented at events, and was very helpful when Voice had a stand in the SGH Main Reception to publicise the Group and the new CanChat service. The business cards and the carers pack to be developed with the Macmillan Information Centre are still work in progress.

A separate [Voice web page](#) has been set up by Ejiro Ejoh, the manager of the MacMillan Information Centre and Estelle Le Galliot, the Macmillan Cancer Information officer has developed a strong social media presence for Voice.

St George's Trust set up a new **Patient Partnership Engagement Group (PPEG)** in 2018 to involve patients across every division of St George's. It consists of 15 Patient Partners, members of staff from all divisions and governors of the Trust. Voice as one of the strongest patient groups will always have a representative on this group and has been used as a model for the other patient groups which need to be formed. Hopefully the two way exchange of information between Voice and PPEG will be of great benefit to both.

Throughout the year members of the CORE group and some general members have been actively involved in various projects. These have included:

- Attending workshops to develop the Cancer Strategy for South West London
- Speaking at the educational project to develop cancer skills and knowledge for nurses on surgery wards.

- Attending focus groups and reviewing the website for the development of the Ambulatory Oncology Service.
- Reviewing the Macmillan Patient Information pack.
- Completing surveys and attending focus groups for the Macmillan Primary Care Nursing project team which is to review the post treatment care by GP nurses for cancer patients.
- Attending a **Prehabilitation workshop** organised by the Treatment and Recovery advisor at Macmillan
- Attending meetings of the South West London Collaborative Commission
- Helping with the annual Macmillan Coffee morning which raised £4k for the local fund.
- Attending the NHS consultation event of the 10 year plan for Cancer.
- Attending the NHS consultation event on the 10 year plan relation to long term conditions.
- Attending the launch of the new Urology service at Queen Mary's Hospital.

Several Core members attended a Health and Well-being event organised by the Macmillan Information Centre for SGH Cancer patients. They were able to explain the benefits of Voice membership to the attendees.

The major piece of work this year has been the design and development of a telephone support service for Cancer patients and carers, manned by cancer patient and carers, called **CanChat**.

The feedback from previous listening events always highlighted how valuable the attendees found the opportunity to talk to other people who had a personal experience of a cancer diagnosis. To answer this need, Voice decided to revive the idea of a **telephone service** which had been tried but failed some ten years before due to lack of support from the St George's Executive.



This time, with great support from both the Cancer directorate and the Macmillan Information Centre, a group of enthusiastic volunteer patients and carers, a six month pilot service was launched in March 2019. Macmillan Cancer Support provided a grant of £1372.00 to train staff in terms of understanding helplines and how to train the volunteers.

To guide the design and operation of the service a Listening event was held and attended by 35 patients and carers plus several staff. This was followed by some focus groups to refine the service offering and the procedures. The Breast Cancer Care Charity, has run a similar service called 'Someone like me' for over 17 years and the charity was very generous with their time and advice on setting up our service and helped to run the three telephone training sessions for the volunteers. So far, nine volunteers have been trained and are taking calls, but with a full launch and a publicity campaign now planned, it is hoped this number will be increased as the demand and awareness of the service grows.

The publication of the **5 year strategy for St George's** highlighted the new focus on Cancer services at St George's and in anticipation of the detailed Cancer strategy expected to be published in August, Voice decided to consult its membership on what they would like to see in terms of future Cancer services.

The consultation took the form of a **Listening Event**, which was held in June. There were over 60 attendees and it was quickly realised that the aspirations for St George's would require some large projects and large budgets. To be ready to support these projects Voice has established a sub group for Fund Raising for specific Cancer projects. Whilst realistically the funds raised may not be sufficient for any large projects it is felt that the patient power and attendant publicity will be very valuable. Veronique Furze a loyal and long serving member of the Voice Core group has undertaken to Chair this group and anyone interested can **contact Veronique** via the Macmillan Information Centre.

Two issues of Cancer Connect have been published this year under the editorship of Ejiro Ejoh with contributions from Voice members. Copies are available from the Macmillan Information Centre as well as the website.

The Voice core group