

Developing and Improving Service Frameworks for Patient Care.



**Feedback from the Public consultations held in Wandsworth
from April 2013 to March 2014.**

Foreword

Wandsworth Clinical Commissioning Group (WCCG) came into being on 1 April 2013, taking over from Wandsworth Primary Care Trust as the local commissioner of health services for the residents of Wandsworth. Reporting to the CCG Board and as part of its governance structure, the CCG set up a number of Clinical Reference Groups tasked with developing and improving service frameworks to improve patient care. A key duty for these groups is to ensure that the public voice is included within the decision-making process and so, in order to support this, the CCG commissioned Lifetimes to provide a series of community engagement events during 2013/14.

The engagement programme consisted of a series of 6 highly successful and different events (with a 7th arranged for early 2014/15), covering a range of health-related topics. Led by individual Clinical Reference Groups, each event provided an important opportunity to engage with the community about their work and inform service development and commissioning decisions through a range of activities.

Lifetimes provided valuable support to organise each event, both in the run-up and on the day. Most importantly, they facilitated access to a broad range of individuals and groups from across Wandsworth, enabling a wide range of opinions and needs to be voiced.

Thanks to the team at Lifetimes and everyone who attended these events for their valued contribution.



Andy McMylor
Director of Delivery and Development,
Wandsworth Clinical Commissioning Group

End of Life Care Community Engagement Event

Aims of the Day

- To engage with the Wandsworth community about care and services for people who are thought to be in the last year of their life;
- To provide an opportunity for invited groups and individuals to learn about the delivery of end of life care in Wandsworth;
- To provide an opportunity for invited groups and individuals to feedback to commissioners and providers about gaps and shortcomings in current service provision;
- To provide an opportunity for commissioners and providers to engage with invited groups and individuals about key areas of service delivery to gain further insight and to inform future commissioning;
- To provide an opportunity for informal networking.

Key questions and issues raised by the End of Life Care Clinical Reference Group.

1. If you or a friend/family member were ill and in the last year of life who would you turn to or where would you prefer to go for care, help, support and advice?
2. Thinking about your cultural, religious and spiritual backgrounds and needs, what would be important in terms of care if you or your friend/family member were seriously ill and /or living with a chronic illness and in the last year of life?
3. Do you believe that Health and Social Care services, as set up at present, work for you or people that you know with end of life care needs?
4. How would you like the community to be represented in discussions about end of life care in the Wandsworth Clinical Commissioning Group?

Feedback from the participants

- *Initially due to shock and confusion people may not know what they want and we should be prepared that they may always change their mind.*
- *There needs to be collaboration between services and family members, working together to gain all views and take into account all needs- keeping a balance.*
- *Multi agency assessment e.g. involve those who know the person best including community organisations, faith groups, voluntary sector services and friends.*
- *Cultural considerations are very key at all stages and plays a huge part in how someone wants to die. Community organisations already working with families have a lot of untapped knowledge that is not being utilized and captured regarding cultural and religious needs.*
- *Having volunteers sitting with people at EOL who do not have family and look at addressing the social isolation issue of people who may die alone.*
- *Events like today are really positive and the CRG could have more events such as today.*

‘Fantastic event’

‘Well done to everyone-I have learnt so much’

Get to Know Cancer – it's preventable, treatable and beatable

Aims and Purpose of the day:

- Increase awareness of cancer among the population of Wandsworth
- Promote the need for early diagnosis of cancer
- Listen and improve the experience of care for cancer patients and those who care for patients with cancer within Wandsworth
- Recognise and address the quality of life for those people living with and beyond cancer
- To identify areas for improvement

Key questions and issues raised by the Cancer Care Clinical Reference Group

1. Patient Experience

- Tell us about your experiences of cancer care in Wandsworth?
- What would you say makes good cancer care?
- In what way could cancer care be improved in Wandsworth?

2. How can we improve CCG feedback to patients and patient involvement

- How would you like to be involved with the CCG and the decisions it makes?
- What have been the barriers to getting involved?
- Do you know of the current ways the CCG communicates its news?
- How would you like the CCG to communicate what it is doing and how it responds to your suggestions?

3. The Future

- What sort of services would you like to see in Wandsworth
- What would you like to achieve?

Feedback from the participants

- *Focussing on early diagnosis*
- *Ensuring patient information is relevant to patient needs and is understandable – either in written form or spoken*
- *Patients are treated with respect and dignity*
- *Communication between services is paramount*
- *Support for carers*

'Everything is well organised and I especially enjoyed the group discussions'

'I will take the feedback to colleagues; follow up;

take note of patient's feedback'

Diabetes – The Way Forward to a Healthier You

Aims and Purpose of the day:

- Promote the activities of the Diabetes Clinical Reference Group
- An opportunity to network with health care professionals such as dieticians, diabetes specialist nurses and pharmacy advisors and offer feedback.
- Promote healthy recipes and awareness of alternative healthy ingredients.
- Understand ways to make healthy lifestyle improvements and offer Health Checks.

Key issues raised by the Diabetes Clinical Reference Group

- **Prevention** of Diabetes
- **Promotion** of services available in Wandsworth
- **Stabilising** your condition
- **Managing** your condition
- **Well being including healthy eating for the condition** and alternative healthy ingredients
- **Informal networking** and feedback

Feedback from the participants

- *I will be more attentive to preventing the courses of Diabetes e.g. reading labels on bottles and packets, food portions, the importance of good foot care*
- *Conversation mapping, info tables, friendly staff*
- *The facilitators were very supportive and clear in their instructions and the workshops were outstanding*
- *The interaction between the people in groups was very positive learning new information especially about food portions, food labelling and foot care*
- *Refer myself to GP to check for diabetes*
- *The senior Podiatrist gave a brilliant presentation and Desmond and Conversation mapping was very interesting.*
- *It would be great if this event could reach more people.*
- *On a personal level I will be even more vigilant in managing my diabetes in future.*
- *I will continue to improve taking care of my long term conditions*
- *The different tables allowed participants to sample and gain wide-ranging information - the discussions encouraged participation*
- *The opportunity to be with people of similar experience*
- *The whole day was a learning experience*

‘This was a most informative and well organised event and the information gained is just superb.’

‘I will write to the CCG to inform them of how beneficial I found this event’.

Self Management: Take Control of your Life and your Long Term Condition

Aims of the Day

Provide people with long term conditions and carers with:

- Information about Wandsworth Self Management Programme (WSMP)
- Experience of the new “Introduction to WSMP” Session for 2014-2015.
- Opportunity to meet & ask questions of previous WSMP attendees and the WSMP team
- The ability to explain to others what Self Management is and how it will benefit them
- Information about the Wandsworth Self Help Groups Project
- Opportunity to meet people from Wandsworth self help groups, find out what they do, why people go to groups, how you can work with them

Key messages and information from the Self Management Clinical Reference Group

- Content and signposting to Wandsworth Self Management Programme
- Understanding the benefits of Self Help Groups
- Outline of Self Help Wandsworth Programme of support for Self help groups
- Introduction to the Community Directory care4me as a public tool for social prescribing
- Outline and introduction into Expert Patients Programme and experience a taster EPP session

Feedback from the participants

- *No matter what the illness, helping yourself and most of all wanting to do it is the 1st step*
- *It's an empowering course to help patients motivate themselves to improve health and get the most out of their experience in the health system*
- *Anyone can set one up - and joining a community is an important factor in improving health and wellbeing*
- *They have beginnings and endings as well as middles that may be problematic. And help is available.*
- *I did not realise that there was a self help group to support those who would want to set up a group*

‘Fantastic and well understood’

‘Excellent information and contacts made’

Cardiovascular Health in Wandsworth

Aims of the day

- Information about Cardiovascular Health, aimed at local residents, community group, carers and health workers.
- Assisting residents to find out more about services available in Wandsworth and promoting healthy lifestyles
- Provide an opportunity for patients and groups to feedback about local services
- Provide a forum for suggestions for improvements to Wandsworth's Cardiovascular health services

Key questions and issues raised by the Cardiovascular Health Clinical Reference Group

1. Tell us how cardiovascular disease affects you, the people you know, or the people your organisation represents:
2. Can you list the diet and physical activity factors that affect your cardiovascular health?
3. How could you help us in promoting healthy lifestyle messages to your communities? Would you need any support from us in doing this?
4. What did you learn from the marketplace?
5. Did you know about any of these existing cardiovascular services?
6. Do you know of any other cardiovascular services that work well, or not so well?
7. Were you aware of the health inequalities in the borough before today's event? From your perspective why is this?
8. How confident do you feel that you / your community could change their behaviour to reduce your/their CVD risk?
9. Do you think individuals face barriers in accessing cardiovascular services? What are they?

Feedback from the participants

- *Physical side effects mean people respond, but it's harder if there are no immediate effects*
- *Take tailored messages to groups: Churches, old people's clubs, army clubs, etc.*
- *Take health checks, blood pressure tests and information to groups*
- *Encourage young people in Asian/Caribbean communities to teach older people about healthy eating*
- *Social networking can be useful and an investment*
- *Expert Patient Programme is a great programme*
- *Health inequalities stem from other kinds of inequalities. Those with financial worries and other priorities may not make the best dietary or lifestyle choices*
- *Confident now we know services are out there*

'Good coverage of relevant topics'

'Excellent information, informative, useful, very well organised, loved it'

Living Well with Dementia

Aims of the Day

- To give presentations from people with dementia, offer carers' perspectives, and an overview of current services and plans from Wandsworth Commissioners
- Deliver workshops in order for participants to offer feedback to NHS commissioners and providers about getting the right help at the right time
- Provide Information stalls and resources on coping with dementia and where to get help

Key messages and themes from the Dementia Care Clinical Reference Group

1. How the diagnosis impacts the whole family
2. Life after Diagnosis- Lived Experience discussion
3. Improving Outcomes for People with Dementia
4. Community support to live well with dementia
5. Staying healthy and living well with dementia
6. Emotional and Social Care Support to live well with dementia
7. Carer Information Support Programme taster session

Feedback from the participants

- *Personal insight into families' experiences of living with dementia*
- *Great idea to have a live interview with the couple who are living with dementia.*
- *Have taken away lots of information to better equip myself on this topic.*
- *Hopefully more identification of needs will help build on the development and commissioning of appropriate services*
- *The event went a long way towards providing information and tools which will be very helpful.*
- *Information given was delivered in a steady way with many handouts to take away and study at a later date*
- *Very informative and have a better understanding of dementia & the different forms*
- *Great information regarding living well with dementia & having quality of life*
- *Will incorporate the lesson learnt into the courses I facilitated for both Formal and Informal carers*
- *It has inspired me I will feel more confident signposting*
- *A new awareness of activities available that I can refer clients to and ideas of alternative ways to develop existing resources e. g online carers courses*
- *I will push myself to run more groups and activities in community*

'Really enjoyed the event and have taken a lot away to think about.'

'Event superb for raising awareness'

Statistical overview of events

The overall programme was very successful with a total of **481 attendees** from a wide variety of different stakeholder groups. There was great support and feedback from all sectors but particularly from the following groups;

- BME leaders and groups
- Faith groups
- Elderly groups
- Local service providers
- Local Voluntary and Community groups
- Carers groups
- Individuals with long-term conditions and associated groups
- Physical Disabilities groups
- Learning Disabilities groups
- Patient groups
- Mental health service user groups
- Self Help Group members

The theme/topic of each of the programme events was chosen by each Clinical Reference Group to meet their priorities and objectives for engagement and discussion with the community. The feedback received was evaluated after each event and an **83% overall rating of 'Excellent' was achieved**. The Lifetimes team developed and facilitated the events in a number of ways depending on the requirements of each of the CRG's. The Lifetimes team feel that the wide variety of different forms of event delivery played a large part in the success of the programme. Some examples are illustrated below.

- Workshops facilitated and evaluated on a variety of themes/topics;
- Stakeholder consultation meetings on services and gaps in provision;
- Screening and evaluation of new resources- such as self-help DVDs or resources;
- Networking lunches to promote and facilitate better partnership approaches;
- Promotional events for Voluntary and community sector groups and/or members of the public to market and advertise local services;
- Strategic consultation meetings to map services and identify areas for improvement in service provision.

'Really enjoyed the networking and the food'

'Very valuable use of my time today - great!'

'Excellent information and contacts made' 'Thank you'

'Very informative and relevant'

'Very useful for my work in the community'

Afterword

Lifetimes was delighted to be commissioned by Wandsworth Clinical Commissioning Group to manage the tailored Community Engagement Programme which facilitated closer working relationships and conversations with the local voluntary and community sector groups and the wider public. As the Council for Voluntary Services in the borough, we recognised the importance of ensuring the events were accessible to the hardest to reach and most seldom heard groups and dissemination of information to their community was required.

Lifetimes provided a supported process for each of the Clinical Reference Groups with full project management, co-ordination, facilitation, evaluation and administrative support for the events. CRG's were able to focus on getting the best outcomes through engagement and discussion. We endeavoured to ensure that each event was delivered in an innovative, individual way and we were very pleased that the events were so well supported. The information was disseminated and cascaded far and wide by attendees and the feedback from all the events was fantastic.

Lifetimes feels that following any consultation with the community, there should be feedback and to this end we have published this report to promote continuation of this dialogue.

This year we continue our work alongside the CCG with two new developments in the community; our Self Help Wandsworth Programme and the continued development of our multi-lingual Community Directory Care4me, which we are pleased to report, is being used by the public, health and social care professionals for social prescribing and other voluntary organisations in Wandsworth delivering services to the public.



Tina Champion
Chief Executive Officer
Lifetimes –Council of Voluntary Service for Wandsworth