

**PATIENT PARTICIPATION GROUP
(PPG)
NEWSLETTER**

June 2019 – Issue No 17

email: ealccg.ppe@nhs.net

web: www.ealingccg.nhs.uk/get-involved/patient-participation-groups

TELL US WHAT YOU THINK

Involvement Hub



The Involvement Hub supports patients, carers, staff and the public who want to find out more about participation – both how to do it and how to get involved.

It is a source of information and resources which will help people to develop their knowledge, skills and confidence to get involved in the design and delivery of health services. The site also includes examples of good practice and links to learning and involvement opportunities.

For more information please visit the NHS England website at

<https://www.england.nhs.uk/participation/>

Moorfields Consultation Update

Oriel is running a public consultation between 24th May and 16th September 2019 and want to receive the views of as many patients, public, staff and partners as possible to inform plans. This consultation is focused on the proposal to move Moorfields' services and the UCL Institute of Ophthalmology (IoO) from their sites at City Road, Islington to the St Pancras Hospital site in Camden, including the important issue of access.

Taking these views into account, as well as evidence for service change and value for public money, commissioners will decide during the winter of 2019/2020 whether the proposed move of Moorfields' services from City Road should proceed to the next stage of planning.

Oriel is also seeking your views on whether you have suggestions for alternative suitable solutions for the proposed centre.

There are various ways to get involved and share your views on the proposal:-

You can attend an open discussion on **Wednesday 26 June 2-2.30pm** at West Acton Community Centre, Churchill Gardens, West Acton, London W3 0JN. You can register to attend via the link below.

<https://www.eventbrite.co.uk/e/proposed-move-of-moorfields-eye-hospital-west-acton-discussion-tickets-61801749697>

You can complete the online feedback survey <http://oakhamwarp.dinksurveys.com/Moorfields>

You can also download a copy of the survey and return it by email to moorfields.oriel@nhs.net or send it via post to Freepost Oriel (no stamp or other address needed)

For more information visit <https://oriel-london.org.uk/get-involved/how-to-give-your-views/>

Diabetes Workshops – What Matters to You?



The London Diabetes Clinical Network is running workshops for people with diabetes on **the 25th June**. The aim is to understand what outcomes matter to you. The day will be split into discussing type 1 diabetes in the morning and type 2 diabetes in the afternoon, both workshops require separate registration. The event is being organised to:

- Update on progress made since the last workshop held on 3 December 2018
- Provide an update on work to capture the ‘outcomes that matter to people living with Type 1 & Type 2 diabetes’
- Share examples of London good practice
- Identify other London good practice and opportunities to make improvements to the care and support people living with Type 1 & Type 2 diabetes receive
- Invite comments on how we can further involve people living with diabetes in the London Diabetes Clinical Network programme
- Announce our recruitment launch for Type 2 Diabetes Patient Champions to join the London Diabetes Clinical Network programme

If you would like to register for these workshops you can do so through the links below:

1. **Outcomes that matter to people living with T1 diabetes taking place on the morning on Tuesday 25 June** (refreshments from 8.30am ahead of prompt 9.30am start, with lunch at 12.30pm) – <https://www.eventbrite.co.uk/e/outcomes-that-matter-to-people-living-with-type-1-diabetes-in-london-tickets-62198820346>
2. **Outcomes that matter to people living with T2 diabetes taking place on the afternoon on Tuesday 25 June** (lunch from 12.30pm ahead of prompt 1.30pm start) - <https://www.eventbrite.co.uk/e/outcomes-that-matter-to-people-living-with-type-2-diabetes-in-london-tickets-62198824358>

The workshops take place at to be held at Etc Venues Victoria, 1 Drummond Gate, Westminster, London, SW1V 2QQ. If you have any questions regarding the event please contact england.diabetes-ldncn@nhs.net.

Support during your Bereavement Journey



In 2018/19 the NHSE (London region) End of Life Care Clinical Network undertook a project focusing on the provision and availability of information to support bereaved Londoners. Findings showed a lot of information and services are available to bereaved people, but that access to this is not universal. This can result in people not receiving relevant information and support. A leaflet co-produced by professionals and citizens with lived experience of bereavement and received feedback from the public was developed.

- When someone in the UK dies, information about what needs to happen next can be found at: www.gov.uk/after-a-death
- If you are bereaved and would like to speak with someone, you can call Cruse Bereavement Care for free on Tel: 0808 808 1677 or visit www.cruse.org.uk
- Child Bereavement UK offers support for families and professionals when a child dies or when a child grieves national helpline 0800 02 888 40 www.ataloss.org
- Independent Age has information & advice on a range of subjects 0800 319 6788 www.independentage.org/information/personal-life/when-someone-dies
- Marie Curie has information on a range of issues including practical, legal and financial. 0800 090 2903 or www.mariecurie.org.uk/help/support/supportdirectory/bere

This was discussed at the last PERF meeting and members agreed it would be useful to have available at practices and in the community. The leaflet can be accessed at the website below.

<http://www.londonscn.nhs.uk/wp-content/uploads/2019/06/Bereavement-Leaflet.pdf>

The NHS Long Term Plan – No-one Left Behind

A Long Term Plan engagement event with marginalised communities took place in March 2019. A report was conducted by NHS England and Working with Everyone.

Key findings and suggestions have been summarised below.

- There was great similarity in the barriers faced by the communities when accessing services, regardless of the type of service involved
- Digital services should assist and not replace existing services and current options for people to engage in healthcare should remain available
- The reality of digitalisation must be addressed, as well as individual and community perception, which may be inaccurate, and based on fear.
- Individuals from marginalised communities were unlikely to seek help, so link workers would need to take a proactive approach, in particular link workers involved in social prescribing
- Costs associated with social prescribing activities, such as subscription apps or gym membership were a significant barrier
- For many in the refugee/migrant community mental health problems were not recognised, often regarded not as an illness but a decision
- Mental health assessments for refugees on first contact would be a great benefit
- Using GPs to promote the benefits of immunisation and screening during new patient checks

HEALTH CAMPAIGNS

*Diabetes Awareness Week
10th - 16th June*

Diabetes week aims to raise awareness of diabetes and this will help tackle the stigma many people with all types of diabetes feel.

Diabetes can be complicated and hard to understand so Diabetes UK wants to help people know more about diabetes. Not just as a condition, but about how it feels to live with it.

One in 15 people live with diabetes. That's 4.7 million people in the UK – more than cancer and dementia combined. That includes one million people who don't even know they have diabetes.

Type 1 and Type 2 are the two main types of diabetes. There are rarer types too. What they all have in common is they raise sugar levels in the blood. And that can seriously damage the body

Why people get diabetes is complicated. Some things increase your risk of developing it, from genetics and ethnic background to gender, age and lifestyle factors. But sometimes it isn't clear why people get it.

It is much more than just tablets or injections. Every day involves a thousand little questions, decisions and things to remember. This includes appointments, checks and calculations for what to eat. It is your care on your shoulders and knowing things won't always go to plan.

When someone has diabetes, just getting through the day can be a monumental achievement. But it doesn't mean life stops. People have become professional athletes, topped the charts and ruled the country with diabetes.

It might make life harder but it doesn't have to change your ambitions or adventures.

For more information visit
https://www.diabetes.org.uk/get_involved/diabetes-week

Whilst the awareness week has passed there are still useful messages that can be used in practices.

*Sarcoma Awareness Week
3rd – 9th July*



Sarcomas are uncommon cancers that can affect any part of the body, on the inside or outside, including the muscle, bone, tendons, blood vessels and fatty tissues.

15 people are diagnosed with sarcoma every day in the UK. That's about 5,300 people a year.

There are around 100 different sub-types of sarcoma.

Getting an accurate picture of the sarcoma landscape is important, which is why Sarcoma UK collate the most recent sets of data and information from the four UK nations to get an updated snapshot of how sarcoma affects the UK.

- There are three main types of sarcoma: soft tissue sarcoma, bone sarcoma and gastrointestinal stromal tumours (GIST).
- About 670 cases of bone sarcoma are diagnosed every year in the UK.
- Seven in ten (71%) sarcomas diagnosed in the UK are soft tissue sarcomas.
- The majority of people are diagnosed when their sarcoma is about the size of a large tin of baked beans (10cm).

Sarcoma survival rates have been very gradually increasing over the last two decades in the UK.

- Almost eight in 10 people (78%) diagnosed with sarcoma in the UK will live up to a year.
- The average percentage of people living three years after being diagnosed with sarcoma in the UK is 64.5%.
- The five-year survival rate for sarcoma is 55%.

For more information visit
<https://sarcoma.org.uk/get-involved/sarcoma-awareness-week-2019>

EVENTS, CONFERENCES, WORKSHOPS, SEMINARS

Southall Community Sports Day

Help to Design a New Online Platform

National Institute of Health Research (NIHR) are inviting patients living with a health condition and carers who have experience of getting involved in NHS PPE activities to take part in a group feedback workshop to help design the patient and public section of a new online platform they are developing to publish the findings of NIHR funded research.

This is an opportunity for patients living with a health condition to help develop an online platform that aims to communicate the impact of NIHR research to the wider public in a more accessible and inclusive way.

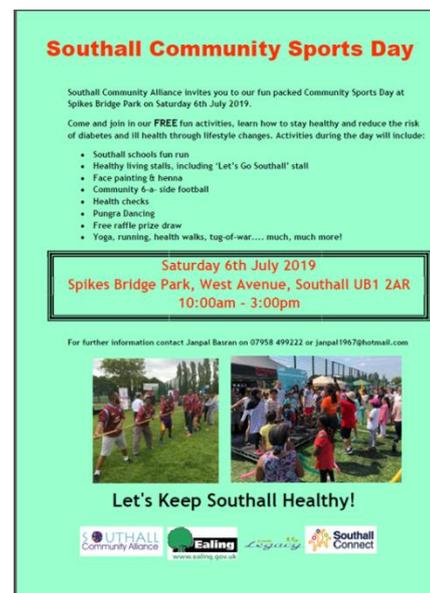
The workshop to be held on **Thursday 27th June, 2-5pm** in **Central London** will include 5-6 participants and will be facilitated by the website developers. Participants will be shown some mock up content for feedback and further discussion. Members of NIHR's CCF PPIE team will also be there to support you on the day.

As a thank you for your participation, there is an offer of an honorarium of £75 for attending the meeting and any other expenses such as travel and child care etc. will be reimbursed. Should you have any access requirements please let NIHR know in advance.

To book your place at the workshop you can send an email to sabeena.subba@nihr.ac.uk by the **19th June 2019**.

Southall Community Alliance will be holding a Community Sports day on **Saturday 6th July 2019** at **Spikes Bridge Park, West Avenue, Southall UB1 2AR, 10-3pm** where you can learn how to stay healthy and reduce the risk of diabetes and ill health through lifestyle changes. Activities during the day will include:-

- Southall Schools fun run
- Health Checks
- Community 6-a-side football
- Yoga
- Pungra Dancing
- Running, health walks and much more



Southall Community Sports Day

Southall Community Alliance invites you to our fun packed Community Sports Day at Spikes Bridge Park on Saturday 6th July 2019.

Come and join in our **FREE** fun activities, learn how to stay healthy and reduce the risk of diabetes and ill health through lifestyle changes. Activities during the day will include:

- Southall schools fun run
- Healthy living stalls, including 'Let's Go Southall' stall
- Face painting & henna
- Community 6-a-side football
- Health checks
- Pungra Dancing
- Free raffle prize draw
- Yoga, running, health walks, tug-of-war.... much, much more!

Saturday 6th July 2019
Spikes Bridge Park, West Avenue, Southall UB1 2AR
10:00am - 3:00pm

For further information contact Janpal Basran on 07958 499222 or janpal1967@hotmail.com

Let's Keep Southall Healthy!

Logos for Southall Community Alliance, Ealing, and Southall Connect are shown at the bottom.

To register for the 6-a-side football you will need to complete the registration form below.



Sports Day
 registration form 2019

Please complete and return by **Friday 28th June 2019**.

For further information please contact Janpal Basran on 0795849922 or janpal1967@hotmail.com

PPG Awareness Week

Glossary

Patient Participation Awareness Week takes place on **10-15 June 2019**. The Week aims to promote the role and benefits of PPGs to patients, the public and health professionals, to create more understanding of the value of true patient participation also to promote the support available from N.A.P.P.

ECCG-Ealing Clinical Commissioning Group

GP-General Practitioner/General Practice

NAPP-National Association of Patient Participation

NHS-National Health Service

PPE-Patient and Public Engagement

PPG-Patient Participation Group

ECVS-Ealing Community and Voluntary Services

NWL Wheelchair Service Newsletter

This newsletter contains useful information for wheelchair users such as Personal Wheelchair Budgets and how to find alternatives to wheelchairs for those with unmet needs.



WOULD YOU LIKE MORE INFORMATION?

National Association of Patient Participation (NAPP)

You can access some useful free information about PPGs on the NAPP website. But if you would like to have full access to their resources your practice would need to pay an annual subscription fee to NAPP. More information is on their website www.napp.org.uk

The latest e-bulletin can be found at <https://www.napp.org.uk/Ebulletin%20MAY%202019.pdf>

WE WANT TO HEAR FROM YOU!

If you have any ideas, suggestions or comments on the newsletter

Please send your contributions to our new email address

Ealccg.PPE@nhs.net

Previous editions of the newsletter can be found on our website

<https://www.ealingccg.nhs.uk/news,-publications-and-policies/publications.aspx?n=6363>