

PATIENT PARTICIPATION GROUP (PPG) NEWSLETTER

May 2019 – Issue No 16

email: ealccg.ppe@nhs.net

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



TELL US WHAT YOU THINK

Improving Cancer Care in West London

We are looking for individuals with experience of cancer services in west London to join our Patient Advisory Group.

RM Partners, the West London Cancer Alliance, puts patients, their families and carers at the heart of our work to transform cancer services, including patient experience and care.

Our active, engaged Patient Advisory Group (PAG) is an essential part of this work, helping to provide patient insight, leadership and advice on our work programme and the projects we run.

We are now recruiting additional members to ensure we have access to people with a wide range of knowledge and experience as well as a passion to improve cancer services.

Interested? We are looking for people who have been treated for cancer or cared for someone with cancer at a hospital in west London within the past 5 years.

The closing date for applications is Friday 31st May 2019.

More information including an application form is available on our website at: <https://rmpartners.nhs.uk/patient-advisory-group-recruiting-new-members/>

If you have any questions please contact Fiona Carr, patient involvement and communications manager, at Fiona.Carr3@nhs.net

Hammersmith & Fulham CCG will be running a public consultation from **8th April to 24th May 2019**. The consultation is to gather feedback from members of the public on two potential changes in the CCG:

1. Potential change to the opening hours of the Hammersmith Hospital urgent care centre.
2. Potential change to number of weekend hubs currently available in H&F CCG.

Have your say by attending one of our events.

- **Thursday 23rd May, 10am-12pm** Sobus, 20 Dawes Road, SW6 7EN <https://bit.ly/2Hsh6SZ>
- **Friday 24th May 10.30am- 12.30pm (event for older people)**, Irish Cultural Centre Board Room, 5 Black's Road, W6 9DT <https://bit.ly/2JHBana>

To help us plan refreshments and seating, please register: search for the above workshop on www.eventbrite.co.uk

You can also have your say on the proposals by

- You can fill in the survey: <https://www.surveymonkey.co.uk/r/hammersmithurgentcare>
- You can write to: FREEPOST HEALTHIER NORTH WEST LONDON
- You can email: hafccg.engagement@nhs.net

Further information can be found at the website below

<https://www.hammersmithfulhamccg.nhs.uk/your-voice/consultations-and-events/find-out-more-about-the-consultation.aspx>

Calling all Young Carers aged 16-24

Join the NHS England Young Carer Health Champion programme in July 2019



The Young Carers Health Champion programme was established in 2015 to support improved health literacy, promote health and wellbeing and develop the capacity of young carers to participate in planning and development of young carer friendly services. It aims to support service change through young carer voices. The 12-month programme is made up of young carers (aged 16 - 24) from across the country. They will experience self-development, be part of healthcare initiatives that aim to improve young carer identification and support and develop an action plan with outcomes that further support young carer friendly services. Recruitment is underway for the July 2019 programme. The 12-month programme consists of; three residential weekends which must be attended with a Support Worker from your Young Carer Organisation, regular virtual contact as a group through our closed Facebook group and opportunities to participate and contribute to healthcare events and workshops.

Those keen to be considered for this programme should email Paula Cruise with their name, age and Young Carer Organisation Support Worker contact details to Paula.Cruise@nhs.net or call Paula on 07800 171820 if you have any questions. Closing date for applications is **7th June 2019**. Confirmation of acceptance on the programme will be sent the following week

Parkrun Practice Initiative

Have you considered registering your GP practice to be a Parkrun Practice to help promote free 5K parkruns to benefit both your staff and patients?

In an exciting and innovative initiative, the Royal College of General Practitioners (RCGP) is collaborating with parkrun UK to promote the health and wellbeing of staff and patients. Under this initiative, GP practices across the UK are encouraged to develop close links with their local parkrun to become parkrun practices.

What is parkrun?

- Free, weekly 5k events, every Saturday morning, in areas of open space
- 2k junior parkruns for 4-14 year olds and their families on Sunday mornings
- Over 850 locations across the UK
- Organised by local volunteer teams
- Walk, run, jog, volunteer or spectate - take part in any way that suits you
- Open to all, including those who are inactive or have health conditions or disabilities
- Opportunity to socialise, make friends and be part of a welcoming, supportive community

Involvement will help practices:

- Improve the health and wellbeing of practice staff
- improve the health and wellbeing of patients and carers, reducing the need for lifelong medication
- Raise awareness amongst the parkrun community of services that practices provide
- Contribute to the development of a local community and environment that is centred around wellness generation
- Support the UK-wide movement to scale up social prescribing activities

RCGP are encouraging GP staff to pledge to participate in a Parkrun on **Saturday 1st June 2019**. Visit the RCGP link website for more information: www.rcgp.org.uk/parkrun

Dying Matters Awareness Week

As part of Ealing CCG’s Advance Care Planning programme, we promoted “Dying Matters Awareness Week” between 13 and 19 May with several community engagement events at Ealing care homes and the local library. At the engagement events Marie Curie, Macmillan and Coordinate My Care (CMC) spoke to members of the public about communicating to friends, family and loved ones their wishes about future care, including where they want to die and their funeral plans. Patients are now able to begin their own CMC record, with the launch of ‘MyCMC’. Care plans created by the patient in conjunction with their doctor can be shared with relevant health professionals, including urgent care centre staff and the London Ambulance Service. This ensures everyone knows the patient’s wishes, and in an emergency this can be taken into account. Further information about CMC and MyCMC is available at <https://www.coordinatemycare.co.uk/>



The Grange Care Centre – 14th May 2019

Kashmir (Local Authority), John and Christine (Marie Curie), Anna (Macmillan) and Sherry (The Grange Care Centre)



Sycamore Lodges 15th May 2019

Sophia (MyCMC), Kashmir (Local Authority), Angad (ACP Clinical Lead), Sheona and John (Marie Curie)

✓ 63 out of 79 practices responded.

✓ Do you have a current active PPG? Yes/No

Answer	Percentage (%)	No. of responses
Yes	95.24	60
No	4.76	3
Total		63

✓ Is your PPG representative of your practice population? Yes/No

Answer	Percentage (%)	No. of responses
Yes	84.13	53
No	15.87	10
Total		63

✓ Do you have regular meetings? If yes, how are they run (face-to-face, virtual, both)

Face to face	58
Virtual	6
Both	5

✓ Majority of PPG meetings were held in April, September and November

✓ Steps taken to ensure the PPG represents the diverse group of the practice population
Practices responded with these key areas for engagement

Face to face meeting	19
Virtual meeting	4
Notice Board, posters, etc.	16
Promotion to all groups	37
Promotion on website	16
At registration	16
Patient Survey	3
Newsletter	4
Text Invites	3
Leaflet	4

HEALTH CAMPAIGNS

Stroke Awareness Month

Make May Purple for stroke is our annual stroke awareness month, taking place every May.

Stroke strikes every five minutes in the UK. It can happen to anyone, of any age, at any time. It's vital to know how to spot the warning signs of a stroke in yourself or someone else. Using the FAST test is the best way to do this.



Face: Can the person smile? Has their face fallen on one side?

Arms: Can the person raise both arms and keep them there?

Speech problems: Can the person speak clearly and understand what you say? Is their speech slurred?

Time: If you see any of these three signs, it's time to call 999.

There is no way of knowing if symptoms will pass or get better when they first start, so you need to seek immediate medical help. A stroke is a medical emergency. Always dial 999. The quicker the person arrives at a specialist stroke unit, the quicker they will receive appropriate treatment.

The FAST test helps to spot the three most common symptoms of stroke. But there are other signs that you should always take seriously. These include:

- Sudden weakness or numbness on one side of the body, including legs, hands or feet.
- Difficulty finding words or speaking in clear sentences.
- Sudden blurred vision or loss of sight in one or both eyes.
- Sudden memory loss or confusion, and dizziness or a sudden fall.
- A sudden, severe headache.

If you spot any of these signs of a stroke, don't wait. Call 999 straight away.

Ambulance paramedics are trained in stroke, and will take the person to the best hospital for specialist treatment.

For more information visit Stroke Association at <https://www.stroke.org.uk>

Rheumatoid Arthritis Awareness Week

17th - 23rd June

This year's theme is #AnyoneAnyAge. We want to challenge those misconceptions of 'arthritis' being a condition of the elderly or associated with ageing. With your help we can highlight to the nation that Rheumatoid arthritis is an 'equal opportunity' disease - showing no age or race discrimination!

The auto-immunity element of rheumatoid arthritis (RA) as well as other inflammatory forms of arthritis distinguishes the conditions from the most common form of arthritis – osteoarthritis which is more associated with 'wear and tear' and ageing. It is this reason why we are focusing more this year on RA being an auto-immune disease that can strike at any age.

Auto-immunity means a misdirected immune response that occurs when the immune system goes awry and attacks the body itself. Autoimmunity is present to some extent in everyone and is usually harmless. However, autoimmunity can cause a broad range of human illnesses, known collectively as autoimmune diseases including rheumatoid arthritis.

The best way to raise awareness and challenge misconceptions of RA is by sharing your stories of living with RA. We'd also like to hear from friends, family, employers, teachers, colleagues and health professionals. Do you have a story to tell about someone with RA? Can you share your story with us? If so you can contact media@nras.org.uk.

For more information visit National Rheumatoid Arthritis Society at <https://www.nras.org.uk/ra-awareness-week-2019>

EVENTS, CONFERENCES, WORKSHOPS, SEMINARS

PPG Awareness Week

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.

The resource pack can be accessed at this link.
<https://www.napp.org.uk/AWARENESS%20RESOURCE%20PACK%202019.doc>

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.



Wheelchair Service
Newsletter NWL Jan :

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%20APRIL%202019.pdf>

Glossary

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

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>