

Patient Leadership Summit

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Friday 29 March 2019 De Vere West One Conference Centre, London



Chair and Speakers Include:

Jonathon Hope MBE
Patient Leader

David Gilbert
Co-Founder
The Centre for Patient Leadership
& Patient Director
The Sussex Musculoskeletal Partnership (Central)

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"The health sector needs to learn how to work with patient leaders" Tessa Richards The BMJ Dec 2017

"The concept of patient leadership is emerging as one important new way of working collaboratively with patients and carers...Patient and carer leaders can raise the profile of improving experience of care and can have a real impact on action being taken in response to patient and carer feedback." NHS England

"Patient leaders bring a credible voice, and can work with system leaders to create a compelling case for change. This gives the system 'permission to act'. Patient leaders influence health services' priorities, placing a greater emphasis on the experience of care. Patient leaders can help to design services on the ground, and when system leaders involve patient leaders and carers in this service design, they are able to focus more closely on what patients and carers want." NHS England

This national summit chaired and co-produced with Jonathon Hope MBE will focus on the important issue of Patient Leadership and how you can support patients in your organization to co-design and improve services, how you can help patients to develop patient leadership skills and how to effectively work with patient leaders.

In recent years, NHS policy makers and leaders have increasingly moved towards engaging and involving patients, not only in their care but also in the design of services. Reports such as 'no decision without me' and 'increasing accountability' have come to symbolise the need for patients and professionals to work more closely together. In the Five Year Forward View the NHS clearly committed to directly 'engaging' with communities and citizens in new ways, involving them directly in decisions about the future of health and care services'.

Increasingly, in response to this call to action and the growing pressure on services, charities, think tanks and organisations across the NHS are turning to patients to gain irreplaceable insight into how organisations, services and cultures need to be changed. Increasingly, Patient Leaders are at the forefront of this change, building collaborative relationships with fellow patients, trusts and community services, especially in areas of patient experience and patient engagement. Work is being done by the King's Fund, the NHS, the Coalition for Collaborative Care and many trusts across the NHS to explore the concept of Patient Leadership and to develop Patient Leadership programmes.

However, since the concept and practice of Patient Leadership is still an emerging field in healthcare science, and as is often the case with any new ideas, is only spreading in isolated pockets of best practice across the NHS, there remains a very significant number of staff and organisations who are unfamiliar with what a Patient Leader is and of the potential patient-centred leadership skills, roles and capabilities they can bring to the NHS. There is also a lack of understanding of the considerable strategic advantages of involving Patient Leaders, especially, but not exclusively, in future strategic planning, areas such as assurance and validation and service delivery and design at Board level or below.

In addition, another barrier to building a broader momentum behind Patient Leadership approaches is that large areas of the NHS England and the NHS are still focused strategically on a PPI mindset rather than a 'Patient Leadership and Public Involvement' (PLPI) mindset with only a few organisations putting together comprehensive organisation-wide patient leadership strategies to effectively recruit, support and collaborate with emerging local Patient Leaders. Thus many trusts Patient and Public Involvement Strategies do not yet specifically highlight the potential of Patient Leaders.

If you feel that your organisations or key members of your staff such as Patient & Public Engagement Managers, Service-Design Leads, Assurance Leads, Directors of Patient Experience, Governors, Non-executive Directors or others need to be brought up to date on emerging best practice in this area then this national summit will provide essential advice, tips and practical solutions to implement patient leadership within your service. The conference features presentations and extended workshops from patient leaders who have made a difference in practice, and organisations that have established patient leadership as a core part of their culture. There will also be an extended focus on developing training in patient leadership and implementing a patient leadership programme in your service.

Follow the conference on Twitter #patientleadership

10.00 Chairman's introduction

Jonathon Hope MBE

Patient Leader

- what is Patient Leadership?
- why the NHS Needs more Patient Leaders
- why is patient leadership key to the future of the NHS?
- how are Patient Leaders helping shape the future of services?
- moving forward

10.45 How can organisations support patients and carers to shape services?

Ian Donaghy

Author 'Dear Dementia' & 'The Missing Peace'

The Missing Peace is described as 'a 200 page hug' for people losing those close to them exploring the power of kindness, family and friendship and how to avoid making mistakes at a most sensitive time

- what is experience of care?
- end of life care planning for dementia: a personal journey
- ensuring engaged, informed individuals and carers
- the little things that make a big difference
- meaningfully engaging and involving people
- my experience in working with services to improve care and change attitudes

11.30 Question and answers, followed by tea & coffee at 11.40

12.00 EXTENDED INTERACTIVE SESSION: Facilitating patient partnership for improvement and governance

Lead Facilitator:

David Gilbert

Co-Founder

The Centre for Patient Leadership

& Patient Director

The Sussex Musculoskeletal Partnership (Central)

- transforming relationships between healthcare organisations, health professionals and patients
- a new approach: patients as trusted equals in decision making
- working with patients and carers to improve quality and safety
- working with patients and carers to monitor services
- my role as a Patient Director
- interactive session: working through the engagement cycle

13.20 Question and answers, followed by lunch at 13.30

14.00 Patient leaders in action: delivering services

Jack Martin

Public Affairs Officer and Development Lead Hafal

Hafal is an organisation managed by the people we support: individuals whose lives have been affected by serious mental illness

- changing the culture
- a hospital run formally and legally by people with experience of serious mental illness
- ensuring lived experience is integral to the service
- practical examples and advice

14.30 Young People as Patient Leaders

Rachel Jury

Patient Leader

- my journey to becoming a Patient Leader
- how organisations can effectively support patient leaders

15.00 Developing a patient leadership programme at a local level

Helen Edmunds

Head of Leadership and OD Kent Surrey and Sussex Leadership Academy

with Lorraine Copnall

Leadership and OD Consultant Kent Surrey and Sussex Leadership Academy

and Professor Lis Paice

Non-Executive Director The Hillingdon Hospitals NHS Foundation Trust

- our effective patient leader programme
- tips for delivering a patient leadership programme in your trust
- the Kent Surrey and Sussex Leadership Academy Programme

15.30 Question and answers, followed by tea at 15.40

16.00 Recruiting and supporting Patient Leaders to co-design and improve

Carol Munt

Patient Partner & Advocate, Honorary Lecturer & Doubleday Affiliate Manchester Medical School, NHSE Always Events National Advisory Group, NHS Horizons #Project A Falls Collaborative

- the importance of 'co-production' in everything you do
- recruiting, motivating and sustaining Patient Leaders
- working with the challenges of maintaining good Patient Leader involvement
- supporting patient leaders to co-design and improve services, and to be involved in programme governance

16.30 The Importance of Involving and Engaging BME Patient Leaders

Naila Hope

Patient Leader

- my Journey to Patient Leadership
- supporting BME patients and carers to share their perspective
- putting BME Patient's and carers cultural needs on the agenda
- ensuring BME voices acted upon

16.50 Question and answers, followed by close

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Download

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Venue

De Vere West One Conference Centre, 9-10 Portland Place, London, W1B 1PR. A map of the venue will be sent with confirmation of your booking.

Date Friday 29th March 2019

Conference Fee

- £365 + VAT (£438.00) for NHS, Social care, private healthcare organisations and universities.
 £300 + VAT (£360.00) for voluntary sector / charities.
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The fee includes lunch, refreshments and a copy of the conference handbook. VAT at 20%.

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