







## SIXTH ANNUAL CONFERENCE AND AWARDS CEREMONY

**EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE** 

## 27-28 February 2020

University of West London London, UK

**Conference Brochure** 





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## WELCOME!

## Dear Conference Delegates, Speakers, ChairPersons, Students, and Friends,

We are delighted to welcome you to the Sixth Annual Conference and Awards Ceremony of the European Society for Person Centered Healthcare (ESPCH6). Our purpose at ESPCH6, representing the work of the ESPCH more widely, is to 'import' the historic tenets of humanistic medicine/healthcare, into a data-driven modern context, with a laser-sharp focus on the modern healthcare imperative of higher quality care at sustainable or lowered cost.

As in previous years, **ESPCH6** brings together a wide range of distinguished speakers and chairpersons from across the globe, including the United States of America, Canada, Australia, Germany, Switzerland, Denmark, and, in the United Kingdom, colleagues from the University of Oxford, University of West London, Manchester Metropolitan University, Kingston University, St. George's University of London, the University of Hull, and the University of Gloucester.

Over ESPCH6's two intensive days, 33 presentations will be delivered across 11 academic sessions, spanning a wide range of study areas of immediate relevance to the development and implementation of person-centred approaches within health and social care systems. Debates will take place as part of extended panel discussions, each of which includes a specific panel discussant. A key feature of ESPCH6 is the inclusion as speakers of a wide range of patients and patient advocacy organisations, alongside a wide variety of clinicians, academics and colleagues from the pharmaceutical and healthcare technology industries.

Following the conclusion of Day One of ESPCH6, the Society will hold its 2020 Annual Awards Ceremony, at which the President and Chairman of Council of the Society, Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc), will confer the Presidential Medal, the Senior Vice-Presidential Medal, the Platinum, Gold, Silver and Bronze medals of the Society, the Book Prize and the Essay Prize, the Society's prizes for qualitative, quantitative and mixed methods research, the Young Teacher and Young Researcher prizes, and the ESPCH prizes for patient advocacy.

The ESPCH is a professional membership body for clinicians of all disciplines, social care professionals, academics working within the health and social care sciences, patient, carers, policymakers, and others. During the course of ESPCH6, delegates not already members of the Society will have the opportunity to apply for membership (Distinguished Fellow, Fellow, Member, Associate, Student) at reduced rates. Membership of the ESPCH affords full access to the European Journal for Person Centered Healthcare, the official journal of the Society, and to the e-Bulletin of the ESPCH. Application forms will be available at the Registration Desk.

In concluding, we extend our gratitude to Professor Peter John CBE BA, MA, MSc, PGCE, DipEd, PhD, Hon DEd, FRSA, FHEA, MIoD, Vice Chancellor and Chief Executive of the University of West London, for granting the Society use of the superlative, state-of-the-art facilities of the Weston Hall Conference Suite at UWL's Ealing Campus, the base of the newly created European Institute for Person Centred Health and Social Care.

Collegially,



**Professor Andrew Miles** BMedSci MSc MPhil PhD DSc (hc)

ESPCH Senior Vice President/Secretary General & Editorin-Chief, European Journal for Person Centered Healthcare: Professor of Person Centred Care & Co-Director, European Institute for Person Centred Health and Social Care, University of West London; Hon. Professor of Person Centred Care, St. George's University Teaching Hospital Campus, London, UK



#### Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc) DSc (hc)

ESPCH President & Chairman of Council & Chairman, Editorial Board, European Journal for Person Centered Healthcare; Visiting Professor, European Institute for Person Centred Health and Social Care, University of West London, UK; Chief Clinical Officer, Healthcare at Home, UK

## DAY 1 **SESSIONS**

**THURSDAY** February 27, 2020







## DAY 1 **PROGRAMME**

February 27, 2020

#### 08:00 Registration & Refreshments

Welcome to the University of West London 09:00 Professor Anthony Woodman BSc MSc PhD, Deputy Vice Chancellor and Provost for Health, University of West London, UK

#### 09:05 Presidential Address

Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc) DSc (hc), President and Chairman of Council, European Society for Person Centered Healthcare

#### Early Morning Session

FOCUS ON NEW MODELS OF HEALTHCARE, CO-PRODUCTION/EDUCATION, AND CHRONIC ILLNESS

#### Early Morning ChairPerson

Professor Andrew Miles, Professor of Person Centred Care & Co-Director, UWL European Institute for Person Centred Health and Social Care; ESPCH Senior Vice President/Secretary General; Editor-in-Chief, European Journal for Person Centered Healthcare & Hon. Professor of Person Centred Care, St. George's University Hospital Campus, University of West London, UK

#### 09:10 **KEYNOTE1**

The GEM Model: A Model of Health Based on Generalized Empirical Method Dr. Patrick Daly, Research Associate, Lonergan Institute at Boston College, Chestnut Hill, Massachusetts, USA

#### 09:40 KEYNOTE 2 - 2020 ESPCH Platinum Medal -

Co-Production, Co-Education and Person-Centered Healthcare Practice - Everyone Included Dr. Amy Price, Senior Research Scientist, Stanford Anesthesia Informatics and Media (AIM) Lab, Stanford University School of Medicine, USA; Research Editor, Public and Patient Partnership Strategy British Medical Journal & Department of Continuing Education, University of Oxford, UK

#### - 2020 ESPCH Quantitative Methods Research Prize -10.10

What do the healthcare experiences of people with long-term conditions tell us about person-centered care? A systematic review

Ms. Myriam Dell'Olio, Doctoral Student, Academy of Primary Care, Hull York Medical School, University of Hull, UK

10:30 What does it mean to be person-centred in the care of people and their families living with HIV?

Dr. Michelle Croston, Senior Lecturer & Advanced Nurse Practitioner, Department of Nursing, Faculty of Health, Psychology & Social Care, Manchester Metropolitan University, UK

#### Panel discussion with delegate participation 10:50

(with invited panel discussant Dr. Vije Rajput)

#### 11:10 Morning Break & Refreshments

Late Morning Session FOCUS ON PROFESSIONAL/INSTITUTIONAL EMPATHY AND PATIENT AND CARING ROBOTICS

#### Late Morning ChairPerson

Sir Jonathan Elliott Asbridge, Chief Clinical Officer, Healthcare at Home & Visiting Senior Clinical Professor, European Institute for Person Centred Healthcare, University of West London, UK

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#### 11:30 KEYNOTE 3 - 2020 ESPCH Gold Medal -Why every person-centred healthcare consultation needs a generous dose of empathy Dr. Jeremy Howick, Director, Oxford Empathy Programme & Senior Researcher and Impact Fellow, Oxford Faculty of Philosophy, University of Oxford, UK

- 12:00 Humanoid Robots as Expressions of Transcultural Caring in Nursing Florida, USA
- 12:20 Spirituality and Artificial Intelligence: Can Human Caring Be Replaced by Robots? Colonel Dr. Marcia Potter, Master Clinician, United States of America Air Force & Adjunct Professor, Uniformed Services University of the Health Sciences, USA
- 12:40 Panel discussion with delegate participation (with invited panel discussant Professor Michael Loughlin)

#### 13:00 Luncheon

A 25 minute video from Parkinson's Concierge will be played in the Lecture Theatre 13 15-13 40

#### Early Afternoon Session

FOCUS ON PATIENT AND PUBLIC INVOLVEMENT IN THE IMPLEMENTATION OF PERSON-CENTERED **CARE APPROACHES WITHIN MODERN HEALTH SYSTEMS - I** 

#### Early Afternoon Chairperson

Dr. Amy Price, Senior Research Scientist, Stanford Anesthesia Informatics and Media (AIM) Lab Stanford University School of Medicine, USA; Research Editor, Public and Patient Partnership Strategy British Medical Journal & Department of Continuing Education, University of Oxford, UK

#### 13:40 KEYNOTE 4 - 2020 ESPCH Senior Vice-President's Medal for Excellence-The experience of being a patient

Ms. Rachel Power, Chief Executive Officer, The Patients Association, UK

- 14:10 2020 ESPCH The Patient Advocacy Prize -Patient Engagement, Living with Parkinson's Concierge, UK
- 14:30 Real People, Real Stories, Real Support. Melanoma UK brings the "My Melanoma App" to patients, giving them a voice. Corporate Partnerships, Melanoma UK
- 14:50 Panel discussion with delegate participation (with invited panel discussant Sir Jonathan Asbridge)

#### Mid Afternoon Session FOCUS ON PATIENT AND PUBLIC INVOLVEMENT IN THE IMPLEMENTATION OF PERSON-CENTERED **CARE APPROACHES WITHIN MODERN HEALTH SYSTEMS - II**

#### Mid Afternoon ChairPerson

Dr. Michelle Croston, Senior Lecturer & Advanced Nurse Practitioner, Manchester Metropolitan University, Manchester, UK

- 15:10 Putting the Patient Voice at the Centre of Medicinal Cannabis Policy & Research Lead, The Centre for Medicinal Cannabis, UK
- 15:30 Rare disease patient views: mental health and person-centred care Dr. Amy Hunter, Director of Research, Genetic Alliance UK
- 15:50 2020 ESPCH Silver Medal -50 years well travelled - sharing and caring with the OI (Osteogenesis Imperfecta) community Ms. Patricia Osborne, Chief Executive Officer, Brittle Bone Society, UK
- 16:10 Panel discussion with delegate participation (with invited panel discussant Dr. Amy Price)



Professor Marilyn A. Ray, Colonel (Ret.), United States Air Force Nurse Corps & Professor Emerita and Adjunct Professor, The Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton,

Ms. Charlotte Allen and Mr. Russ Bradford, Parkinson's Patients and Co-Founders of Parkinson's

Ms. Gillian Nuttall (1) and Ms. Diane Cannon (2), (1) Founder & Chief Executive Officer, (2) Director of

Mr. Jonathan Liebling, Co-Founder and Director at Cannabis Patient Advocacy and Support Services,



#### 16:30 Afternoon Break & Refreshments

#### Late Afternoon Session FOCUS ON PATIENT ENGAGEMENT AND SOCIAL AND RELATED PRESCRIBING

#### Late Afternoon ChairPerson

Ms. Jane Teasdale, Principal Owner, Co-Founder and Director of Business Development, Mosaic Home Care Services & Community Resource Centres, Toronto, Ontario, Canada

- 16:50 Integrating patient engagement and quality improvement, evidence from a 7-year journey Mr. Shahid Sardar, Associate Director for Patient Engagement, The Princess Alexandra Hospital, NHS Trust, UK
- Personalising Dementia Care through music why, how, and the benefits of using music for people living with dementia and their carers
  Ms. Grace Meadows, Programme Director, Music for Dementia 2020, The Utley Foundation, UK

#### 17:30 - 2020 ESPCH Mixed Methods Research Prize -

Understanding wellbeing outcomes in primary care arts on referral interventions: a mixed methods study Ms. Samantha Hughes, Doctoral Student, School of Natural and Social Sciences, University of Gloucestershire, UK

17:50 Panel discussion with delegate participation (with invited panel discussant Dr. Rick Morton)

#### 18:10 Closing Remarks ~ Close of Day 1

**Professor Andrew Miles**, Professor of Person Centred Care & Co-Director, UWL European Institute for Person Centred Health and Social Care; ESPCH Senior Vice President/Secretary General; Editor-in-Chief, *European Journal for Person Centered Healthcare* & Hon. Professor of Person Centred Care, St. George's University Hospital Campus, University of West London, UK



## DAY 1 ABSTRACTS

## THURSDAY

February 27, 2020

#### 09:10 KEYNOTE 1

The GEM Model: A Model of Health Based on Generalized Empirical Method Dr. Patrick Daly, Research Associate, Lonergan Institute at Boston College, Chestnut Hill, Massachusetts, USA

In this talk, I introduce a comprehensive model of health based on the generalized empirical method of Bernard Lonergan, which integrates the empirical method of natural science and the phenomenological method of historical and related human sciences in a way that is unique among contemporary thinkers. The GEM model, in turn, offers a unique framework - a higher viewpoint - for integrating the manifold viewpoints of clinical practice, the humanities (the drama and narrative of human living), health science and health policy in a methodically dynamic and critically progressive fashion in order to address the many pressing problems of contemporary healthcare.

#### 09:40 KEYNOTE 2 - 2020 ESPCH Platinum Medal -Co-Production, Co-Education and Person-Centered Healthcare Practice - Everyone Included

Dr. Amy Price, Senior Research Scientist, Stanford Anesthesia Informatics and Media (AIM) Lab, Stanford University School of Medicine, USA; Research Editor, Public and Patient Partnership Strategy British Medical Journal & Department of Continuing Education, University of Oxford, UK

#### BACKGROUND

Research and healthcare practice continue to grow in scope with minimal guidance for Patient and Public Involvement (PPI). The quality of responsiveness, replication and respectful co-production and shared decision making in health care may depend on the methods used to conduct and report co-production.

#### AIM

To assess which methods might be adapted to improve the conduct and degree of patient and public co-production in diverse but important areas within health care and in the work leading up to research transition from lab to clinical care.

#### METHODS

A mixed-methods participatory action approach was adopted and includes a blend of multiple approaches and methods. We will propose and justify the use of an Everyone Included approach rather than a Patient Included Model and identify its use in medical education, shared decision making, research, and social care.



#### FINDINGS

Overall, we outline why and how teams struggle with coproduction and we report on the strategies to improve engagement. In research and in care, health and research professionals join end-users in expressing conflict about where and how to do and report co-production succinctly and honourably without interfering with other necessary tasks, reporting and discussion.

#### CONCLUSIONS

This work demonstrates co-production with the public across multiple settings and even with minimal funding can improve research and care. Additional guidance was identified as beneficial by stakeholders.

10:10

#### - 2020 ESPCH Quantitative Methods Research Prize -

What do the healthcare experiences of people with long-term conditions tell us about person-centered care? A systematic review

Ms. Myriam Dell'Olio, Doctoral Student, Academy of Primary Care, Hull York Medical School, University of Hull, UK

#### INTRODUCTION

Growing numbers of people now live with long-term conditions. For each person, the challenges are multiple and unique to that individual. In recognition of this, health policy places greater emphasis on the delivery of person-centred care (PCC). However, patients report declining levels of such care. One reason for this may be a mismatch between patient and professional/policy understanding of PCC.

#### AIM

To understand PCC from the perspectives of people with long-term conditions.

#### METHODS

A systematic review of qualitative literature was conducted. Databases searched included ASSIA, BNI, CINAHL, the Cochrane Library, Embase, Medline, PsycINFO, PubMed, Scopus, Web of Science, and grey literature databases. Two reviewers independently screened and selected the studies, assessed their quality, and extracted data. Fifty-four records were analysed through meta-ethnography.

#### RESULTS

Four themes emerged: the healthcare system as a battlefield, the healthcare system as a maze, patients' accounts of personhood, and the importance of patient enablement. A person-centred healthcare system is described by this review as one that values personhood and enables patients to build knowledge with their clinician in order to manage their illness in a safe, caring, and accessible environment.

#### CONCLUSION

PCC does not depend on the efforts of the clinician alone. but results from a collaboration with the patient and needs to be enabled by the wider organisational and educational systems. Efforts directed at the implementation of PCC might be bound to fail if the healthcare policy agenda does not address the role of the patient's personhood in clinical practice, and its integration in educational settings.

#### 10:30 What does it mean to be person-centred in the care of people and their families living with HIV?

Dr. Michelle Croston, Senior Lecturer & Advanced Nurse Practitioner, Department of Nursing, Faculty of Health, Psychology & Social Care, Manchester Metropolitan University, UK

This presentation will provide a brief history of humanistic care that has formed the foundations of person-centred care within the HIV clinical context. Changes in the HIV disease area with be explored with regards to how we maintain the humanistic legacy of HIV care, whilst achieving national and international eradication targets. Finally, the presentation will explore how services could be delivered to ensure that people living with HIV are at the centre of their care.

#### 11:30 KEYNOTE 3 - 2020 ESPCH Gold Medal -Why every person-centred healthcare consultation needs a generous dose of empathy

Dr. Jeremy Howick, Director, Oxford Empathy Programme & Senior Researcher and Impact Fellow, Oxford Faculty of Philosophy, University of Oxford, UK

In this plenary lecture, Oxford researcher Dr. Jeremy Howick will explain how healthcare practitioners can improve patient-centered healthcare with a dose of empathy. He has spent the last 10 years researching the ethics and effects of placebos, and positive/empathic communication, and in this lecture he will share the cutting edge science of empathic communication. He will also: (a) explain what evidence says about relationship between empathy, the placebo, and chiropractic, and (b) outline his experience with the recent trial of placebos for back pain that was aired on the BBC. Using stories from the past and present to illustrate scientific conclusions, the audience is guaranteed to be informed and entertained.

#### 12:00 Humanoid Robots as Expressions of Transcultural Caring in Nursing

Professor Marilyn A. Ray, Colonel (Ret.), United States Air Force Nurse Corps & Professor Emerita and Adjunct Professor, The Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, Florida, USA

The purpose of this presentation is to address "humanoid robots as expressions of transcultural caring in the health sciences." Robotic technologies are used in diverse technological environments and now introduced into practice for application in aging and "high-tech" health care ESPCH6

settings. This presentation will address complex issues first with a brief history of robots, second, appreciation of the meaning of a significant human attribute, consciousness in relation to artificial intelligence and robotic technology, and third, caring science as expressed through transcultural/ multicultural phenomena in nursing and health care. The presentation will give the audience an understanding of the complexity of the ethical dilemmas of "humanoid robots for care" or "humanoid caring robots", such as, highlighting the intrinsic and extrinsic meanings of the inter-relational "call and response" of diverse patients and professionals in healthcare situations. Healthcare professionals, engineers, social scientists, linguists, ethicists, and others, even theologians or mystics are challenged to understand and work together to determine the "why, how and where," especially of the meaning of consciousness, transcultural caring, and the "human heart" in the planning, engineering, and implementation of humanoid caring robots in healthcare.

#### 12:20 Spirituality and Artificial Intelligence: Can Human Caring Be Replaced by Robots? Colonel Dr. Marcia Potter, Master Clinician, United States of America Air Force &

Adjunct Professor, Uniformed Services University of the Health Sciences, USA

Throughout history mankind has sought ever-increasing knowledge and application of that knowledge. The computer age has ushered in new ethical issues to uncover and solve. At the heart of modern artificial intelligence (A/I) development lies the of very essence of what it means to be fully human: the reconceptualization of the self. Contemporary architects of A/I promote the concept of intellect as the ultimate concept of humanness. Ethicists and theologians argue the heart and spirit constitute self, thus humanness. This paper seeks to explore the concept of caring as a specifically human attribute that cannot be replicated by machine and the ethical considerations for the promotion of A/I as human adjunct.

#### 13:40 KEYNOTE 4 - 2020 ESPCH Senior Vice-President's Medal for Excellence-The experience of being a patient Ms. Rachel Power, Chief Executive Officer, The Patients Association, UK

The Patients Association is a charity that represents patients. Its CEO, Rachel Power, briefly introduces the organisation, and outlines the programme of work on patient experience that it is currently undertaking. This presentation gives a preview of the provisional results of its initial research and scoping phase. It begins by considering the current discourse on patient experience, and argues that it is largely concerned with performance management, and seen from the perspective of providers and system, not patients. It then considers possible ways to develop a more broadbased understanding of patient experience, and looks at the acceptability of the term 'patient' and possible alternatives before considering wider factors that might usefully be built into a broader definition of patient experience.

14:10 - 2020 ESPCH The Patient Advocacy Prize -Patient Engagement, Living with Parkinson's Ms. Charlotte Allen and Mr. Russ Bradford, Parkinson's Patients and Co-Founders of Parkinson's Concierge, UK

Parkinson's Concierge Founders, Charlotte Allen & Russ Bradford, share an insight into what it is like living together with Parkinson's and Caring for each other. They give hope about the future and spread awareness, outline the daily problems they face and the side effects they experience every day and how they overcome these challenges. They also discuss the situations life threw at them before they met. They are a unique business model. Both of them have dedicated the rest of their lives to helping others worldwide who are affected by this degenerative, incurable condition. They help families, offer support at diagnosis stage, as well as understand what its like to be a carer. They campaign for all those with Parkinson's who are not able to do so for themselves. They fundraise, make partnerships with companies who offer products and services that can "make a difference". They talk to Pharma, Research Hospitals, Medical Tech companies. Their work is being recognised throughout the Parkinson's Community and within the Medical Profession and Pharma. They are Parkinson's Advocates, Public Speakers, Advisers on Research Committees.

They tell it "how it is", and talk about "how it should be". They are outspoken about the difficulties they face – both individually, as well as on behalf of the community. Being classed as vulnerable, categorised as having a Severe Mental Impairment, what changes need to be implemented within the outside world to make the life of a Person With Parkinson's easier, and target those who can help them with their mission. They know, they care.

We invite you to attend the exclusive screening of our short film - STAGES - showing within the Lecture Theatre 13:15 - 13:40pm (during the Luncheon of the first day of the ESPCH6 Conference, Thursday 27<sup>th</sup>). Charlotte Allen and Russ Bradford will bring home the message that it is all about the improvment of the quality of life of all those affected with Parkinson's - they are not giving their talk from a text book, they are real people living every day with Parkinson's.

#### Real People, Real Stories, Real Support. 14.30 Melanoma UK brings the "My Melanoma App" to patients, giving them a voice. Ms. Gillian Nuttall (1) and Ms. Diane Cannon (2), (1) Founder & Chief Executive Officer, (2) Director of Corporate Partnerships, Melanoma UK

In recent years, immuno-oncology therapies have transformed melanoma treatment. However, despite improvements in clinical outcomes, there is a deficit in granular patient-reported outcome data. The Melanoma UK observational study explores the real-world impact of melanoma by collecting data from melanoma patients via a bespoke 'bring your own device' app.

Launched late 2017, the app was developed by the patient advocacy group Melanoma UK, in collaboration with Vitaccess Limited, a digital health scale-up and The Roval Marsden NHS Foundation Trust.



Adults with any type or stage of melanoma (current active users: 429) complete validated PRO measures at their own convenience via their smartphone, instead of only during clinic visits. Optional features designed to help participants to manage their condition and its treatment include the ability to prospectively build an exportable record of symptoms, mood and side effects, a clinician-validated knowledge section and a community feature allowing participants the option to communicate with and search for other users.

Scientifically invaluable, the data is available in real-time and securely transferred from each smartphone to secure storage where they are anonymised and aggregated for analysis. The philanthropic business model encourages research via free dataset access to academic researchers and via a paid subscription for industry. Findings from the study have been presented at national and international conferences and the Vitaccess/Melanoma UK profit share supported a £10k donation, funding a whole-body mole mapping machine.

Patient-led development through regular feedback sessions and workshops allows for a patient centric approach and ongoing study improvements.

The Melanoma UK observational study allows for recruitment of a broader range of patients than is possible in clinical trials. The output is data can be used by health researchers, to build a granular, real-time understanding of the impact of disease and treatment on participants' everyday lives.

Melanoma UK is the number one leading patient support group in the UK. It helps patients and families navigate the sometimes very difficult pathway following a diagnosis of melanoma including death. Melanoma UK is a founder member of the Parliamentary Melanoma Taskforce set up in 2010. It has actively participated in regular appraisals of melanoma treatments when they appear before The National Institute for Health Care Excellence (NICE) and Scottish Medicines Consortium (SMC) since 2011. At Melanoma UK, the team comprises of only people affected by melanoma, and this adds to the uniqueness of the organisation, as they deal first-hand with the fallout of this devastating disease. Melanoma is increasing year on year and is now becoming the fastest killing cancer, with a population consisting of approximately 16,000 people being diagnosed in the UK every year and circa 8 people dying every day. At Melanoma UK, the team works tirelessly and passionately to support those affected by melanoma.

#### REFERENCES

- The Impact of Melanoma and Drug Treatment in the Real World. ClinicalTrials.gov Identifier: NCT03379454. NIH U.S National Library of Medicine. Website: https:// clinicaltrials.gov/ct2/show/NCT03379454 Published December 20, 2107. Updated December 20, 2019. Accessed February 23, 2020.
- Published data from "My Melanoma App". Vitaccess. Website: <u>https://vitaccess.com/publications</u>

#### 15:10 Putting the Patient Voice at the Centre of Medicinal Cannabis Policy

Mr. Jonathan Liebling, Co-Founder and Director at Cannabis Patient Advocacy and Support Services, & Research Lead, The Centre for Medicinal Cannabis, UK

Cannabis, consumed as medicine, is unique in many ways. The big differences are firstly, never before have we introduced a new medicine into our healthcare system that 100s of 1000s of patients have been consuming

for decades and secondly, there are 1000s of different variations that work best for different people rather than for different conditions. For these reasons our medical systems and profession need to demonstrate pragmatism, flexibility and compassion and listen to patients' experiences. It has never been more important to place the "Patient Voice" at the forefront of decision making.

## 15:30 Rare disease patient views: mental health and person-centred care

Dr. Amy Hunter, Director of Research, Genetic Alliance UK

Rare diseases are often chronic, multi-systemic and can take years to diagnose. It is well established that long term conditions significantly increase risk of mental health issues, but the relationship between rare disease and mental health has not been extensively studied. This is despite the fact that (1) there are specific challenges with rare disease that may increase vulnerability to mental health issues and (2) there is a good body of anecdotal evidence documenting the mental health consequences of living or caring for someone with a rare disease.

Key findings relevant to person-centred care:

- Around half of patients and carers are never asked about their or their child's mental health by healthcare professionals; well-handled discussions can be a source of relief and lead to referrals for support but insensitive interactions can lead to distress and a reluctance to seek help for physical and mental health.
- Mental health provision is rarely coordinated with other rare disease care.
- Patients and carers feel strongly that access to professional psychological support should be easier, and that there is much room for improvement in tailoring and quality.
- Patients and carers do not feel that their or their child's mental health is treated as equally as important as physical health by healthcare professionals: parity of esteem is lacking.

15:50 - 2020 ESPCH Silver Medal -50 years well travelled – sharing and caring with the OI (Osteogenesis Imperfecta) community

Ms. Patricia Osborne, Chief Executive Officer, Brittle Bone Society, UK

Brittle Bone Society's CEO, Mr. Patricia Osborne, will provide an overview of the 50 plus year journey the Brittle Bone Society have been on to support the Osteogenesis Imperfecta (OI) Community.

You will hear about the vital and costly mobility equipment the charity fundraise for: their popular events, updates on research and how they advocate for change for the OI community with senior policy makers and governments. The presentation will show strong links with NHS healthcare professionals. Ways in which the charity utilise their own members as advocates sharing their lived experiences.

Patricia will recap on the UK Charity's early beginnings; on founding member Margaret Grant MBE, her amazing battle to establish the first meaningful support agency in the UK,

and possibly anywhere in the world, for the then virtually unheard of condition of Osteogenesis Imperfecta. Patricia will explain their 'building bridges to better bones' project, and how relationships with other rare bone groups sharing the same clinicians will help them realise goals.

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A review on current therapies – TOPAZ and ASTEROID. After years of no specialisation, suddenly new therapies being trialled specifically for OI, and how the charity ensure their community are informed.

You will hear about the Charity's practical idea to safeguard, then to gift their precious archives to the local University– and how that HISTORY BONES Project has now translated into a grant from the Wellcome Trust – what benefits they hope to gain from that new enterprise.

An insight into the Governance of the charity and the calibre of trustees, the passion involved, the skills required. The powerful links with sister groups in Europe and the USA. The Charity's commitment and co-operation within the ERN framework, their support of the ERN Bond representation group.

#### 16:50 Integrating patient engagement and quality improvement, evidence from a 7-year journey

Mr. Shahid Sardar, Associate Director for Patient Engagement, The Princess Alexandra Hospital, NHS Trust, UK

Working together with patients to develop services designed around the needs of our patient groups, sometimes called 'co-production' is a growing area of interest and research, (Verschuere et al. 2012, Alford 2009; Bovaird 2007; Osborne et al. 2012). However, insight into the process of coproduction is exceptionally limited, and "interest should not be confused with progress or consensus" (Beresford, 2019). Still less is the link explicitly made to quality improvement.

This paper proposes the development and proliferation of a unique model of co-production, tested over the last seven years at a small district-general hospital in the East of England in Harlow at The Princess Alexandra Hospital NHS Trust. The model draws on and is inspired by the seminal work of the American public policy theorist in the U.S. Department of Housing, Education, and Welfare (HUD), Sherry Arnstein (1969) and offers a structured and potentially highly replicable way forward for healthcare communities seeking to embed a sustainable approach to co-production in healthcare settings.

The critical success factors for implementation enable the systematic reconstruction of systems of governance and control around 'coproduction groups' of which there are now 16 in Harlow reaching around 600 people. In this brief presentation the audience will hear from patients themselves about the impact of this work, and the relational and processual structures which need to be in place to replicate the model.

#### Day 1 Abstracts

17:10 Personalising Dementia Care through music – why, how, and the benefits of using music for people living with dementia and their carers

> Ms. Grace Meadows, Programme Director, Music for Dementia 2020, The Utley Foundation, UK

Music. What do you think of when you read that word? It will make you think of someone, something, or a time gone by. It will evoke a feeling, a memory, a sensation. It may bring a smile, a tear or laughter. Ultimately, it will connect you with who you are and those around you. Music does that, it has the power to connect us. When words are not enough, too much, or no longer available, music enables communication. It can often express the unspeakable.

Music is a 'thing' we all have a relationship with, both individually and collectively, regardless of how we perceive or define our individual musicality.

With the number of people living with dementia set to rise significantly over the next decade, and with no pharmacological solution on the horizon and people living longer, how are we going to work with people with dementia and those caring for them to help them to live as well as they can?

Music is personal but what are the benefits to the individual living with dementia, those caring for them and the places and spaces they fill? How can we harness its power to enhance and enrich the quality of life for people living with dementia? How can music be used to help make personalised care just that, personalised, meaningful and individual?

Increasingly, the power of music to enhance and enrich health and social care, specifically dementia care is becoming more valued for its ability to deliver personalised care. Because with music, it's about being with and not doing to.

> 'Be with people, meet them where they are at, and lives can be transformed'

#### 17:30 - 2020 ESPCH Mixed Methods Research Prize -

#### Understanding wellbeing outcomes in primary care arts on referral interventions: a mixed methods study

Ms. Samantha Hughes, Doctoral Student, School of Natural and Social Sciences, University of Gloucestershire, UK

#### BACKGROUND

Arts on Prescription programmes are designed to support the mental health and wellbeing of patients with a variety of clinical needs within the community. Despite a number of studies reporting benefits, there are some patients that do not see improvements in their wellbeing. Yet, there is limited research investigating the reasons for this. The present study aimed to address this deficit.

#### METHODS

Using a sequential mixed methods design the present study sought to understand why some participants (N=312) experienced an increase in wellbeing and others did not (N=95) after attending an Arts on Prescription intervention based in the South West of England between 2009 and 2016.



#### RESULTS

Quantitative comparisons between the 2 groups identified little differences, aside from age and baseline wellbeing (WEMWBS scores), with those that improved being slightly younger and having lower wellbeing at the outset. A process model depicting the perceived facilitative and inhibitive factors of attending the programme was developed from the qualitative findings. This model suggests that the social aspect of the course may be implicated in the participants differential outcomes with those that showed a decrease in wellbeing reporting difficulties in interacting with others during the intervention. Further, the participants who reported an increase in wellbeing felt vulnerable to "relapse" when finishing the course due to uncertainties regarding future support and their ability to maintain their wellbeing without the provision of the programme.

#### CONCLUSIONS

The results suggest a need to promote communication among groups in such interventions with the hope that this will provide a more facilitative environment for all participants to benefit. Such programmes should consider follow-on options to ensure the participants feel supported and confident in managing their wellbeing once the course comes to an end. The findings are pertinent to those commissioning primary care art interventions, ensuring that referral policies and pathways are designed for optimal effectiveness and for tailoring social prescribing programmes to suit the participants' specific needs.



## Awards Ceremony PROGRAMME

## **THURSDAY**

February 27, 2020

(By S	AWARDS CEREMONY (2020) OF THE EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE
18:45	<b>Opening Address</b> <b>Professor Andrew Miles</b> BMedSci MSc MPhil PhE European Society for Person Centered Healthca
18:50	On the application of Ray's Model of Care: Healing (Guest Lecture on behalf of Lieutenant General Don Winner of the 2020 ESPCH Presidential Medal) Colonel Dr. Marcia Potter, Master Clinician, Unit Uniformed Services University of the Health Sci
19:15	Questions
19:20	Presentation of Awards Professor Sir Jonathan Elliott Asbridge DSc (hc) Council, European Society for Person Centered
19:50	President's Remarks
20:00	Networking Reception with Drinks, Canapes and M
21:00	Close of Event

### On the application of Ray's Model of Care: Healing Healthcare Through Person-Centered Caring

Colonel Dr. Marcia Potter Master Clinician, United States of America Air Force & Adjunct Professor, Uniformed Services University of the Health Sciences, USA on behalf of Lieutenant General Dorothy Hogg Surgeon General, United States Air Force, USA - Winner of the 2020 ESPCH Presidential Medal -

Focusing on the multiple domains of caring as explicated in Bureaucratic Caring Theory, Colonel Dr. Marcia Potter, on behalf of Lieutenant General Dorothy Hogg, will lead the audience through the applications of caring in the diverse roles nurses and healthcare staff encounter in all levels of the health system. Providing real life exemplars and lessons learned, she will demonstrate how this theory awakens recognition of caring opportunities, extends healing to patients, staff, academia, organizations and systems of healthcare. Deeply rooted in this is the unshakeable belief of the purpose, value, and capacity to care as well as the responsibility to bring caring to the forefront of healthcare endeavors.

## DAY 1 **2020 ESPCH AWARDS CEREMONY**

THURSDAY February 27, 2020



D DSc (hc), Senior Vice President & Secretary General, are

g Healthcare Through Person-Centered Caring rothy Hogg, Surgeon General, United States Air Force,

ted States of America Air Force & Adjunct Professor, iences, USA

DHSc (hc) DSc (hc), President and Chairman of Healthcare

Music



## 2020 ESPCH AWARDS

### President's Medal for Excellence Lieutenant General Dorothy Hogg

In recognition of her work and leadership in implementing person-centered care within the United States of America Air Force.

## Senior Vice-President's Medal for Excellence

#### **The Patients Association**

In recognition of the superlative work that the Patients Association is doing in promoting personcentered approaches to health and social care. (The medal is awarded to Mr. Rachel Power on behalf of The Patients Association.)

### Platinum Medal

#### Dr. Amy Price

In recognition of her work in advancing patient and public involvement in healthcare research and services delivery.

### **Gold Medal**

### Dr. Jeremy Howick

In recognition of his work in advancing the understanding of and necessity for empathetic approaches within modern health and social care systems.

### Silver Medal Brittle Bone Society

In recognition of the superlative work that the Brittle Bone Society is doing in promoting personcentered approaches to the care of people and their families living with Osteogenesis Imperfecta. (The medal is awarded to Ms. Patricia Osborne on behalf of Brittle Bone Society.)

#### **Bronze Medal**

#### Sickle Cell Society

In recognition of the superlative work that the Sickle Cell Society is doing in promoting personcentered approaches to the care of people and their families living with Sickle Cell Disorder. (*The medal is awarded to Mr. John James OBE* on behalf of Sickle Cell Society.)

## Qualitative Methods Research Prize Ms. Myriam Dell Olio

Presented for excellence in person-centered healthcare research, and in recognition of: Dell ´Olio M, Pask S, Seymour J. Reeve J. What do the healthcare experiences of people with long-term conditions tell us about person-centred care? A systematic review. *European Journal for Person Centered Healthcare*. 2020. (*The prize is awarded to Ms. Myriam Dell 'Olio and on behalf of her research team.*)

### Mixed Methods Research Prize Ms. Samantha Hughes

Presented for excellence in person-centered healthcare research, and in recognition of: Hughes S, Crone DM, Sumner RC, Redmond M. Understanding wellbeing outcomes in primary care arts on referral interventions: a mixed method study. *European Journal for Person Centered Healthcare*. 2019; 7(3): 530-539. (*The prize is awarded to Ms. Samantha Hughes and on behalf of her research team.*)

### Essay Prize Dr. Marcela Almeida

Presented for clinical insight and depth of wisdom and in recognition of:

Almeida M. Lessons from Marias: what the titleness and nameless taught me that elite medical institutions couldn't teach me. *Journal of Public Health*. 2020; fdz121. DOI: 10.1093/pubmed/fdz121

### **Book Prize**

### Dr. med. Bruno Kissling & Mr. Peter Ryser

Presented for clinical insight and depth of wisdom and in recognition of:

Kissling B, Ryser P. Die ärztliche Konsultation: systemisch-lösungsorientiert "The Medical Consultation: systemic and solution-oriented". Göttingen, Germany: Vandenhoeck & Ruprecht; 2019.

(The prize is awarded to Dr. Bruno Kissling and on behalf of his co-author, Mr. Peter Ryser.)

#### Young Teacher Prize Dr. Karishma Jivraj

Presented In recognition of her work in personcentered healthcare education.

### Young Researcher Prize Dr. Rajni Lal

In recognition of her work on shared decisionmaking, choosing wisely and the BRAN Project.

### The Patient Advocacy Award BAYER AG Pharmaceuticals

In recognition of the company's integration of patients' insights in global studies of Retinopathy of Prematurity (ROP).

(The prize is awarded to Dr. Markus Langen on behalf of his team at BAYER AG.)

## The Patient Advocacy Award Parkinson's Concierge

In recognition of the superlative work that Parkinson's Concierge is doing in promoting person-centered approaches to the care of people and their families living with Parkinson's Disease.

(The prize is awarded to Ms. Charlotte Allen & Mr. Russ Bradford on behalf of Parkinson's Concierge.)

### ESPCH Honorary Distinguished Fellowship Dr. Patrick Daly

In recognition of his work in the philosophy of health.

### ESPCH Honorary Distinguished Fellowship Dr. Michelle Croston

In recognition of her work in advancing the understanding and implementation of personcentered strategies in the care of people and their families living with HIV/AIDS.

### ESPCH Honorary Distinguished Fellowship Colonel Dr. Marcia Potter

In recognition of her work and leadership in implementing person-centered care within the United States of America Air Force.



## 2020 ESPCH BOOK PRIZE



### Die ärztliche Konsultation: systemisch-lösungsorientiert

### "The Medical Consultation: systemic and solution-oriented"

Authors: Bruno Kissling & Peter Ryser Publisher: Vandenhoeck & Ruprecht - Verlage Publication: October 2019 ISBN-10: 3525403941 ISBN-13: 978-3525403945 Language: German Get it at: <u>Vandenhoeck & Ruprecht</u> or <u>Amazon</u> Summary: Presentation on 2nd Day of ESPCH, Friday 28th, 12:20, by Dr. Bruno Kissling.

### 2020 ESPCH ESSAY PRIZE

### Lessons from Marias: what the titleness and nameless taught me that elite medical institutions couldn't teach me

Author: Marcela Almeida Journal: *Journal of Public Health* Publication: January 2020 DOI: <u>10.1093/pubmed/fdz121</u>

In an era of rapid advancements in healthcare and technology, sophisticated treatments and pressure for speedy recoveries, contemporary physicians are often led to neglect some of the support pillars of medicine: That science, guidelines and protocols should not come before the individual; prescriptions serve little purpose without books and literacy; medications are not a substitute for nourishment. That hearing lamenting stories and watching tears run through despondent, downcast faces are sometimes our only resort. That social justice is a powerful healing instrument. That rather than treating the sickness, we shall treat the sickhelpless, deprived, forsaken and in need.



## What is? **GLOBAL RETINOPATHY OF PREMATURITY (ROP) STUDY**

Dr. Markus Langen PhD, Clinical Study Manager & Lead, Global Cross-Functional Study Team, BAYER AG.

#### Background

At Bayer we are committed to putting patients at the center of everything we do. One opportunity in which we have collaborated, and integrated patient insight is in the development of recruitment and retention (R&R) materials. When embarking in the development of patient recruitment and retention materials for our global Retinopathy of Prematurity (ROP) study, we realized that we had to offer these parents the best support we could during a very difficult time of expectant premature labor. To help ensure we were keeping patient centricity at our focus, we engaged with external patient networks in 4 countries (Brazil, Germany, Japan and Spain) to complete concept testing of the recruitment and retention materials developed. Concept testing was completed for both the base study (20090) as well as the long-term follow up study (20275), both spanning across 33 countries in Asia Pacific, Europe, North and South America.

#### Methodology & Outcome

In general, face to face interviews were conducted with parents at risk of pre-term pregnancy or parents whose newborn premature children had suffered from ROP and treating health care professionals (HCPs). During these interviews, parents/HCPs were provided with the developed R&R materials and asked to provide feedback on each. R&R materials reviewed included: booklet, tabletop informed consent visual aid, poster, websites, study logo/ name and coloring/activity books.

The consolidated outcome from the concept testing provided meaningful feedback related to images, text and intended use of each of the creatives, which was then globally adapted. Additionally, the concept testing completed in Japan led to the development of 2 new creatives which were subsequently adapted for global use in the study. An excerpt of key concept test feedback follows below:

- Robustness of information and branding generates credibility that enhance tendency to adhere to the program.
- Informs, teaches (including neonatologists), reassures parents about the process and above all is seen as a hope of special follow-up of the child.

- Material seen as useful to be used as complimentary information in support of decision to participate in trial.
- Some of the medical illustrations and text were 'scary' and/or too complex for parents and were subsequently adapted.
- "I looked everywhere for information about prematurity and found nothing reliable, especially on the Internet. I had to buy a book. Here[in this material] there is much that I saw in the book, but easier to understand. I liked it a lot" – Mother.
- "Very complete. I liked it a lot, I also learned many things about ROP" - Neonatologist.

#### **Participants**

This concept testing was led internally by the Study Team, Patient Recruitment and Retention Team and support from the Patient Insight and Engagement community. Externally the following organizations led the concept testing:

- Brazil- IPSOS Healthcare
- Germany: Kindernetzwerk
- Japan: Child Life Specialist Network
- Spain: Institut de Recerca Sant Joan de Déu In recognition of this activity the Institut de Recerca Sant Joan de Déu invited Bayer to present at an event they hosted (November 2019) with the Spanish Federation of Pharma Companies which was focused on patient involvment in drug development.

## DAY 2 **SESSIONS**

FRIDAY February 28, 2020







## DAY 2 PROGRAMME

#### 08:00 Registration & Refreshments

#### 09:00 Welcome to Day 2

Dr. Thomas Fröhlich, Physician, Heidelberg, Germany & Vice President (Western Europe), European Society for Person Centered Healthcare

#### Early Morning Session FOCUS ON HEALTHY AGEING,

**BEHAVIOURAL SCIENCE, AND DECISION-MAKING** 

#### Early Morning ChairPerson

Dr. Jeremy Howick, Director, Oxford Empathy Programme & Senior Researcher and Impact Fellow, Oxford Faculty of Philosophy, University of Oxford, UK

#### 09:10 **KEYNOTE 5**

Intrinsic capacity and "healthy" ageing: where do the domains of the clinical, the non-clinical, the person, and the social and emotional and community intersect? On the need to consider holistic, empathic processing within general needs/falls risks assessment in community-based homecare Ms. Jane Teasdale, Principal Owner, Co-Founder and Director of Business Development, Mosaic Home Care Services & Community Resource Centres, Toronto, Ontario, Canada

#### 09:40 **KEYNOTE 6**

Harnessing the science of human behaviour for effective patient engagement and co-production Mr. Dan Berry, Director of Behavioural Science at Hill+Knowlton Strategies, UK

#### 10:10 - 2020 ESPCH Young Researcher Prize -

Shared decision-making, choosing wisely and the BRAN Project

Dr. Rajni Lal, Specialist Registrar in Geriatrics/Internal Medicine and Fellow in Perioperative Medicine for Older People undergoing Surgery (POPS), Guy's and St. Thomas' Hospitals Foundation NHS Trust, UK, and Blacktown & Mount Druitt Hospital, Western Sydney Local Health District, Sydney, Australia

10:30 Statistical compassion - moving to coherent involvement of equity considerations in clinical and commissioning decision-making

Dr. Vije Rajput, NHS General Practitioner, Stonydelph Health Centre, Tamworth, Clinical Director LTCs, Clinical Commissioning Group (SESSP CCG), and Hon. Clinical Teacher, Keele University, Staffordshire, UK

10:50 Panel discussion with delegate participation (with invited panel discussant Dr. Karishma Jivraj)

#### Morning Break & Refreshments 11:10

### Late Morning Session

FOCUS ON FAMILY-CENTERED CARE, FRÖHLICH GROUPS, AND THE MEDICAL CONSULTATION

#### Late Morning ChairPerson

Dr. Patrick Daly, Research Associate, Lonergan Institute at Boston College, Chestnut Hill, Massachusetts, USA

11:40 Illustrating the difficulty of introducing a "personalised" scale into family-centred care: The "Alarm Baby Distress Index" (ADBB)

Dr. Mette Kjer Kaltoft, Health Visitor, Municipality of Copenhagen & Senior Guest Researcher, University of Southern Denmark, Denmark

ESPCH6

12:00 Fröhlich Groups - well known tools to enhance person-centeredness and clinical team building Dr. Thomas Fröhlich, Physician, Heidelberg, Germany & Vice President (Western Europe), European Society for Person Centered Healthcare

#### 12:20 - 2020 ESPCH Book Prize -

The medical consultation: systemic solution-oriented and person-centered Dr. Bruno Kissling, Family Physician and Teaching Doctor, Bern Institute of General Practitioner Medicine, Board Member of the Swiss Society for General Medicine, Swiss Delegate to the World Medical Association and WONCA, & Co-Editor-in-Chief, Primary Care, Bern, Switzerland

#### 12:40 Panel discussion with delegate participation

(with invited panel discussant Dr. Ankita Batla)

13:00 Luncheon

FOCUS ON PERSON-CENTERED CARE, **ARTIFICIALINTELLIGENCE (AI) AND THE DIGITAL HEALTH REVOLUTION** 

#### Early Afternoon Chairperson

Mr. Faisal Ahmed, Director of Innovation and Business Transformation, WPP Health Practice, London, UK

- 13:50 How Digital Health is changing patient centricity in healthcare London, UK
- 14:10 *ReMeLife* Rewards Based Person-Centred Care through Digital Activities Dementia, Mild Cognitive Impairement & Learning Disabilities), London, UK
- 14:30 The AI Opportunity in Healthcare: Define Real Patient Value through the Patient's Lens USA
- 14:50 Centralized personal medicine big picture of digital transformation Imaging Clinician, Berlin, Germany
- Panel discussion with delegate participation 15:10 (with invited panel discussant Dr. Marcia Potter)

15:30 Afternoon Break & Refreshments

### Late Afternoon Session

FOCUS ON INNOVATIONS IN PERSON-CENTRICITY BY THE PHARMACEUTICAL AND HEALTHCARE TECHNOLOGY INDUSTRIES

#### Late Afternoon ChairPerson

Professor Andrew Miles, Professor of Person Centred Care & Co-Director, UWL European Institute for Person Centred Health and Social Care; ESPCH Senior Vice President/Secretary General; Editor-in-Chief, European Journal for Person Centered Healthcare & Hon. Professor of Person Centred Care, St. George's University Hospital Campus, University of West London, UK

- 15:50 What does it mean to be patient centred for a pharmaceutical company? Companies of Johnson & Johnson, UK
- 16:10 Patient Centricity in the Pharmaceutical Industry: what needs to change? of Clinical Pharmacology, Barts Health NHS Foundation Trust and Visiting Senior Lecturer, Kings College, UK
- 16:30 Co-creating a Patient Portal Ms. Malar Subramaniam, Patient Engagement Manager, Regional Medical Lead - Anti-Infectives & Senior Scientific Advisor - Women's Healthcare, Bayer Pharmaceuticals, Berlin, Germany
- 16:50 Embedding Patient Engagement to Optimize Study Design and Conduct and Autoimmune (RIA), R&D BioPharmaceuticals, AstraZeneca Pharmaceuticals, UK



Dr. Myles Furnace, Digital Health and Data Lead, UK & Ireland Speciality Care at IPSEN Pharmaceuticals,

Mr. Simon Hooper, Co-founder of ReMeLife and RemindMeCare (Digital Technology for Elderly Care,

Dr. Bharat Tewarie, Founder and Board Advisor, Boston BioPharma Consultants, Boston, Massachusetts,

Dr. Guenther Brueggenwerth, LifeHub UK Lead, Bayer Pharmaceuticals, UK, & Radiologist - Senior

Mr. James Fitzpatrick, Director of Patient Engagement & Government Affairs, Janssen Pharmaceutical

Dr. Paul Robinson, European Lead, Patient Innovation, MSD Pharmaceuticals, Senior Hon. Lecturer

Dr. Clare Nott, Clinical Program Director, Research and Early Development, Respiratory, Inflammation

## DAY 2 ABSTRACTS

### **FRIDAY** February 28, 2020

09:10 KEYNOTE 5

Intrinsic capacity and "healthy" ageing: where do the domains of the clinical, the non-clinical, the person, and the social and emotional and community intersect? On the need to consider holistic, empathic processing within general needs/falls risks assessment in community-based homecare Ms. Jane Teasdale, Principal Owner, Co-Founder and Director of Business Development, Mosaic Home Care Services & Community Resource Centres, Toronto, Ontario, Canada

In a 2017 paper, "Operationalising the Concept of Intrinsic Capacity in Clinical Settings", the WHO stated that Intrinsic Capacity "is a composite of all the physical and mental attributes on which an individual can draw", that healthy ageing "depends upon an individuals' Intrinsic Capacity, their environment and the interactions between the two." Studies have found that subjective successful ageing is often independent of disability and chronic physical illness. Addressing healthy ageing means we must move beyond the clinical and the support of functional abilities to address the wider social and emotional components of self and the relationship of self with environment.

This presentation addresses empathic person centered processes, interfaces and interactions at the point at which the domains of the clinical, non-clinical supports, the person and community intersect. These are most evident in the general needs' assessment in community settings and the parallel processes of falls risks assessment and their conceptualisation. Domains have both environment and scope and it is the specific attributes of each that are relevant when conceptualising and realising person centered care.

Many standard assessment processes lend the appearance of "viewing windows" where the person is measured and assessed, and outcomes rendered with respect to their deficits. Planning for intrinsic capacity requires, over and above clinical baselines, that we know the person, their preferences, life history, capacities and environments.

The presentation addresses empathy, its social and neurological underpinnings as important components of person centered processes. According to Decety (2015), empathy is "an interpersonal communication system that elicits response from others, helps to determine priorities within relationships, and holds people together in social groups".

As we develop person centered care we also realise that the wider model is dependent on assets, environments and interactions within our communities that lie beyond the immediate domains of clinical and non-clinical supports.

#### 17:10 **Ouestions**

#### 17:30 MULTI-STAKEHOLDER PANEL DISCUSSION: Implementing person-centered care within modern health systems

#### Panel ChairPerson

Mr. Mikis Euripides, Policy and Public Affairs Lead, WPP Health Practice, London, UK

#### **Panel Discussants**

- **Mr. Lasse Funch Jacobsen**, Senior Lead of Patient Research and Alliances at LEO Pharma, Denmark
- **Mr. James Fitzpatrick**, Director of Patient Engagement & Government Affairs, Janssen Pharmaceutical Companies of Johnson & Johnson, UK
- **Professor Sir Jonathan Asbridge**, Chief Clinical Officer, Healthcare at Home; Deputy Chairman, Oxford Health NHS Foundation Trust & ESPCH President, London and Oxford, UK
- Ms. Charlotte Allen, Parkinson's Patient and Co-Founder of Parkinson's Concierge, UK
- Dr. Amy Price, Senior Research Scientist, Stanford Anesthesia Informatics and Media (AIM) Lab, Stanford University School of Medicine, USA; Research Editor, Public and Patient Partnership Strategy *British Medical Journal* & Department of Continuing Education, University of Oxford, UK
- **Dr. Vije Rajput**, General Practitioner, Private Practice, Stonydelph Health Centre, Tamworth, Clinical Director LTCs, Clinical Commissioning Group (SESSP CCG), and Hon. Clinical Teacher, Keele University, Staffordshire, UK

#### 17:55 Reflections on ESPCH6: highlights, inspirations, ways forward Dr. Ankita Batla, Chief Medical Office Lead - Health Insights and Patient Partnerships, WPP Health Practice, WPP London Headquarters, UK

#### 18:15 President's Closing Remarks & Close of ESPCH6

**Professor Sir Jonathan Elliott Asbridge** DSc (hc) DHSc (hc) DSc (hc), President and Chairman of Council, European Society for Person Centered Healthcare





#### 09:40 KEYNOTE 6 Harnessing the science of human behaviour for effective patient engagement and coproduction Mr. Dan Berry, Director of Behavioural

Mr. Dan Berry, Director of Behavioural Science at Hill+Knowlton Strategies, UK

Behavioural science (behavioural economics) offers promising yet commonly overlooked insights and evidence to help the healthcare system become genuinely personcentred.

Insights from behavioural science allow us to more fully understand the real-life, everyday judgements and decisions made by clinicians and patients- when we're busy, distracted, and potentially stuck in bad habits. In particular, behavioural science helps us overcome what is often a gap between people's good intentions – to genuinely put the person at the heart of their care – but subsequent actions falling short.

This session will give tangible examples of how behavioural science can support us in our goal of person-centred healthcare, with case study examples bringing to life seemingly simple actions we can all to that can scale-up to make a substantial impact. It will conclude by signposting to sources of further information and reading.

#### 10:10 - 2020 ESPCH Young Researcher Prize -Shared decision-making, choosing wisely and the BRAN Project

Dr. Rajni Lal, Specialist Registrar in Geriatrics/Internal Medicine and Fellow in Perioperative Medicine for Older People undergoing Surgery (POPS), Guy's and St. Thomas' Hospitals Foundation NHS Trust, UK, and Blacktown & Mount Druitt Hospital, Western Sydney Local Health District, Sydney, Australia

#### INTRODUCTION

Perioperative shared decision making (SDM) is a collaborative process where the clinician and patient come to a decision on the most appropriate treatment option, based on clinician's expert knowledge and patient's needs, values and preferences. SDM was highlighted in 2016 through the Choosing Wisely initiative ensuring appropriate interventions and reducing unnecessary treatments through improving patient-physician conversations.

Perioperative medicine for Older People undergoing Surgery (POPS) is a multidisciplinary geriatrician led Comprehensive Geriatric Assessment (CGA) and optimisation service managing emergency and elective patients throughout the surgical pathway. 1500 elective patients a year are assessed and optimised through the outpatient clinic. Internal POPS team governance suggested that quality, shared decision making was being undertaken, but discussions were inconsistently recorded and patient experience had not been fully evaluated. A quality improvement project was undertaken as part of implementing the Choosing Wisely programme across the trust. Benefits of surgery, Risks of surgery, Alternatives to surgery and doing Nothing (BRAN).

#### AIM

Improve the quality and consistency of documentation of SDM conversations

#### METHODS

The study was conducted in inner city teaching hospital serving a tertiary surgical referral population within the geriatrician led POPS service. Participants including clinicians and disciplines working within outpatient clinic, and consecutive patients attending within the study period (June 2019- Dec 2019). BRAN tool format was introduced to discuss and document the surgical decision.

#### STUDY DESIGN

Mixed methods quality improvement project involving observational data collection, Plan Do Study Act (PDSA) cycles, nominal group technique and survey methodology. Results: POPS letters initially containing no SDM documentation, had an increase to 74% all or partly completed SDM following implementation of BRAN tool, Results showed increase in patient and clinician satisfaction with SDM process (p<0.001).

#### CONCLUSION

BRAN tool provides a structured approach when discussing and documenting SDM, and standardised structure allows effective communication with other specialities.

#### 10:30 Statistical compassion - moving to coherent involvement of equity considerations in clinical and commissioning decision-making Dr. Vije Rajput, NHS General Practitioner, Stonydelph Health Centre, Tamworth, Clinical Director LTCs, Clinical Commissioning Group (SESSP CCG), and Hon. Clinical Teacher, Keele University, Staffordshire, UK

Equity impact reflects the number of population QALYs lost or gained in moving from Old (current intervention) to New (contemplated intervention). In the exemplar UK implementation Claxton's NHS Willingness to Pay per QALY is the numeraire. Any weight from 0 to 100% may be assigned to the equity criterion but its presence affirms that it is persons-as-citizens who experience any opportunity harms or benefits arising from actions within the health service commons. A fast and frugal generic preference sensitive Multi-Criteria Decision Analysis (MCDA)-based tool can include an equity outcome criterion enabling decision support to those making decisions about individual cases, particularly clinicians and clinical commissioners operating within the budget and time constraints of their practices.



#### 11:40 Illustrating the difficulty of introducing a "personalised" scale into family-centred care: The "Alarm Baby Distress Index" (ADBB) Dr. Mette Kjer Kaltoft, Health Visitor, Municipality of Copenhagen & Senior Guest Researcher, University of Southern Denmark, Denmark

The Alarm Baby Distress Scale (ADBB) is a measure of 'infant social or relational withdrawal' increasingly being used worldwide, and now being implemented in several Danish municipalities. I became interested in the scale as part of my health visiting role, looking into the nature of the instrument. It is important to note it is an index, rather than a scale, and that the equal weights assigned to its eight five-level Likert scales have no empirical basis. The cutoff conventionally applied to decide on further action (≥5 out of a maximum 32) seems to have been arrived at by considering its sensitivity and specificity, ignoring the crucial role of prevalence in determining its predictive values, and hence implicit trade-offs between 'false alarm' and 'false reassurance' rates. Examination of the main empirical papers shows the numbers of false alarms accepted to avoid one false reassurance ranging from 56 to 2.5 across cut-offs from 4 to 8. We developed an online support tool relevant to those making both policy and clinical decisions regarding the use of ABDD. Potential users can enter a range of sensitivities and specificities for ADBB, and the estimated population prevalence of 'infant withdrawal', to establish the effect of various cut-offs (between 4 and 10) on the relative number of True/False Positives and True/False Negatives generated. At the policy level, decision makers need to place a value on the consequences of each of these four states in order to arrive at an optimal decision, taking into account their frequency. Legally informed consent to any action based on the index - including referral - requires outlining its potential benefits and harms in this individual case, so those administering the instrument need to be competent in delivering this. However, this is difficult in the family context, with a baby and parents bringing greater complexity compared with the single adult context of personcentredness. I will report briefly on my initial personal experience in the local context, where ADBB is administered at the 2 months visit, in conjunction with two self-reported parental scales ('Edinburgh Postnatal Depression Scale' and 'Gotland').

#### 12:00 Fröhlich Groups – well known tools to enhance person-centeredness and clinical team building

Dr. Thomas Fröhlich, Physician, Heidelberg, Germany & Vice President (Western Europe), European Society for Person Centered Healthcare Florida, USA

We propose the establishment of non-hierarchical groups in healthcare. Like musicians performing in a synchronised, nicely attuned way, we aim to achieve a best-possible harmonious overall composition of processes enacted by healthcare providers and receivers. Partial disharmony, resulting from unrelated, solipsistic or unintentionally ineffective and insufficiently adapted processing occur in every institution. To change this, the group trains resonanceand adaptation-based interaction, as an alternative to those management approaches that just add seemingly static, decontextualized and objectified items to each other. Awareness on mental and bodily levels, flexibility and ingenuity of interpretation, critical approach to the common preliminary, fast and automatized initial attributions, best possible attuned, empathic implementation of another's perspective is trained. A good balance of ownness with positive relatedness is to be achieved, resulting in pride and contentment in the participants. This sounds idealistic, and yes, it is. We are allowed to do so, because we do not judge morally what goes right or wrong; instead, we see it in a pragmatic, resource-oriented perspective.

Our approach is based on our group's advanced model of biopsychosocial interaction, issuing meaning and meaningful relatedness right from the start. Model development was needed since surprisingly in biology, sociology and even psychology meaning and the subject virtually disappeared over time. Concerning sociology, for example, the British sociologist Tom Shakespeare wrote that its common structuralist approach "hardly talks about subjects", and that the alternative agency approach "does make space for subjects, but from the outside, not from the inside". Fröhlich groups resemble Balint and Osler groups. Thanks to the wider horizon of the underlying the BPS model, they also apply a wider horizon concerning contributing material, procedural and systemic factors. In also issuing the biological, somatic level, they intentionally focus on bodily feelings. They encourage patients and all healthcare professionals to take part. By use of formalised gestures and roles, as-if play and impro theatre, disclosure of personal feelings is avoided. Presence of an experienced moderator serves to guarantee respectful, joyful and effective interaction.

#### 12:20 - 2020 ESPCH Book Prize -

The medical consultation: systemic solutionoriented and person-centered Dr. Bruno Kissling, Family Physician and Teaching Doctor, Bern Institute of General Practitioner Medicine, Board Member of the Swiss Society for General Medicine, Swiss Delegate to the World Medical

Association and WONCA, & Co-Editor-in-

Chief, Primary Care, Bern, Switzerland This book presents a practical approach to a person centred, bio-psycho-social and solution-oriented medicine. The authors describe how to organize the consultation to give orientation to both the doctor and the patient, how to build up a trusting relationship, how to communicate with the patient using active listening and how to formulate questions that help reveal relevant clinical facts and integrate the patient into the therapeutic process, how to coach the patient so he can reflect on his symptom / problem / situation and its interaction with his living context, how to take into account the patient's ideas, concerns, expectations and understand what meaning he attributes to his situation. The authors see the consultation as an interactive process between doctor and patient. Both of them being experts at "eve level" with their specific fields of competences: the patient of his illness and the doctor of the disease. On this ground doctor and patient can create a common reality for shared decision making in the field of the ubiquitous uncertainty. They can develop person-centred solutions of high quality, satisfying both of them - and with a cost optimizing effect for the health system.

The authors structure the consultation within 7 steps. They suggest a practical set of efficient questions and reflect on how and why the complex interaction between doctor and



patient works. Special chapters treat main topics, which interweave all parts of the consultation.

The outlined consultation-process is based on the concept of systemic solution-oriented psychology, transferred into the context of family medicine and further developed by Peter Ryser, a social worker, systemic solution-oriented advisor and supervisor, in interaction with family doctors, including Bruno Kissling.

This book is an interactive co-production of two authors with different professional competences.

### 13:50 How Digital Health is changing patient centricity in healthcare

Dr. Myles Furnace, Digital Health and Data Lead, UK & Ireland Speciality Care at IPSEN Pharmaceuticals, London, UK

Digital Health goes beyond new technologies entering the medical space. It is driving a cultural transformation of traditional-based medicine and creating a new way of delivering healthcare; moving away from our episodic, reactive sick-care approach towards a continuous and proactive health-care model. This presentation will give a broad overview of Digital Health and how it is changing patient centricity in healthcare. We will explore how Digital Health is already impacting patients and changing the way we, as healthcare professionals, will interact with our patients and populations in the years to come, using technology in the right way to solve the right problems and deepen our connection with people.

14:10 ReMeLife - Rewards Based Person-Centred Care through Digital Activities Mr. Simon Hooper, Co-founder of *ReMeLife* and *RemindMeCare* (Digital Technology for Elderly Care, Dementia, Mild Cognitive Impairement & Learning Disabilities), London, UK

Person-centred care is the cornerstone of care across the care journey. Yet how can carers provide it when generally they know little about the person? Tech can solve this. RemindMecare (aka ReMe) delivers digital activities, from cognitive, reminiscence, music and sensory activities to family photo streaming, and captures activity outcomes data (a unique data set called Electronic Life Records data; ELR= preferences, moods, habits, memories, life story, family, etc). ReMe enables bespoke activities, family and community connectivity and integration with care software, Alexa, robots and wearables. ReMe provides across care sector portable person-centric digital activity and care solutions for both consumers and care organisations, whilst also achieving government policy, cost savings for consumers, businesses and public sector bodies such as improved hospital admission, earlier discharge and reduced GP visits, and generates data for research.

'To be known socially its Facebook, for business its LinkedIn; for healthcare, to be known for who you are from diagnosis to end of life, its ReMeLife'. With the recent launch of this members engagement platform, ReMeLife and its companion app ReMe, address maintaining care in the community, loneliness, community engagement, health and social care data portability, data ownership, GDPR compliance and CQC reporting, consumer engagement and self-care management, whilst achieving cost savings and efficiencies. An 8-80 year-old globally usable app (G Cloud, NHS Digital, EMIS approved) with proprietary Alexa care skills, that's multi-platform/cultural/cross-generationally capable, ReMeLife supports the person cared for, home care, assisted living, care homes and hospitals.

Marketed via integrations and partner channels such as hospital groups, corporates (ie Sharp, Amazon), wearables (ie Pingbit), care software (ie Everylife Pass, Epiccare) and robots (ie Genie), ReMeLife is today building the ReMC token using blockchain to address the key issues of trust, consumer data ownership and self-management, as well as to support the care journey through rewards-based personalised care incentivisation. For, at the core of ReMeLife is the belief that knowing the person and engaging in fun activities must be at the heart of the care process, whilst also central to the ethos is that citizens, whilst supporting their care needs, should be able to own and benefit from their personal data.

#### 14:30 The AI Opportunity in Healthcare: Define Real Patient Value through the Patient's Lens Dr. Bharat Tewarie, Founder and Board Advisor, Boston BioPharma Consultants, Boston, Massachusetts, USA

Creating value in today's changing healthcare environment requires us to harness the power of Artificial Intelligence (AI) to gain deeper and more meaningful insights from our patients. Learn about an example of such a deep insight generation during a lecture from Dr Bharat Tewarie about a recent original research study using Quid, an AI tool, including natural language processing and machine learning, to analyze over 500,000 patient voices across 10 chronic disease areas over 10 years. The results indicated that the majority of patients were seeking better support for the emotional and long-term challenges of living with their diseases, rather than pure medical issues. Indeed, six of the top eight unmet needs were more emotional than medical.

This landmark study using the "lens" of the patient is the largest of its kind to offer healthcare stakeholders improved understanding of the real needs of patients with chronic conditions, starting by treating them as people, rather than a set of symptoms. It clearly showed that caring for our patients comprehensively means addressing not only medical, but also their emotional and social need.

## 14:50 Centralized personal medicine – big picture of digital transformation

Dr. Guenther Brueggenwerth, *LifeHub* UK Lead, Bayer Pharmaceuticals, UK, & Radiologist - Senior Imaging Clinician, Berlin, Germany

Dr. Guenther Brueggenwerth will introduce Bayer's novel *LifeHub* UK focusing on collaborations with academia and startups in Al driven patient centered solutions for radiology and other clinical areas. He will elaborate on the implications that this age of disruption has for big pharma and how Bayer is embracing digitalization and bringing new innovations to patients by leveraging artificial intelligence. Some examples will be shared on how new digital development models can bring benefit to the individual patient.

#### 16:10 Patient Centricity in the Pharmaceutical Industry: what needs to change? Dr. Paul Robinson, European Lead, Patient Innovation, MSD Pharmaceuticals, Senior Hon. Lecturer of Clinical Pharmacology, Barts Health NHS Foundation Trust and

Visiting Senior Lecturer, Kings College, UK

ESPCH6

Pharmaceutical companies have been on a journey. Historically, companies' prime relationship was with prescribers with sales representatives providing information upon which prescribers decided what was best for a patient. The relationship between the prescriber and the patient was paternalistic. As individual prescribing freedom was eroded, pharmaceutical companies then moved their focus to the payers, providing information to Formulary Committees, Primary Care Organisations and the like, for them to decide what medicines patients had available to them. Direct communication between pharma companies and patients was rare, and even frowned upon.

Over the last 5-10 years, many companies have realised that in our quest to improve the health and well-being of patients, we need to understand what is important to patients, and the best/only way to do that is to speak with and listen to patients. Many companies now engage patients in designing clinical research, creating health literate communication materials and helping prioritise and refine the various products that are produced. This has taken both a mindset shift within the pharmaceutical industry, and a need for processes and guidelines for the protection of all sides.

This talk will describe the journey that MSD has been on, and some of the industry-wide activities that are shaping the new landscape.

### 16:30 Co-creating a Patient Portal

Ms. Malar Subramaniam, Patient Engagement Manager, Regional Medical Lead - Anti-Infectives & Senior Scientific Advisor - Women´s Healthcare, Bayer Pharmaceuticals, Berlin, Germany

Patients are almost spoiled for choices in terms of information that is available on the internet regarding their conditions. Unfortunately, it can be difficult to ascertain reliable sites that offer accurate information. Many pharmaceutical companies today offer patient websites around different topics, but while there are several sites where patients can contact Bayer directly, these can be difficult to find.

We want to create a single patient portal, or landing page, for Bayer where patients can easily access information and services that matter to them. As we want to truly embody the spirit of patient centricity, we worked on a plan to co-create the portal together with patients.

We first conducted a survey with German patients using an ethnographic smartphone app called MyInsights. Patients received various tasks from us via the app, which they could answer by text, voice message or by sending us back pictures/videos. Based on the feedback received, we then developed and conducted two co-creation workshops in Germany and one workshop in the US to find out what information patients search for online, what current sources they find useful and what an ideal website for Bayer should look like. It was very enlightening for us to discover what patients found important, and also interesting that the feedback was similar from both the US and Germany. A quantitative survey of these ideas and designs will now be circulated to 500 patients in order to validate the input. After this, we can hopefully start building a Bayer patient portal that truly reflects patient insights.

#### 16:50 Embedding Patient Engagement to Optimize Study Design and Conduct

Dr. Clare Nott, Clinical Program Director, Research and Early Development, Respiratory, Inflammation and Autoimmune (RIA), R&D BioPharmaceuticals, AstraZeneca Pharmaceuticals, UK

This discussion will be an opportunity to provide details on the interactions AstraZeneca has had with patients and ways of generating patient insights. The presentation details how listening to and understanding the patient perspective has enhanced AstraZeneca's ability to optimize clinical study design making studies more attractive and manageable for patients and their families. Focus is given to AstraZeneca's Patient Partnership Program which provides an open line of communication between AstraZeneca and groups of patients/caregivers with a given disease to learn from each other and co-create patient centric products.

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## **SPEAKERS**, SESSION/PANEL CHAIRPERSONS, **PANEL DISCUSSANTS** & **2020 ESPCH AWARDS WINNERS**



Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc) Professor of Person Centred Care & Co-Director, UWL European Institute for Person Centred Health and Social Care; ESPCH Senior Vice President/Secretary General; Editor-in-Chief, European Journal for Person Centered Healthcare & Hon. Professor of Person Centred Care, St. George's University Hospital Campus, University of West London, UK

Professor Andrew Miles is Professor of Person Centered Care and Co-Director of the European Institute for Person Centered Health and Social Care within the School of Biomedical Sciences at the University of West London, UK. He is Senior Vice President and Secretary General of the European Society for Person Centered Healthcare (ESPCH), a major institution he co-founded with Professor Sir Jonathan Asbridge DSc (hc) DHSc (hc) DSc (hc) in 2014. He is Editor-in-Chief of the European Journal for Person Centered Healthcare and Founding Editor-in-Chief of the Journal of Evaluation in Clinical Practice (1994-2019). Professor Miles trained at the University of Wales and its Medical School in Cardiff. Gaining his first Chair in London at the age of 30, he was latterly Professor of Clinical Epidemiology and Social Medicine & Deputy Vice Chancellor of the University of Buckingham UK, holding previous professorial appointments at Guy's, King's College and St. Thomas Hospitals Medical School London, and at St. Bartholomew's and The Royal London Hospitals School of Medicine, London. He is an Honorary Professor of Person Centered Care within the Joint Faculty of Health, Social Care and Education at St. George's University Teaching Hospital London, and a Visiting Professor of Person Centered Care within the Faculty of Medicine of the Medical University of Plovdiv, Bulgaria, and the Faculty of Theology, National University of Bulgaria at Sofia. He has been a Visiting Professor at the State University of Milan and at the Catholic University of Francisco de Vitoria, Madrid. He is a Fellow of the Catholic Medical Association of the United States of America, and a Fellow of the Society of Catholic Scientists. Professor Miles has published extensively within the peer reviewed medical and biomedical press. He is coeditor of some 47 medical textbooks published in direct association with an extensive number of UK medical Royal Colleges and medical and clinical societies in the UK, and has organised and presided over more than 130 clinical conferences and masterclasses in London and elsewhere as part of a major contribution to British national postgraduate medical education. He lectures widely in person-centered care and is a sought after speaker. He is accredited with having changed the direction of the global EBM debate away from scientistic reductionism based on population-derived aggregate biostatistical data and rigid foundationalism, towards the embrace of the complex and the personal within international medicine and health policymaking. He has a profound interest in the modern person-centered management of the long term, multi-morbid and socially complex illnesses, and the methods through which medicine's traditional humanism can be re-integrated with continuing scientific and technological advance.

## **ESPCH6**

## **BIOGRAPHIES**







Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc) DSc (hc) President and Chairman of Council, European Society for Person Centered Healthcare, Chief Clinical Officer, Healthcare at Home & Visiting Senior Clinical Professor, European Institute for Person Centred Healthcare, University of West London. UK

Professor Sir Jonathan Elliott Asbridge has a long and distinguished record of achievement within healthcare system organisation, accreditation, re-configuration and regulation. Gaining appointment to the positions of Chief Nurse of the Oxford University and Cambridge University Teaching Hospitals early in his career, he moved to Bart's and the London NHS Foundation Trust as Chief Nurse and Executive Director of Quality, subsequently becoming Chief Executive. He was the Inaugural President of the UK Nursing and Midwifery Council, and a previous Deputy Chairman of the UK Council for Healthcare Regulatory Excellence. Sir Jonathan has acted as a Government 'Tsar' for Patient Experience in Emergency Care and also for Patient and Public Involvement in Healthcare, has been involved in the development of several major NHS policies, and has conducted several formal Inquiries both in the UK and overseas. He was a Founding Board Member of the European Federation of Nursing Regulators and a Member of the International Council of Nurses Global Observatory on Licensure and Registration. Sir Jonathan was awarded the Degree of Doctor of Science honoris causa for services to healthcare by the City of London University in 2004 and was made Knight Bachelor by HM Queen Elizabeth II for services to healthcare in 2006. In 2016, Sir Jonathan was awarded a second honorary doctorate by Anglia Ruskin University, Cambridge, in recognition of his leadership in person-centered healthcare, and in 2019 received a third doctorate honoris causa from the University of West London where he holds a professorial level appointment at UWL's European Institute for Person Centred Health and Social Care. Sir Jonathan is currently Chief Clinical Officer of Healthcare at Home, Deputy Chairman, Oxford Health NHS Foundation Trust, Oxford, UK, and President and Chairman of Council of the European Society for Person Centered Healthcare.



Professor Anthony Woodman BSc MSc PhD Deputy Vice Chancellor and Provost for Health, University of West London, UK

**Professor** Anthony Woodman is Deputy Vice-Chancellor and Provost for Health with a remit to drive research, enterprise, innovation and external engagement across the University of West London. Until 2007 Professor Woodman was Professor of Translation Medicine at Cranfield University, prior to becoming chief executive of ICRI Global Research; a privately owned knowledge-based organisation providing support and training in clinical drug development in India, Singapore and the UK. Anthony joined the University of West London in October 2011. Professor Woodman studied at Sunderland Polytechnic before gaining a master's degree with distinction in experimental pathology / toxicology followed by a doctorate in pathology both from the Royal Postgraduate Medical School, University of London, with postdoctoral experience at Dublin City University and John Radcliffe Hospital, University of Oxford. His research discipline is molecular oncology and specifically the development and implementation of diagnostic and prognostic platforms informing care and management of cancer patients; research that has been undertaken in collaboration with major pharmaceutical companies including Roche (formally Boehringer Mannheim) and GSK. With over 125 full papers and conference proceedings, Professor Woodman's area of translational medicine was rated 4\* in the 2008 Research Assessment Exercise. Professor Woodman represents the University on the Boards of West London Business and Action Acton.



Dr. Patrick Daly MD MA Massachusetts, USA

Dr. Patrick Daly is currently a research associate at The Lonergan Institute at Boston College, where he is working on a long-term project to develop a philosophy of health based on Bernard Lonergan's generalized empirical method. He received a BS in biology from Providence College in 1969 and an MD from Northwestern University in 1974. He trained in internal medicine on the Georgetown service at the Washington DC VA Medical Center between 1974-1977. He was in private practice in Rhode Island for 23 years and then worked for VA Maine for 12 years, serving as Director of Hospice and Palliative Care there and for VA New England from 2008-2012. After completing an MA in philosophy at Boston College in 2013, Dr. Daly left medical practice in order to pursue his current research project.



-2020 ESPCH Platinum Medal-Dr. Amy Price DPhil (Oxon) Continuing Education, University of Oxford, UK

Dr. Amy Price worked as a Neurocognitive Rehabilitation consultant and in International Missions before sustaining serious injury and years of rehabilitation. She emerged with a goal to build a bridge between research methodology, research involvement and public engagement where the public is trained and empowered to be equal partners in health research. Amy's experience has shown her that shared knowledge, interdisciplinary collaboration, and evidence based research will shape and develop the future.



Dr. Vije Rajput MBChB MRCGP Keele University, Staffordshire, UK

Dr. Vije Rajput is General Practitioner, NHS UK, with a special interest in quality management and information technology, and he is a member of the Royal College of General Practitioners. As a Clinical Director for Long Term Conditions for a Clinical Commissioning Group (CCG) he is commissioning services for the local population and led a healthcare service redesign for diabetes care. He is active in the field of technology enabled care and delivered a mobile phone telehealth service. His current research interests include the application of decision support tools in clinical practice and the successful adoption and assimilation of technology.



### -2020 ESPCH Honorary Distinguished Fellowship-

Research Associate, Lonergan Institute at Boston College, Chestnut Hill,

Senior Research Scientist, Stanford Anesthesia Informatics and Media (AIM) Lab, Stanford University School of Medicine, USA; Research Editor, Public and Patient Partnership Strategy British Medical Journal & Department of

NHS General Practitioner, Stonydelph Health Centre, Tamworth, Clinical Director LTCs, Clinical Commissioning Group (SESSP CCG), and Hon. Clinical Teacher,

**Biographies** 



-2020 ESPCH Qualitative Methods Research Prize-Ms. Myriam Dell'Olio MSc Doctoral Student, Academy of Primary Care, Hull York Medical School, University of Hull, UK

Ms. Myriam Dell'Olio is a PhD student at the Academy of Primary Care, a research group at the Hull York Medical School. Her research interests include person-centered care, healthcare services research, health promotion, and qualitative research methods. In 2012, she got a Bachelor's Degree (Hons) in Speech and Language Therapy, and then worked as a speech therapist in Italy for two years before moving to the Netherlands, where she got a Master's Degree (Hons) in Health and Society. Her Master's programme focused on interdisciplinary research in healthcare settings. Therefore, her internship project focused on "care farming" (healing and health promoting farms), whereas her Master's thesis' project focused on the development of "salutogenic mechanisms" (i.e., mechanisms that "create health") in the lives of students with disabilities. During this period, she also engaged in academic consultancy activities and contributed to the development of extracurricular programmes to foster academic reflection skills. From a methodological perspective, her projects ranged from mixed-methods to qualitative studies, with a prevalence of qualitative research methodologies and techniques, such as phenomenology, phenomenography, life histories, and meta-ethnography. Currently, her PhD project is reaching its final stages, focussing on person-centered care in primary care settings, and aiming to achieve a better understanding of this concept from the perspective of adult patients with long-term conditions.



-2020 ESPCH Gold Medal-Dr. Jeremy Howick BA MSc PhD Director, Oxford Empathy Programme & Senior Researcher and Impact Fellow, Oxford Faculty of Philosophy, University of Oxford, UK

Dr. Jeremy Howick is an Award winning Oxford philosopher and medical researcher and has 15 years of research on evidence-based medicine, placebo effects, and empathy. He has published 3 books, almost 100 peer-reviewed articles, and is the director of the Oxford University Empathy Programme, an interdisciplinary programme whose mission is 'to introduce a dose of empathy into all healthcare consultations'. He is also a leader in medical humanities and has introduced the only humanities module to the Oxford MSc in Evidence-Based Healthcare. He has also promoted medical humanities by founding the Oxford Philosophy and Medicine Network. Dr. Howick is the secretary of the Network, and coordinates interdisciplinary (humanities, medicine) graduate seminars which attract medical and philosophy researchers. He also draws on his 12 years experience at Oxford to coordinate philosophy and other medical humanities researchers at Oxford. In addition, he communicates regularly with the public and has written a book for non-academic audiences called Doctor You (Amazon #1 bestseller). As an expert he has appeared on the BBC, ITV, and Channel 4, and his research has been featured in The Guardian, The Times, Men's Health, the Daily Mail, the Huffington Post, and The Conversation. He speaks regularly at Oxford and internationally to academics and others about his research, why we need medical humanities, and how this can improve health.



#### -2020 ESPCH Honorary Distinguished Fellowship-Dr. Michelle Croston

Senior Lecturer & Advanced Nurse Practitioner, Department of Nursing, Faculty of Health, Psychology & Social Care, Manchester Metropolitan University, UK

Dr. Michelle Croston have been passionate about providing care for people living with HIV since beginning her nursing career. This led her to join the team at North Manchester General Hospital's Infectious Diseases Unit. During this time she gained a diverse range of experiences providing care in an evolving disease area, this has ranged from delivering palliative care to long-term chronic disease management. Her research studies to date have focused on how nurses elicit patients concerns in order to provide person-centered care, how nurses facilitate shared decision-making within HIV care and the effectiveness of person-centred communication training for HIV nurses. She has also led a project involving a national multidisciplinary team, which developed and then evaluated the effectiveness of using a holistic assessment tool within routine HIV care, in order to make consultations patient-centered. In 2011, Dr. Croston joined the National HIV Nurses Association (NHIVA) and, in 2013, was elected as Chair of the Association. During this time, she worked on national initiatives to improve care for people living with HIV and has collaborated with numerous national HIV organisations to raise standards of care. Alongside her national role, she is also an Executive Member of the European HIV Nurse Network (EHNN) and have been involved in developing their educational conferences. This work has led her to be part of the faculty for the International Providers of AIDS Care (IAPAC).



Professor Michael Loughlin PhD

Professor Michael Loughlin is a Professor in Applied Philosophy and co-director of the University of West London's European Institute for Person-Centred Health and Social Care. He is also an Academic Visitor at the Nuffield Department of Surgical Sciences, University of Oxford Medical School and director of the Literature Database Programme, at the Collaborating Centre for Values-based Practice, St Catherine's College. He has written extensively on the relationship between knowledge, science and value in clinical practice, applying arguments developed in his PhD (on the relationship between epistemology and ethics) and early publications to analyses of the nature and role of rationality, evidence, judgement and intuition in medicine and health care. His early work (including a 2002 book, Ethics, Management and Mythology) raised methodological questions about quality measures, bioethics and the use of evidence in health policy. He has written many articles in academic journals and popular media, and addressed international audiences of practitioners and policymakers on evidence-based practice and person-centred care. In 2014 he was elected a Distinguished Fellow of the European Society for Person Centered Healthcare and awarded the Senior Vice President's medal for Excellence, for his foundational work in the Philosophy of Person-Centred Care. He currently chairs the Society's Special Interest Group in Health Philosophy and is Associate Editor of the Society's journal, the European Journal for Person-Centered Healthcare and is currently editing a volume on the philosophy of person-centred care. As Associate Editor of the Journal of Evaluation in Clinical Practice he has edited several special issues on philosophical aspects of health care. He is the editor of Debates in Values-based Practice: Arguments for and Against (Cambridge University Press, 2014). His recent work on medical epistemology has raised questions about scientism and moral realism, defending a humanistic conception of rationality and science in practice.



### Professor of Applied Philosophy and Co-Director, European Institute for Person-Centred Health and Social Care, University of West London, London, UK





**Professor Marilyn A. Ray** RN BSN MSN MA PhD CTN-A FSfAA, FAAN FESPCH (Hon) FNAP

Colonel (Ret.) United States Air Force Nurse Corps & Professor Emerita and Adjunct Professor, The Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, Florida, USA

Professor Marilyn Anne Ray is Professor Emeritus and Adjunct Professor at Florida Atlantic University, Christine E. Lynn College of Nursing, Boca Raton, Florida, USA. She holds a diploma in nursing from St. Joseph Hospital, School of Nursing, Hamilton, Canada; Bachelor and Master of Science degrees in Nursing from the University of Colorado, Denver, Colorado; Master of Arts in Anthropology from McMaster University, Canada; Doctor of Philosophy in Anthropology and Transcultural Nursing from the University of Utah, Salt Lake City, Utah. Ray has held faculty positions at the University of San Francisco, University of California San Francisco, McMaster University, the University of Colorado, and the Eminent Scholar and Professorial positions at Florida Atlantic University. She is certified as an advanced Transcultural Nurse and is a Transcultural Nursing Scholar. Her focus is caring science publishing widely with different chapters and articles, and books, her most recent, Transcultural Caring Dynamics in Nursing and Health Care. She has presented nationally and internationally, and advances new ideas, for example, humanoid caring robots as an expression of multicultural caring. Ray spent two decades studying organizational caring in military and private hospitals. As a retired Colonel in the United States Air Force Nurse Corps, she received the national research award from the Association of Military Surgeons of the United States. Her Theory of Bureaucratic Caring is featured as the cornerstone of the Total Nursing Force Person-Centered Caring Practice Model for the USAF. As a veteran she is serving as a military and veteran partnership liaison with the "Caring-Based Academic Partnerships in Excellence: Veteran RNs in Primary Care (CAPE-V)" program at Florida Atlantic University, Christine E. Lynn College of Nursing, Boca Raton, FL facilitating understanding transitioning from military to veteran culture status for faculty, and veteran students. Professor Marilyn A. Ray will be awarded an Honorary Doctor of Laws degree from McMaster University at the May 20, 2020, Convocation in Hamilton, Ontario, Canada. She is very humbled with this special honor, as she was an alumna of the university in Cultural Anthropology, and also was educational coordinator of primary care nursing (nurse practitioner/family practice programme) in the Faculty of Nursing and Health Sciences at McMaster University.



-2020 ESPCH Honorary Distinguished Fellowship-Colonel Dr. Marcia Potter Col USAF NC RN DNP FNP-BC Master Clinician, United States of America Air Force & Adjunct Professor, Uniformed Services University of the Health Sciences, USA

**Col (Dr.) Marcia A. Potter** is a Board-certified Family Nurse Practitioner and Master Clinician FNP for the US Air Force, integral to the academic and clinical development of Family Nurse Practitioners in the Air Force and Primary Care delivery for more than three million beneficiaries worldwide. Visionary and innovative, Col Potter created the AF Nurse Corps professional practice model, *Person-Centered Caring Partnership Model*, focusing on person-centered caring and development. She initiated multiple projects engendering caring culture change: embedding military chaplains in primary care services, creating a simulation-based caring communication initiative to improve inter-personal relations, and developing the only multi-disciplinary Evidence-Based Practice Council in the US Air Force. Col Potter is also a lead agent for the creation of the Academic Health System for the NCR, linking research, academia, and clinical practice for military medical facilities in the region. Col Potter is the immediate past FNP Consultant to the Air Force Surgeon General, responsible for shaping the FNP profession and mission for full spectrum military readiness. Col Potter's diverse experiences, advanced education, and expertise leads advancements in many areas of professional nursing policy, scholarship, leadership, and clinical practice.



-2020 ESPCH Senio Ms. Rachel Power Chief Executive Officer

**Ms.** Rachel Power joined the Patients Association as Chief Executive in June 2017, bringing with her over 20 years' experience of health and social care in the not-for-profit sector. Since joining, Ms. Power has overseen a significant period of change. Her achievements include the strengthened reputation of the organisation as a credible voice for patients nationally, and a significantly increased and engaged membership. She is now focused on taking the Patients Association to a new level of patient representation and voice. Working to an inclusive strategy, Ms. Rachel Power will be championing issues that matter to patients and members. These will include utilising the value of diversity in addressing health inequalities and ensuring that patients' needs are at the heart of healthtech development. Ms. Rachel power is also a member of the NHS Assembly.



-2020 ESPCH Paties Ms. Charlotte Allen Parkinson's Patient ar

Ms. Charlotte Allen was diagnosed with Parkinson's at the age of 36, she remains grateful that her condition, so far over the last 16 years, does not restrict her from working and enjoying life. However, she remains very aware this could change at any time, due to the many complexities of the condition. Ms. Charlotte Allen is a genuine, approachable person, who wants to do good by helping other People with Parkinson's and make a difference in their lives while she still can. Ms. Allen is the proud owner of two companies, and describes herself as a business entrepreneur, an astute business leader, lively and out spoken individual, and a "risk taker". She loves a challenge, and is a "do-er", who is career minded, and has the ability to identify new opportunities, and so, turn ideas & dreams into a reality. Ms. Charlotte is a very positive, articulate, enthusiastic person looking to inspire and motive others to not "give up" after being diagnosed with Parkinson's. Using her experience, business acumen and contacts within the recruitment industry, she, along with Co-founder Ms. Russ Bradford, have jointly established Parkinson's Concierge. Everyone involved in Parkinson's Concierge either has Parkinson's or has experience working with People with Parkinson's. Describing this business, Ms. Charlotte Allen says: "It's a new and different idea - we are not a Charity but a business which supports everything related to Parkinson's - a "go to" search engine for Parkinson's People, Fundraising, What's On?, What's Happening? If its relating to Parkinson's we will promote it for you!". Ms. Charlotte has also become an active campaigner within the Parkinson's community, and she sits on many steering panels, enrolls, encourages, and participates in research and campaigning opportunities. We understand, care and know how you feel!



#### -2020 ESPCH Senior Vice-President's Medal-

#### Chief Executive Officer, The Patients Association, UK

#### -2020 ESPCH Patient Advocacy Prize-

#### Parkinson's Patient and Co-Founder of Parkinson's Concierge, UK



**Biographies** 



-2020 ESPCH Patient Advocacy Prize-Mr. Russ Bradford Parkinson's Patient and Co-Founder of Parkinson's Concierge, UK

Mr. Russ Bradford is a deeply passionate campaigner for People with Parkinson's (PWP), with key strengths for public speaking to large audiences and a developed keen interest and participation in various research projects and clinical trials. Having felt like he was dropped on the "scrapheap of life" after being former owner of three successful businesses, he was forced to retire on the grounds of ill health. At the same time, losing his family was one of the hardest things to bear. Now he is devoting 100% of his life to finding ways of enabling People with Parkinson's to live a better quality of life, within the "Parkinson's Community". He recognises the PWP who need support and are vulnerable, and through engaging professional bodies, he helps other PWP not to experience "his" journey with Parkinson's and to overcome similar hurdles. Having set up Parkinson's Concierge as a Co-founder and volunteer with the aim of Raising Awareness 365 days a year, both Mr. Russ Bradford and his partner, Ms. Charlotte Allen, network and collaborate across the worldwide domain, promoting the fact that not all People with Parkinson's are old - younger people including children are being diagnosed too. They campaign for PWP, to ensure they are aware of what they are entitled to, and informed of what support is available to them to make their Parkinson's journey through life one they don't fear or face alone.



Ms. Gillian Nuttall Founder & Chief Executive Officer, Melanoma UK

Ms. Gillian Nuttall, the founder of Melanoma UK, had recognised a serious need in the support of melanoma patients and families. Melanoma UK was formed in 2007 following a personal connection with melanoma. In 2002, a young man from Larne in Northern Ireland was diagnosed with melanoma. By 2007 he was terminally ill and, in 2008, he passed away. Ms. Gillian Nuttall started to fundraise so she could help fund research of the disease and raise awareness of the seriousness of melanoma. Prior to forming Melanoma UK, she worked for over twenty five years within the legal profession. This knowledge of the legal system and understanding of procedures and legalities has enabled her to perfectly navigate the complexities of the industry whilst maintaining the patient first ethos of the organisation. There is still much to be done. Melanoma continues to increase, patients and families continue to need support and Ms. Gillian Nuttal continues to make sure that anyone who needs support can obtain it.



Ms. Diane Cannon

Ms. Diane Cannon became a melanoma patient advocate for Melanoma UK in 2013 following the death of her young niece, Claire. The UK based patient advocacy group had been extremely supportive throughout Claire's illness, and following a number of years raising much needed funds for Melanoma UK, Ms. Cannon decided to take up a more permanent role. In 2016, building on more than 25 years in the corporate world and a further 10 years of running her own business, Ms. Diane Cannon became Director of Corporate Partnerships. Although she has no medical training, her wealth of business acumen, combined with her contagious enthusiasm, extraordinary energy and dedication to help others, Ms. Diane Cannon is an unstoppable force for Melanoma UK.



Mr. Jonathan Liebling

Mr. Jonathan Liebling has been consuming cannabis to alleviate symptoms of depression and anxiety all his adult life. Resulting from legal issues with growing his own cannabis, he decided it was time to stand up and fight for patients right to their medicine, drawing on those and past experiences, influencing and inegotiating skills, and knowledge to campaign and lobby for legal access to cannabis therapeutics in the UK. He worked as a psychiatric nurse, before a career in IT business relationship management. Mr. Jonathan Liebling has dedicated the last 6 years as political director for a patient-centred volunteer organisation providing support for medical cannabis patients whilst lobbying and campaigning for legal access. Following the change in UK law that took effect from 1 November 2018, Mr. Liebling co-founded The Patient Advocacy and Support Services - CannPass - which is a professional advocacy service to support patients, parents and carers whilst promoting safe, effective, affordable and equitable access to medicinal cannabis for all who could benefit. Not-for-profit, Cannabis Patient Advocacy and Support Services provides a range of services to patients who could benefit from accessing medicinal cannabis in what is proving to be a highly restrictive environment.



#### Director of Corporate Partnerships, Melanoma UK

### Co-Founder and Director at Cannabis Patient Advocacy and Support Services, & Research Lead, The Centre for Medicinal Cannabis, UK

**Biographies** 



Dr. Amy Hunter PhD Director of Research, Genetic Alliance UK

Dr. Amy Hunter, as Director of Research at Genetic Alliance UK, ensures that that Genetic Alliance is active in research that is relevant to patients and families affected by genetic conditions. She works with her team to identify and act on any policy implications that arise from research work that is often often carried out in collaboration with university researchers and clinicians. Dr. Amy Hunter's academic background is in molecular biology and she held several managerial roles in biomedical and psychosocial research. Her personal motivation is to see real evidence-based improvements in the support that patients and their families receive; her team's work at Genetic Alliance UK in health care research is significant and exciting for this reason.



-2020 ESPCH Silver Medal on behalf of the Brittle Bone Society-Ms. Patricia Osborne FRSA Chief Executive Officer, Brittle Bone Society, UK

Ms. Patricia Osborne joined the Brittle Bone Society as CEO in 2010 and has worked on three strategic plans. She oversaw the set-up of their Medical Advisory Board, 2012, and Scientific Advisory Board, 2016. The Charity under her direction gained AMRC status in 2016; held their first International Scientific Symposium in London February 2017 and launched their Research Grants Programme later that year. In 2018 they held an International Symposium in Dundee involving 19 countries, 270 delegates including leaders of osteogenesis imperfecta (OI) patient support groups worldwide. Prior to joining the Charity, Ms. Osborne worked in the Media as systems manager (1993-2004, Scottish Media Group SMG Glasgow, Magazines Division) and in Politics serving as a local Elected Member (Elected to South Lanarkshire Council, Fernhill Ward, 2003-2007), then a Parliamentary Researcher to Rt. Hon T McAvoy MP constituency MP & Deputy Government Whip (Westminster, 2004-2009). She was Chair of The National Governing body of sport for Netball in Scotland until 2011. Ms. Patricia Osborne has spent years volunteering on sports council committees and helped set up a national governing body affiliated netball league in Tayside, Scotland 2013. Ms. Osborne attended Reid Kerr College, Paisley, studying Business Studies Administration. Whilst in the media, she attended Glasgow School of Art completing courses in Graphic design; Glasgow College of Building and Printing - Sub editing and Strathclyde University - Internet and communications.



Ms. Jane Teasdale Principal Owner, Co-Founder and Director of Business Development, Mosaic Home Care Services & Community Resource Centres, Toronto, Ontario, Canada

Ms. Jane Teasdale is well known for developing awareness of home and health care issues in the community and for encouraging collaboration between public health, for profit and not for profit service providers in Ontario's Greater Toronto Area. Mosaic Home Care & Community Resource Centres offers a person centered community integrated model of care that is unique to the homecare industry. It operates community resources centres across the Greater Toronto Area that provide information, education, events, space for hobby groups, community and memory cafés and much more. In her presentations around the community, Ms. Jane Teasdale focuses on the importance of a more complete model of care, one that addresses the clinical, the personal supports, the wider non-clinical psychosocial needs of the person and their relationships with community. It is a model with personhood and community at its centre. Ms. Jane Teasdale is also co-chair of the North York Elder Abuse Network and presents regularly on community-based models of care, notably at this year's NICE "13th Annual Knowledge Exchange" in Toronto and at the recent Global International Federation on Aging Conference, "Towards a Decade of Healthy Ageing - From Evidence to Action", where she was also a session chair on a related theme.



Associate Director for Patient Engagement,

Mr. Shahid Sardar is Associate Director Patient Engagement in an East of England NHS Hospital, and is responsible for improving patient activation and experience at The Princess Alexandra Hospital. He began his work at national Mind where he helped the charity reach out to minority groups and challenge attitudes to mental health. He then worked for acute and public health in East London for the seven years leading up to the Olympics in 2012, getting Tate and Lyle and West Ham Football Club to talk to and challenge their staff and fans to make healthier choices, and involving Pepsi Co. in supporting health and wellbeing through their Max brand. Since 2012, Mr. Shahid Sardar has been working for The Princess Alexandra Hospital and for much of that time with Ms. Ann Nutt, National Co-Chair of Shaping our Lives, as a national user activist who wants local people to have a bigger role in shaping their local health services.



Mr. Shahid Sardar BA PGCert (Psy) MSc MBPsS The Princess Alexandra Hospital, NHS Trust, UK



**Biographies** 



Ms. Grace Meadows Programme Director, Music for Dementia 2020, The Utley Foundation, UK

Ms. Grace Meadows is Director of Music for Dementia 2020, a UK wide campaign to help make music available for everyone living with dementia. A life-long musician, Ms. Meadow's passion for music developed early in life through singing, before learning the violin, bassoon and piano. Her love for the bassoon won through and she took up a place to study at the Guildhall School of Music and Drama. During her training, she became interested in how music can be used beyond performance-based experiences to connect with and relate to people. This interest in music and people led her to discovering music therapy and she qualified as music therapist in 2011. She has worked with people across the lifespan, from mums-to-be to older people across health, educational and social care settings. Prior to joining the campaign, Ms. Grace Meadows was the Development Director for the British Association for Music Therapy, advocating for the inclusion of music therapy in health, education and social care services. As part of this role, she began to bring people together around embedding music and music therapy in dementia care. This led to a partnership with The Utley Foundation, with Ms. Meadows supporting with their Commission on Dementia and Music. This paved the way for her joining the Foundation in 2018 to lead the campaign.



Dr. Rick Morton B.Sc (Hons) PhD Global Chief Medical Affairs Officer and Global Head of WG Practice, WPP Health Practice, WPP London Headquarters, UK

Dr. Rick Morton is the Global Chief Medical Affairs Officer and leads the Chief Medical Office in WPP's global Health Practice. He is also an Executive Committee member of the Medical Affairs Professional Society (MAPS) and Board member of the biopharmaceutical company, Biotherapy Services Ltd. Prior to joining WPP, Dr. Rick Morton was Head of International Value & Access at Allergan. He has extensive academic, biopharmaceutical industry and global healthcare consulting experience, across a diverse range of therapeutic areas, notably, Neurosciences, Rheumatology, Rare Diseases, Ophthalmology, GI, Anaesthetics, Immunology & Infectious Diseases. Dr. Morton has previously been head of function in Allergan's Medical Affairs and HEPRA for the EAME region and, prior and to this, worked in Switzerland for Novartis Pharma as a Global Access Lead on early pipeline development assets in rare diseases. He has also extensive drug development and commercialization experience from working as Vice President Consulting at PAREXEL, in addition to a previous role as MD of the Global Market Access consultancy, WG Consulting. He received a doctorate in Neuropharmacology from the University of Manchester, UK and has a B.Sc (Hons) degree in Pharmacology from the University of Liverpool, UK and Health Economics, Brunel University, UK.



-2020 ESPCH Mixed Methods Research Prize-Ms. Samantha Hughes BSc (Hons) MSc GDip MBPsS Doctoral Student, School of Natural and Social Sciences, University of Gloucestershire, UK

Ms. Samantha Hughes is a doctoral student at the University of Gloucestershire, UK. Her particular area of interest is well-being and investigating how this can be supported, sustained and enhanced in vulnerable populations and groups (such as people with mental health needs). Ms. Hughes has been involved in the design, delivery and evaluation of a number of health promoting interventions in primary and secondary health care, and in the community. This has included a focus on activities for health, arts for health, cancer support, nursing, social work and dementia care, mental health and well-being. Her research has spanned quantitative, qualitative and mixed methods designs. She has recently disseminated her findings at national and international conferences and in peer-reviewed journal publications. Ms. Samantha Hughes has worked alongside healthcare professionals, community and charity groups and with the local government to facilitate the application of research into practice. It is this opportunity, in which she is able to observe the impact that research can contribute to a person's life, that continues to drive her passion and enthusiasm for her work. Ms. Hughes is currently working towards her thesis focusing on sense of self and well-being in people living with, and beyond, anorexia nervosa.



Lt. Gen. Dorothy A. Hogg is the Surgeon General, Headquarters U.S. Air Force, Arlington, Virginia. General Hogg serves as functional manager of the U.S. Air Force Medical Service. In this capacity, she advises the Secretary of the Air Force and Air Force Chief of Staff, as well as the Assistant Secretary of Defense for Health Affairs on matters pertaining to the medical aspects of the air expeditionary force and the health of Airmen. General Hogg has authority to commit resources worldwide for the Air Force Medical Service, to make decisions affecting the delivery of medical services, and to develop plans, programs and procedures to support worldwide medical service missions. She exercises direction, guidance and technical management of a \$6.1 billion, 44,000-person integrated healthcare delivery and readiness system serving 2.6 million beneficiaries at 76 military treatment facilities worldwide. Prior to her current assignment, General Hogg served as Deputy Surgeon General and Chief, Air Force Nurse Corps, Office of the Surgeon General, Falls Church, Virginia. General Hogg entered the Air Force in 1984 and has commanded at the squadron and group level, and served as the deputy command surgeon for two major commands. She has deployed in support of operations Enduring Freedom and Iragi Freedom.



-2020 ESPCH President's Medal for Excellence-Lieutenant General Dorothy A. Hogg NP BSN MPA MSN Lieutenant General, Surgeon General of the United States Air Force, Medical Service/Nurse Corps, Office of the Surgeon General, Arlington, Virginia, USA

#### **Biographies**





-2020 ESPCH Bronze Medal on behalf of Sickle Cell Society-Mr. John James OBE Chief Executive Officer, Sickle Cell Society, London, UK

Mr. John James OBE has thirty-three years of experience within the NHS including 4 CEO roles. He was Chair of the West London Cancer network (2002-2005) and Chair of the North West London Diabetes Network (2003-2004). As a senior civil servant for the Department of Health, he served as Program Consultant on leadership for the NHS Next Stage Review and then as Deputy Director for the NHS Medical Director/Director General. He has been Chief Executive of the Sickle Cell Society for the last 5 years. In June 2018, Mr. John James was awarded an OBE as part of the Queen's Birthday Honours.



-2020 ESPCH The Patient Advocacy Award on behalf of Bayer AG-Dr. Markus Langen PhD Clinical Study Manager & Lead, Global Cross-Functional Study Team, Retinopathy of Prematurity, BAYER AG Pharmaceuticals, Leverkusen, Germany

Dr. Markus Langen studied Biology at the Heinrich-Heine University in Düsseldorf and received his PhD in microbiology in 2012. After completing a professional training in clinical research, Dr. Langen started his career with Bayer 2013 as an assistant project leader for non-interventional studies, soon taking over responsibility as a project leader for several NIS in the areas of ophthalmology, oncology, cardiovascular and neurology. Since 2017, Markus is leading cross functional global study teams as a study manager, currently managing a global pediatric phase 3 trial with premature babies suffering from retinopathy or prematurity. For this trial, the study team wanted to offer parents the best possible support during a very difficult time of expectant premature labor. To help ensure keeping patient centricity at focus, the study team engaged with external patient networks in 4 countries (Brazil, Germany, Japan and Spain) to complete concept testing of various recruitment and retention materials developed. Concept testing was completed for both the base study (20090) as well as the long-term follow up study (20275), both spanning across 33 countries globally. Dr. Markus Langen is living in a small village near Cologne with his wife and two daughters. In his free time, he enjoys doing sports like hiking or mountain biking with his family in the nearby forests or playing soccer.



-2020 ESPCH Essay Prize-Dr. Marcela Almeida MD Instructor in Psychiatry, Department of Psychiatry, Brigham and Women's Hospital, Harvard Medical School, Boston, Massachussets, USA

Dr. Marcela Almeida studied as an undergraduate in Rome and graduated from medical school in her native Brazil in 2002. Shortly after receiving her medical degree, she chose to practice in a remote area of Northeastern Brazil, the poorest region of the country. She regards that experience as the most crucial for her medical career, as the lessons she learned there could never be learned from books or otherwise. One of eight psychiatrists in the family, she chose psychiatry as her field, "I'm not very creative, I guess". She moved to North America for her post-graduate studies and completed her residency at the University of Chicago, where she became an avid advocate for minorities and underserved populations, mainly women of color of Chicago's South Side. Dr. Almeida served as Director of the Women's Mental Health and Reproductive Psychiatry at the University of Illinois, the largest specialized program in the U.S., where she treated women with psychiatric manifestations related to their reproductive cycle, including pregnancy, postpartum, infertility and menopause. In addition to patient care, she directed the women's mental health fellowship program and did research that focused primarily on burnout and de-stigmatization of mental illness among Latinas. In 2017, she joined Harvard Medical School's Department of Psychiatry at Brigham and Women's Hospital, where she has been recognized for her passion for mentoring trainees from underrepresented minorities and caring for women with chronic mental illness while striving to reintegrate them into society. She also sits on the board for the Salt and Light Coalition, an organization that works with victims of domestic violence and sex trafficking.



Dr. Thomas Fröhlich MD PhD Physician, Heidelberg, Germany & Vice President (Western Europe), **European Society for Person Centered Healthcare** 

Dr. Thomas Fröhlich is a medically qualified psychotherapist working in Heidelberg, Germany. He initially studied biology at Freiburg University and Heidelberg University, Germany, before proceeding to study medicine and to complete theses in biophysics and medicine in 1978 and 1983, respectively, having graduated in medicine at the University of Heidelberg in 1980. From 1980 - 1986, he worked at the Paediatric Hospital, University of Heidelberg. From 1973-1976 and 1986 - 1987, he worked at the Max Planck Institute for Medical Research, Heidelberg, conducting research in biochemistry, biophysics and human physiology. From 1986-1990, he studied the techniques involved with the psychoanalytic psychotherapy of children and adolescents at the Institute for Analytical Psychotherapy for Children, Heidelberg, Germany and has practiced privately in paediatrics, allergy and psychotherapy since 1988. From 1997, he has collaborated in research at the Institute of Medical Biometry and Informatics, Heidelberg University, with the Technical University Braunschweig, Institute of Medical Informatics (Prof. Reinhold Haux), Hospital of Internal Medicine and Psychosomatics, Heidelberg University (Prof. Gerd Rudolf) and Psychosomatic Medicine, Klinikum rechts der Isar, Munich Technical University, with Professor Peter Henningsen. Dr. Fröhlich has been awarded research grants to develop understanding in his field and he has published extensively. He has conducted ground breaking research on the mathematical representation of psychosomatic interactions in childhood asthma and on the prevalence, psychosomatics and treatment of childhood and adult asthma. He has lectured at the Institute of Medical Informatics Technical University Braunschweig and since 2001 has been CEO of Heidelberg Metasystems GmbH, a research organization mainly focused on asthma prevalence and treatment issues and on IT-supported early detection of common chronic diseases in a family medicine private practice setting. Dr. Thomas Fröhlich has developed a web-based IT tool for the treatment of self-reported stress and symptoms of psychic and organic diseases in paediatric and family medicine private practice contexts, which may be viewed at: www.medkids.de.



**Biographies** 



Mr. Dan Berry BA MSc Director of Behavioural Science at Hill+Knowlton Strategies, UK

Mr. Dan Berry is Director of Behavioral Science at global communications agency Hill+Knowlton Strategies, which is part of WPP Health Practice. He joined Hill+Knowlton Strategies in 2016 from the UK civil service, where he set up and led the behavioural insights team in the Department of Health and on secondment to NHS England. He leads research projects and campaigns across a range of healthcare, sustainability and change management programmes. Mr. Dan Berry has run more than thirty behavioural trials and evaluations, the majority of them in health and wellbeing. These include innovative and low-cost strategies to improve medication adherence, vaccination rates, and influence optimal prescribing by clinicians. There are few people more experienced at applying behavioural insights to such practical and tangible challenges. Several of Mr. Berry's trials have been published in respected journals, including The Lancet. He was winner of the UK Government's Social Research Award for research "of high quality that is innovative and demonstrates practical value". Since 2015, Mr. Dan Berry has been a trustee of a UK neurological health charity, The Dystonia Society. He was previously head of policy and campaigns at the MS Society. He has an MSc in public policy from University College London and a BA from the University of Warwick.



#### -2020 ESPCH Young Researcher Prize-

#### Dr. Rajni Lal MBBS MPH

Specialist Registrar in Geriatrics/Internal Medicine and Fellow in Perioperative Medicine for Older People undergoing Surgery (POPS), Guy's and St. Thomas' Hospitals Foundation NHS Trust, UK, and Blacktown & Mount Druitt Hospital, Western Sydney Local Health District, Sydney, Australia

Dr. Rajni Lal is a dual trainee in Geriatric and General Internal Medicine. Originally from Australia, she is currently completing her fellowship in Perioperative Medicine for Older People undergoing Surgery (POPS) at Guys and St Thomas Hospital. She established and chairs TRIPOM Australia New Zealand which provides free online educational resources to trainees interested in perioperative medicine.



#### -2020 ESPCH Young Teacher Prize-

Dr. Karishma Jivraj PhD PGDip BSc (Hons) AFHEA CPsychol Lecturer in Mental Health and Health Psychology, Faculty of Health Education and Society, University of Northampton and Senior Teaching Fellow, Faculty of Psychology and Human Development, Institute of Education (IOE), University College London (UCL), London, UK

Dr. Karishma jivraj is from a Psychology background, gaining academic and research experience within a range of community mental health settings and research institutions over the past 10 years. Her primary interests have revolved around implementing recovery focused approaches in mental health services, which involve promoting therapeutic relationships, shared decision making and person centred care for individuals experiencing mental health conditions. Dr. Karishma has recently finished her PhD which explored service user and clinician perceptions of therapeutic relationships, shared decision making and attitudes towards medication. Within her role as a Lecturer and Senior Teaching Fellow in Higher Education, she works on imparting knowledge and skills required for students wishing to pursue careers in mental health and health psychology. From a research perspective, Karishma continues to translate key findings from her PhD research into evidence based practice with the aim to improve mental health service delivery.



Dr. Mette Kjer Kaltoft PhD Health Visitor, Municipality of Copenhagen & Senior Guest Researcher, University of Southern Denmark, Denmark

Dr. Mette Kjer Kaltoft obtained her PhD in 2015 with the thesis Towards improved decision quality in personcentred healthcare: exploring the implications of decision support via Multi- Criteria Decision Analysis at the Research Unit of General Practice, Department of Public Health, University of Southern Denmark (SDU). Her professional background includes a MPH in sexual and reproductive health and rights, post-graduate courses at Mayo Medical Center and obstetrics at a WHO-accredited Baby-Friendly Birth Center in Rochester Minnesota, USA, intensive care pediatric and community nursing, outreach projects in sexual and reproductive health, and health visiting in multi-ethnic communities. Her research interests extend into Health Impact Decision Analysis, Translational Health, and Middle Eastern Studies and Modern Standard Arabic, along with research positions and work as a R&D nurse at Odense University Hospital (OUH) Svendborg Sygehus which preceded her PhD study: Action research investigating the delivery of Annalisa-based decision support to patients with Inflammatory Bowel Disease in St. Mark's Hospital, London, and Royal Prince Alfred Hospital, Sydney. The findings are being fed into the Danish context and related translation. Following a major interest since 1984, Dr. Kaltoft has been exploring ways to help translate policy for equity in access to health into practice, also literally; and thus, to a multi-criteria decision-analytic focus. Dr. Mette Kaltoft has just ended a nationally funded project to develop decision support tools involving an application integrated with the EHJ in the Region of Southern Denmark with the aim to be linked to the national e-health portal. Dr. Kaltoft is currently a board member of the Danish Society of Digital Health.



Dr. Bruno Kissling MD Primary Care, Bern, Switzerland

Dr. med. Bruno Kissling, 1949, is a family doctor. He worked in private practice (1982 bis 2019) in Berne, Switzerland. He was a board member of the Swiss Society of General Practice (1995-2003), Swiss delegate to the World Organization of Family Doctors WONCA (2000-2009), co-founder and co-editor-in-chief of the Swiss journal for family medicine Primary Care (2001-2014) and a teaching doctor at the Institute of Family Medicine, University of Berne. He published countless articles about family medicine in national and international journals. He participated in the documentary film trilogy "At the doctor's side" by Sylviane Gindrat (2013). He co-authored three books: "Die ärztliche Konsultation - systemisch-lösungsorientiert" ("The Medical Consultation - systemic and solution-oriented"; Vandenhoeck & Ruprecht, 2019), "Ich stelle mir eine Medizin vor... - Briefwechsel einer jungen Ärztin mit einem erfahrenen Hausarzt" ("I imagine a medicine... – letters between a young doctor and an experienced family doctor"; Rüffer & Rub; Auflage, 2018) and "Qualität in der Medizin - Briefe zwischen einem Hausarzt und einer Ethnologin" ("Quality in medicine – letters between a family doctor and an anthropologist"; EMH Schweizerischer Ärzteverlag; Auflage, 2015).



### -2020 ESPCH Book Prize Co-Winner-

Family Physician and Teaching Doctor, Bern Institute of General Practitioner Medicine, Board Member of the Swiss Society for General Medicine, Swiss Delegate to the World Medical Association and WONCA, & Co-Editor-in-Chief,

#### **Biographies**



**Biographies** 



#### -2020 ESPCH Book Prize Co-Winner-Mr. Peter Ryser Dipl. Sozialarbeiter HFS Scholar, Social Worker & Emeritus Lecturer, Lucerne School of Social Work and the Centre for Systemic Counselling, Bern, Switzerland

Mr. Peter Ryser, 1948, is a licensed social worker since 1973. He was further educated in Gestalt therapy, family therapy and neurolinguistic programming. He has worked in systemic counselling and supervision in drug rehabilitation, couples and family counselling for many years. He taught communication and supported team development and organisation in various educational institutions, private enterprises, social organisations and hospitals in Switzerland and Germany. He developed and led a master's degree course in systemic counselling at the Institute of Applied Psychology (IAP) in Zurich. He developed a postgraduate program for physicians in systemic solution-oriented counselling and still offers supervisions and counselling to groups of physicians, individuals and enterprises. Mr. Pater Ryser was a lecturer at the Lucerne School of Social Work and at the Centre for Systemic Counselling in Bern. He is an emeritus of the Swiss Society for Systemic Therapy and Counselling (Systemis).



Dr. Ankita Batla MBBS MBA Chief Medical Office Lead - Health Insights and Patient Partnerships, WPP Health Practice, WPP London Headquarters, UK

Dr. Ankita Batla is a medical doctor by training with a post graduate degree in management and has extensive experience in the healthcare communications sector. Dr. Ankita's leadership roles have involved research, strategy and insights with some of the biggest healthcare companies in pharmaceuticals, nutrition, health services and public health. She has a deep interest in patient engagement both from a physician and an industry perspective. She has been instrumental in setting up the patient-partnerships initiative at the WPP Health Practice. Dr. Ankita Batla has founded a charity called Jatan Sansthan in India which provides remedial education and employability skills to women and children. She volunteers at Barnados and at Great Ormond Street Hospital with her therapy dog 'Apollo'.



Mr. Faisal Ahmed Director of Innovation and Business Transformation, WPP Health Practice, London, UK

Mr. Faisal Ahmed has been involved in digital marketing for over 20 years, having been part of the start-up team at Amazon Europe launching many firsts in e-commerce which are now standard practices, as well as launching the first digital strategies and e-commerce channels for 90 Football clubs as head of e-commerce at Perform Group. Mr. Ahmed also launched a new careers service called 'Plotr' in the UK digitally for the cabinet office. He has launched many firsts in healthcare such as iPad detail aids, mobile apps, artificial intelligence platforms and augmented reality apps. He has also co-authored the first digital marketing book in Healthcare, 'Digital Unblocked: A Beginner's Guide to Digital Pharma'; PM Society; 2013, and been nominated as a top 10 innovator in healthcare. Mr. Faisal Ahmed has advised, Politician's, Aston Villa football club and Burberry Foundation on digital strategies. He also runs the longest running podcast on Digital health called 'Digitallysick' and has just released a book on marketing strategy in todays connected world called 'SKIP AD IN 5: The ad-blocker's guide to brand planning'; independently published; 2018.



Dr. Myles Furnace BMBS Digital Health and Data Lead, UK & Ireland Speciality Care at IPSEN Pharmaceuticals, London, UK

Dr. Myles Furnace was a physician in the NHS for 4 years before transitioning into the pharmaceutical industry in 2018. His last clinical role was the Neuroendocrine Tumour Clinical Fellow at the Royal Free Hospital, London. He began working in the commercial division of the UK affiliate at IPSEN as part of the Neuroendocrine Tumour Brand Team. He is now the Digital Health and Data Lead for the UK + Ireland at IPSEN where he implements digital health initiatives supporting the brands and creating new value for the organisation. His passion is Digital Health- progressing a cultural transformation in traditional medicine through disruptive solutions and innovative approaches to improve patient outcomes and create new value in healthcare. Dr. Myles Furnace is also part of the Tech London Advocates Healthtech working group which aims to accelerate innovation in healthcare and life sciences by bringing together all stakeholders across the healthcare ecosystem.



Dr. Bharat Tewarie MD MBA Boston, Massachusetts, USA

Dr. Bharat Tewarie is trained as a medical doctor (MD) with a MBA and has gained an extensive background in multiple aspects of BioPharma Management and Medical Devices including P&L responsibility, Corporate Strategy, Marketing, Sales, Product Launches, Medical Affairs, and Business development. He acquired impressive world-wide expertise in a wide diversity of settings and geographies (USA and Europe) in both global and local roles and leading global business franchises in BioPharma and Medtech to great success. During his extensive career, Dr. Bharat Tewarie has held positions with increasing medical and commercial responsibilities at Boehringer Ingelheim, Roche, Serono International, EMD Serono and Merck Serono. After working for the last 5 years as the EVP & Chief Marketing Officer and member of the Executive Committee of UCB, he founded in 2020 the advisory firm Boston BioPharma Consultants. Dr. Bharat Tewarie is a thought leader on the topic of Patient Value, Product Launches, Patient Experience, Digital Technologies and specifically AI to address biopharma business challenges. Last year, he became the lead author of a landmark publication about Artificial Intelligence and Patient Value in the New England Journal of Medicine/Catalyst in January 2019 titled "Unmet Needs: Hearing the Challenges of Chronic Patients with Artificial Intelligence". Furthermore, at an interview at the 2019 World Economic Forum in Davos, he spoke about the need to break down silos in which healthcare stakeholders operate and together align on a definition what "value for patients" means, so it can be measured, maximized and rewarded appropriately.



Founder and Board Advisor, Boston BioPharma Consultants,

**Biographies** 



Mr. Simon Hooper Co-founder of ReMeLife and RemindMeCare (Digital Technology for Elderly Care, Dementia, Mild Cognitive Impairement & Learning Disabilities), London, UK

Mr. Simon Hooper, an ex-geologist, is a co-founder of *ReMeLife*. He and Mr. Etienne Abrahams are on a mission to bring tech to the care process, courtesy of personal experience of the lack of person-centred care tech available during their own families care journeys. Having worked for four years with care groups, those cared for in the community, hospital wards and care organisations, Mr. Simon Hooper's developed a broad knowledge of the care sector and its potential for tech adoption.



Dr. Guenther Brueggenwerth MD LifeHub UK Lead, Bayer Pharmaceuticals, UK, & Radiologist - Senior Imaging Clinician, Berlin, Germany

Dr. Guenther Brueggenwerth is a Specialist Radiologist holding a German diploma 'Diagnostics Radiology'. He was working several years as a general radiologist and team leader introducing PACS (picture archiving and communication system) into the hospital. In 2002 he joined the industry and worked for Bayer at clinical Research & Development in clinical studies Phase I to IV in Berlin, Germany. Important areas were process development of central independent evaluations, new contrast media for the Bayer Radiology portfolio, and novel treatments for Oncology, Cardiovascular, Women's Health and Pulmonology. Since October 2019, Dr. Guenther Brueggenwerth has moved to the UK and is leading the Radiology part of the newly opened Bayer LifeHub UK (Reading, Berkshire) with focus on open innovation and AI driven solutions.



Mr. James Fitzpatrick MA Director of Patient Engagement & Government Affairs, Janssen Pharmaceutical Companies of Johnson & Johnson, UK

Mr. James Fitzpatrick has worked for Janssen in a number of roles since 2014 and heads up the Patient Engagement and Government Affairs team in the UK. He has overseen the creation of this team since its inception and has driven the change in how Janssen works with patients and Patient Groups since 2015. Before Janssen, he worked for 8 years in political communication and followed that with various roles in the charitable sector, working for both international development and healthcare charities over a 3 year period. Mr. James Fitzatrick studied Economics and Politics at Glasgow University and still devotes some of his free time as a trustee of an equine welfare charity based in Devon.



Dr. Paul Robinson MBBS FFPM DSc FRCP European Lead, Patient Innovation, MSD Pharmaceuticals, Senior Hon. Lecturer of Clinical Pharmacology, Barts Health NHS Foundation Trust and Visiting Senior Lecturer, Kings College, UK

Dr. Paul Robinson qualified in medicine in London, and after several years in NHS cardiology, joined the medical department of Merck Sharp & Dohme Ltd., a major US pharmaceutical company, running clinical trials and providing medical support to regulatory, drug safety and commercial functions. Having worked for the company in the UK and the USA, he is now the EU lead for patient engagement, being the interface between patient advocacy groups and the company. He has served 10 years on NICE, making recommendations on cost effectiveness of medicines and continues a regular clinical commitment in clinical pharmacology at St Bartholomew's Hospital, London



Germany

Ms. Malar Subramaniam is currently the Global Patient Engagement Manager at Bayer Pharmaceuticals, based in Berlin, Germany. In this role, which fits well with her passion for patients and ethical best practice, she works with both internal and external stakeholders to optimize and advance group-wide patient engagement capabilities and execution, as well as create sustainable relationships with patients & caregivers. Ms. Malar graduated with a Master of Pharmacy (Clinical Pharmacy) from the National University of Singapore, and earned her Bachelor of Science in Pharmacy from the University of Iowa in the United States. She has ten years of clinical pharmacy experience from working in three countries - the US, Malaysia and Singapore. She also worked for several years in medical communications where she drove innovative projects for various global pharmaceutical companies in the Asian region before joining Bayer. Ms. malar Subramaniam moved to Berlin after 5 years as a medical advisor in Bayer Malaysia, where she focused on Women's Health and Anti-Infectives in both Malaysia and Singapore, leading several initiatives for better patient care in endometriosis and contraception.



#### Ms. Malar Subramaniam MPharm [Clin Pharm] Global Patient Engagement Manager, Regional Medical Lead - Anti-Infectives & Senior Scientific Advisor - Women's Healthcare, Bayer Pharmaceuticals, Berlin,





Dr. Clare Nott PhD Clinical Program Director, Research and Early Development, Respiratory, Inflammation and Autoimmune (RIA), R&D BioPharmaceuticals, AstraZeneca Pharmaceuticals, UK

**Dr. Clare Nott**'s interest in clinical research stems from her time studying cardiovascular disorders for her PhD from the University of Birmingham, UK. Her early industry career focused on project management of Ph1 studies and enabling technologies. She first joined AstraZeneca as a Study Delivery Operational Specialist and progressed to Study Delivery Program Leader before joining Medimmune as an Associate Director Clinical Operations. Most recently, Dr. Clare Nott was appointed as Clinical Program Director at AstraZeneca R&D BioPharmaceuticals unit . She has overseen multiple Ph1 to Ph2b trials in Asthma, COPD, Atopic Dermatitis and Idiopathic Pulmonary Fibrosis. She is a strong believer in incorporating the patient voice into clinical trial design and supporting digital initiatives to streamline study forecasting and planning.



Mr. Mikis Euripides Policy and Public Affairs Lead, WPP Health Practice, London, UK

**Mr. Mikis Euripides** is senior director at WPP Health leading their policy, public affairs and patient advocacy work across several regions. He spent a decade in the patient group sector in the UK including Director of Policy & Public Affairs at Asthma UK and Director of Policy & Strategy at Prostate Cancer UK. During his time in the sector, he led a number of major public health campaigns including the introduction of smoke-free legislation in England in 2007. Mr. Euripides has campaigned for access to the latest treatments for patients in respiratory and oncology and established multiple cross-sector campaigning initiatives. He also commissioned the largest outcomes study globally, for men surviving prostate cancer. Mr. Mikis Euripides spent 3 years in the pharmaceutical industry working for MSD UK, leading their patient engagement strategy and the company's health literacy workstream which led to the first study to examine health literacy levels across England and to explore the likely impact on the population in everyday situations. Hecurrently supports WPP Health's Patient Partnership Programme.



Mr. Lasse Funch Jacobsen MS IBC Senior Lead of Patient Research and Alliances at LEO Pharma, Denmark

**Mr. Lasse Funch Jacobsen** brings 10 years of experience from working in pharma – the last 3 years in Patient Engagement teams across two different pharma companie He has helped establish functions that ensures that the patient's voice is not only heard, but also implemented throughout the value chain from early research to product. Mr. Lasse Funch Jacobsen has been part of numerous initiatives and coalitions across Academia, Patient Organisations and Industry working together to help improve the lives of people living with chronic diseases.



### **European Society for Person Centered Healthcare**

### February 2020

www.pchealthcare.org.uk