



ESPCH5

THE FIFTH ANNUAL CONFERENCE AND AWARDS CEREMONY
EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE

University of West London
Brentford Site (Paragon)
December 6-7 2018





ESPCH5

Conference Brochure

Table of Content

5 **ESPCH5 Welcome Address**

Profiles

- 6 New Vision for Mental Health Project
- 8 MOSAIC Home Care Services & Community Resources Centres
- 10 MAKEtoCARE Initiative
- 12 European Parkinson's Disease Association

ESPCH5 Conference Programme

- 14 First Day Sessions 6-12-2018
- 17 Second Day Sessions 7-12-2018

ESPCH5 Conference Abstracts

- 20 First Day Presentations 6-12-2018
- 26 Second Day Presentations 7-12-2018

32 **Biographies of ESPCH5 Speakers, Session ChairPersons, Panel Discussants and 2018 ESPCH Award Winners**



Fifth Annual Conference and Awards Ceremony European Society for Person Centered Healthcare

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

We are delighted to welcome you to the Fifth Annual Conference and Awards Ceremony of the European Society for Person Centered Healthcare (ESPCH5).

ESPCH5 brings together a range of distinguished speakers and chairpersons from across the globe, including the United States of America, Canada, Australia, Germany, Portugal, Romania, Bulgaria, Italy, Denmark, and, in the United Kingdom, colleagues from the University of Oxford, University of West London, University of Kent, St. Mary's University, University of Plymouth, Manchester Metropolitan University, University of Warwick, Imperial College of London and St. George's, University of London. Over the intensive two days of ESPCH5, some 30 presentations will be delivered across 9 academic sessions, spanning a wide range of areas of study 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 in addition to the session presenters and session chairpersons.

Following the conclusion of Day One of ESPCH5, the Society will hold its 2018 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, and the Young Teacher and Young Researcher prizes. The Society is honoured to recognise the indefatigable efforts of this year's medal and prize winners in their relentless work to ensure that our ever-increasing scientific knowledge base is properly contextualised – which is to say, applied within a humanistic framework of care that treats patients not as subjects, objects or complex biological machines, but rather as persons.

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 ESPCH5, 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 free access to the *European Journal for Person Centered Healthcare*, the official journal of the Society, and to the electronic newsletter, the *e-Bulletin*, of the ESPCH. Application forms will be available at the Registration Desk.

In concluding for the present, we extend our gratitude to Professor Peter John 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 Conference Suite of Paragon House, with its panoramic views of the Metropolis, and its first class catering services.

We look forward to welcoming you to ESPCH5 in London in December 2018.

Professor Sir Jonathan Elliott Asbridge
DSc (hc) DHSc (hc),
President and Chairman of Council,

Professor Andrew Miles
BMedSci MSc MPhil PhD DSc (hc),
Senior Vice President & Secretary General,

European Society for Person Centered Healthcare



ESPCH5

December 6-7 2018

University of West London, Brentford Site (Paragon)



New Vision for Mental Health

www.newvisionformentalhealth.com

THE VISION

A vision of a society that values mental and emotional health by investing a fairer share of the health budget in a coherent system that promotes wellbeing. Working towards this vision, The *New Vision for Mental Health (NVMH)* Project currently consists of:

- An evolving, proposed ecological paradigm for mental healthcare in the 21st century. Ecology is the study of inter-relationships within any given frame of reference. Within the 'frame' of mental health, an ecological paradigm is proposed because, looking further than purely biophysical or psychosocial models, it takes account of the widest set of inter-relationships, including those that relate more specifically to emotional, cultural, evolutionary, economic, environmental and existential/spiritual factors. These inter-relationships form a complex web. Hence the paradigm – along with the field of ecology in general – is partly informed by the emerging field of complexity science.
- A website – www.newvisionformentalhealth.com – containing a growing collection of, currently with a surplus of 280, items of news, information, opinion and ideas.
- Possibilities for future developments dependent on feedback and received ideas or suggestions, for example, staging of a national or inter-national conference

WHY

THE NVMH Project was created out of frustration with failings of – and tangled confusion within – the current mental health care system. A system brought by heavy dependence on pills and the profit they bring, psychiatry relying on misunderstandings and myths, and therapy building on methods which can hinder than help the patient – Richard Bentall in *“Doctoring the Mind: Why Psychiatric Treatments Fail”*. The Star*D Trial, the largest and longest study of antidepressants ever conducted, with more than 4000 patient participants, showed a below-threshold improvement of the patients during their first 12 weeks of therapy with antidepressants combined with high quality of care under usual clinical

conditions. The results of this study clearly contradicts the established effectiveness of antidepressants. The authors of the Star*D Trial conclude that the reason behind the poor performance of antidepressants shown in their study was due to the fact that the patients were selected with co-morbid conditions, which is a factor long excluded from industry studies. Hence, they propose that there should be a better understanding of how different people respond to different depression treatments.

There is a growing awareness of the many flaws in the mental healthcare system, together with the limitations of the traditional medical model on which it is largely based. There are growing questions about the current system's underlying paradigm, for example, concerning its:

- Linear, reductionist and binary-logic philosophy of science
- Over-emphasis on categorisation and labelling

Yet, whilst many of the remedies and solutions already exist, and a developing awareness of new approaches and ideas covering the whole field of mental health, knowledge, understanding and insight about them is scattered and fragmented across different individuals and organisations.

The NVMH Project, through its website aims to draw together the various partial answers, ideas and suggestions, and weave them into a coherent framework that will radically improve mental healthcare. In the process it will look to:

- Challenge and shake up some of the current ideas and perspectives.
- Facilitate discussion and engagement across this wide and complex field.
- Cultivate a new approach to the differences of perspective within the mental healthcare field – one that values diversity but also seeks to develop a common framework.

THE NVMH WEBSITE

The website is curated and edited by Mr. Richard Oldfield,

and its content is currently dividable into:

- Five themes:
 1. Emotion-Focused Care: a focus on emotional health as part of the NVMH's vision of mental health, i.e., valuing the emotional heart of service provision and minimising stigma by celebrating diversity.
 2. Focus on Collaborative Practice: supporting each person's unique therapeutic process through listening to their voices and working collaboratively to develop their emotional health and wellbeing. It provides a better balance between the psychological, emotional and pharmacological approaches, and values different ways of knowing about practice. Importantly, it also values professional support, recognising that those who are cared for are better able to care for others.
 3. A Coherent System: NVMH vision is of a simple system of service-based assessment and referral that doesn't rely on an increasingly complex system of diagnostic labelling. It is a mental and emotional health care system that both removes a great deal of the burden from GPs and also recognises the need to resource new approaches such as street triage.
 4. A balanced budget: The NHS in England spends roughly seven times more on biophysical healthcare than on mental and emotional healthcare. The primary reason for this imbalance is that biophysical health is seen as more important than the mental and emotional health, due to the fact that it is observable and more easily measurable, and partly because it's considered more important for economic growth in terms of employment and the capacity to work. However, mental health problems account for 28% of morbidity with an estimated annual cost burden of £77 billion a years (23% of the total burden of disease), meanwhile national spending on mental health services is only 13% of the total NHS expenditure. The NVMH vision is of a budget more fairly divided between biophysical and mental and emotional healthcare.
 5. A Wellbeing Society: The NVMH vision is of a society that recognises the wider factors that impact on mental and emotional health, and which therefore promotes wellbeing through its policies in education, the environment, economics and beyond, with a special focus on children and young people.
- Eight broad subject-areas in which their content evolves and changes through autonomous contributions and feedback:
 1. Clients & Patients
 2. Talking Therapies
 3. New Approaches
 4. Research
 5. Psychiatry
 6. Education
 7. Wellbeing
 8. Culture & Society

In the website's next iteration, the ecological paradigm will be more explicitly described and proposed, including how it can be divided into three concentric layers (with the person-in-connection at the centre) linked to the five themes:

- Layer 1: Practice (e.g. therapist and client):
- Theme: Emotion-Focused Care
 - Theme: Collaborative Practice

Layer 2: Community (e.g. primary mental healthcare system at local level):

- Theme: A Coherent System

Layer 3: Society (e.g. national government policies):

- Theme: A Wellbeing Society
- Theme: A Balanced Budget

These layers and themes will be elaborated in detail by Mr. Ray van der Poel in the Keynote 1 Address on the first day of the ESPCH5 Conference.

GETTING INVOLVED

New Visions for Mental Health Project welcomes contributions to the website with content along the talking points illustrated in the themes and the subject areas, and along its vision of mental healthcare.

To contribute: <http://www.newvisionformentalhealth.com/get-involved/contribute/>

NVMH PROJECT SPONSORSHIP



The Counselling & Psychotherapy Central Awarding Body (CPCAB)
www.cpcab.co.uk

CPCAB is a UK awarding body that is managed by professional counsellors, trainers and supervisors, and it is the only awarding body in Europe to specialise in the field of counselling.

From its beginnings, in 1993, CPCAB has grown to become the UK's leading specialist awarding body in counselling and life coaching. Forming part of the Counselling and Psychotherapy Services Group (CPS) it now offers vocational qualifications in over 130 training centres throughout the UK and overseas with over 11,000 candidates registering each year.

In addition to qualifications it also produced a number of assessment and training DVDs in basic counselling skills and common life and developmental problems.

In part, this success is based on CPCAB's commitment to developing competent counsellors - the only awarding body run by counsellors for counsellors. This practical experience of counselling gives CPCAB unique ability to design and support vocational qualifications in this and related fields. Dr. Anthony Crouch is the current Chief executive of CPCAB.

Credits to Mr. Richard Oldfield; www.newvisionformentalhealth.com; www.cpcab.co.uk; Richard P. Bentall "Doctoring The Mind: Why Psychiatric Treatments Fail"; Penguin UK, 2010; "Results of World's Largest Antidepressant Study Look Dismal"; Dr. Joanna Moncrief, MD, in Mad in America <https://www.madinamerica.com/2018/10/results-world-largest-antidepressant-study-look-dismal/>; "Questions and Answers about the NIMH Sequenced Treatment Alternatives to Relieve Depression (STAR*D) Study — All Medication Levels" in NIMH Practical Clinical Trials <https://www.nimh.nih.gov/funding/clinical-research/practical/star/allmedicationlevels.shtml>.



Person Centered
Community Integrated

MOSAIC

Home Care Services & Community Resource Centres
www.mosaichomecare.com

Mosaic is a private home care company operating in the Greater Toronto Area of Ontario, Canada. The company was set up in 2010 to develop holistic, person centered, community integrated home care with a special focus on the social and emotional needs of its clients and families.

Both founders, Mrs Jane Teasdale and Mrs Nathalie Anderson, had worked previously in the home care industry and expressed issues with a care model focused on the task, that largely ignored the social and emotional, and that was often divorced from important oversight of complex care issues. They also saw a need for collaboration across the for profit, not for profit and public health sectors to achieve the bigger picture of age friendly communities.

Building a more complete model of care would require greater attention to a) a range of dimensions including that of the person, the community and of social and community networks, b) the demands of oversight of complex care issues, c) the organisational, recruitment, training and management demands of a person centered organisation embedded in a wider community habitat, d) the human side of the equation from the perspective of those delivering care, and e) of the much more complex financial modelling and planning required of an holistic organisation.

When it opened its doors for business in September 2010 Mosaic also set up its first community resource centre, on the boundary between York Region and Toronto. Its second centre was established in mid-town Toronto in 2014.

Its resource centres were intended to provide information on community services, fun and educational events and a place for social engagement. Their resource centres also host Memory Cafés, Community Cafés and space for hobby-based sympathy groups. Mosaic also partners with community organisations to foster wider connection and development of social capital and to better use and transform community space.



In early 2014 Mosaic introduced an advanced non-clinical psychosocial framework for interacting and engaging more fully with persons under its care. This is its "The Meaning of Me®" framework discussed in a recent paper in the *European Journal for Person Centered Healthcare* (Volume 6, Issue 3). This model addresses the non-clinical psychosocial needs of the person and complemented person centered service interaction.



Mosaic believes that knowing the person and meaningful dialogue lie at the core of close supportive relationships, both within the clinical and personal domains. These relationships are part of more complex social networks that permeate outwards to the wider social and community networks. In a bid to develop the wider model of social and community networks Mosaic is in the midst of a long-term, multi-faceted, community mapping project that includes engendering closer collaboration community wide. Addressing issues such as loneliness requires multi-faceted frameworks that are also likely central to the success of new developments in social prescribing.

The care in the community model requires a focus on the social and emotional and the community in addition to the skill sets and processes required to deliver and oversee nursing and personal supports. This bigger picture is one of social enterprise, something which the cost constrained public health model, the often siloed not for profit and the margin focused for profit private sector models, individually in their own parts, are presently not capable of delivering.

Mosaic is well known across the Greater Toronto Area, sits on a number of local health committees, and is regularly asked to speak, on community and care related issues, at local events, large national and international conferences, hospitals, health centres and faith-based organisations. It has also received the 2017 Gold Medal Award from the European Society for Person Centered Healthcare for its person centered community integrated model of care.



Credits to Ms. Jane Teasdale & www.mosaichomecare.com



Ms. Nathalie Anderson MBA
Principal Owner, Founder & Director of Operations, Mosaic Home Care and Community Resource Centres.

Mrs. Nathalie Anderson oversees operations at Mosaic and is responsible for the processes, policies, procedures and systems. Mosaic's policies and procedures are designed to meet ISO9000 and industry accreditation standards as well as the requirements of person centeredness, an evolving responsibility as the company pushes the boundaries of organization at the person-centered level. Mrs. Anderson has primary responsibility for planning and budgeting for what is a private company with complex social enterprise characteristics. Mosaic's innovations in service extend beyond person centered care to its "Elder Care Plus™" model that addresses the logistics of linking higher level geriatric care management expertise to the oversight of persons with complex care needs. Oversight of operations at Mosaic is more complex than a typical home care operation. Ensuring operational integrity and flexibility as Mosaic evolves its model of community home care is a challenging responsibility.



Beyond observing and describing the current scenario and its evolution, MAKEtoCARE is promoting a constructive debate at institutional, cultural, scientific and economic level on the future of collaborative and innovative Patient Advocacy.

www.maketocare.it

MAKEtoCARE is a Sanofi Genzyme initiative committed to encourage and facilitate the dissemination of innovative, useful solutions for the daily needs of people affected by any form of disability.

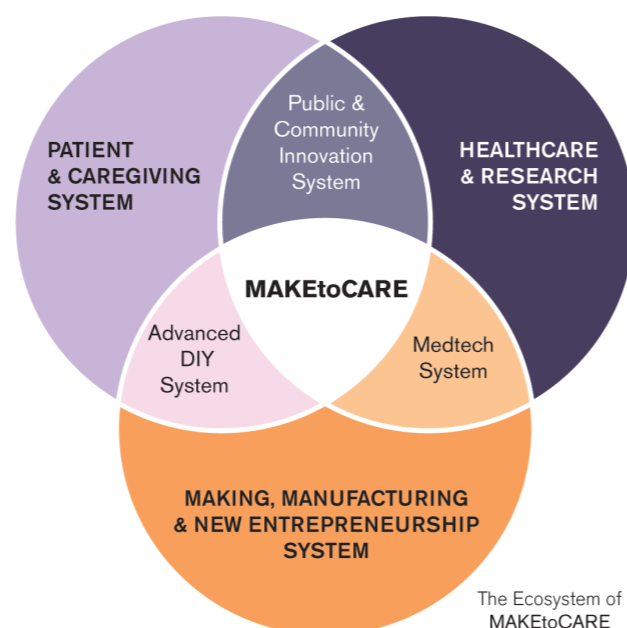
Initially launched as a contest in Italy, now at the third edition, in partnership with the European Maker Faire, MakeToCare later developed in an original research pilot on how healthcare is rapidly changing, and, above all, on the concept that patients and caregivers, together with new players such as makers and fablabs, are the driving force of such change.

The idea of developing a research, took place in 2017, when Sanofi Genzyme asked the support and expertise of Polifactory (www.polifactory.polimi.it/?lang=en) in the construction of a methodological framework to identify and consolidate the first repertoire of cases referring to the Italian context. The MAKEtoCARE research explores the emerging ecosystem made up of innovative patients, independent researchers, research institutions, startups and new entrepreneurs, makers, and laboratories for digital manufacturing that work on the development of products or services capable of ameliorating daily life.

The exploration, still in progress, articulated in three complementary directions:

1. The construction of a general scenario containing the main lines of transformation in the healthcare sector, from social changes to the emerging role of patients as active subjects in the health system, together with the diffusion of digital technologies, such as 3D printing, enabling the transformation of both products and services.

2. The definition of MAKEtoCARE as research, experimentation and innovation ecosystem characterized by the growing diffusion and integration of collaborative practices developed by patients, their relatives, as well as Patient Associations, centers of care and research institutes, with the open design culture of makers, laboratories of shared manufacturing and the world of startups.
3. The first mapping of the MAKEtoCARE Ecosystem referring to the Italian context, with the identification of a first representative dataset of 120 innovative healthcare solutions developed by 188 subjects.



The research was immediately configured as a phenomenological investigation based on explorative mapping of innovative projects, initiatives, experiences and real product-service solutions with the inclusion criteria of being developed through a collaborative dimension that combines scientific culture, design-driven technological innovation, and maker approach. The survey probed systematically the Italian scene in search of all the subjects that populate such ecosystem: the domain of patients and caregivers and their associations, that of scientific research, the field of production in the medical and biomedical area, the network of maker spaces and fab labs, the world of entrepreneurial startups.

Data have been re-elaborated through interpretive infographics maps that support the multi-level reading of the ecosystem to understand who are the subjects, how they relate and coalesce with each other, where they are geographically concentrated or distributed, in which areas of healthcare they operate and what kind of product-service solutions they develop.

From the methodological point of view, the results of this analysis have an exploratory nature with elements of qualitative knowledge but without the pretentiousness of representing any statistical-quantitative value.

On top of the corpus of 120 examples, the reading is accompanied by a repertoire of 16 case studies considered particularly relevant.

The research has also allowed to establish a productive dialogue with the authors of these solutions (belonging to various disciplines). Their individual perspectives are an integral part of the research which encompasses 14 interviews to explain their point of view.

The report was released in 2018, both in Italian and in English, and can be downloaded here: www.maketocare.it/report

The mapping of subjects and projects will be further implemented in a second edition of the report (to be published at the start of 2019). A preview of this second edition will be presented by Dr. Filippo Cipriani on the first day of the Fifth Annual Conference of the European Society for Person Centered Healthcare (ESPCH5).



POLITECNICO MILANO 1863



Credits to MAKEtoCare Dr. Filippo Cipriani



European Parkinson's Disease Association

www.epda.eu.com

WHAT IS THE EPDA

The European Parkinson's Disease Association (EPDA) is the only European Parkinson's disease umbrella organisation – as such, it is the leading voice for Parkinson's in Europe.

The EPDA's vision is to enable all people with Parkinson's and their families to live a full life, and it has been championing and working with the global Parkinson's community for more than 26 years.

EPDA provides information and resources to all Parkinson's stakeholders, raise awareness of the disease's complexities and impact, and advocate for concrete policy change that benefits the Parkinson's community.

WHAT THE EPDA DOES

Engage

THE EPDA Engages and connects with the Parkinson's community across Europe and the globe to champion collaborations and partnerships, to help in developing solutions to unmet needs, and to raise awareness of the impact of the disease with decision makers.

Inform

Through an online library – the biggest in Europe – the EPDA provides up-to-date information, research and resources for Parkinson's stakeholders to educate, advise and share good practices.

Unite

The EPDA represents national Parkinson's associations – that collectively have more than 120,000 members in nearly 30 countries across Europe – and advocate for the rights and needs of more than 1.2 million people with Parkinson's and their families.

Advocate

Provides an authoritative voice on the impact of Parkinson's across Europe and advocates for policy change that benefits the European Parkinson's community.



EPDA STRATEGIC GOALS

Goal 1

To advocate for people with Parkinson's and their families to get the right information at the right time throughout their Parkinson's journey.

Goal 2

To strive for healthcare systems where people with Parkinson's receive early and appropriate treatment and individualised care.

Goal 3

To raise awareness of the complexities of Parkinson's and the impact it has on people's quality of life.

Goal 4

To support the global Parkinson's community in the search for a cure.

SOME EPDA ACTIVITIES

Information and Education

The EPDA hosts the largest online Parkinson's library in Europe. It includes comprehensive, up-to-date information on everything from diagnosis to end of life. Every webpage has been researched, reviewed and validated by European Parkinson's experts including people with Parkinson's and their carers. It is available at www.epda.eu.com. It also produces films and other resources with its partners (particularly member organisations and the treatment industry) that educate the patient and healthcare communities, and advocate for a more patient-centred approach to Parkinson's management.

Parkinson's Life

Parkinson's Life (www.parkinsonslife.eu) is an award-winning online magazine for people affected by Parkinson's. It serves the global Parkinson's community by providing information and inspiration, and helps connect those impacted by the disease. It is funded by the EPDA yet produced by an independent editorial team of professional writers, thereby giving it credibility and authority. It helps increase awareness, inspire advocacy and challenge existing mindsets, and is truly unique within the Parkinson's space: it is a website for the Parkinson's community, driven by the Parkinson's community.

The Parkinson's Disease Composite Scale

The EPDA has developed a new Parkinson's scale (the PDCS) that measures the severity of symptoms experienced by people with Parkinson's in a timely way. It combines motor symptoms, non-motor symptoms and treatment-related complications. It is also simple and relatively fast to use (compared with existing Parkinson's-related scales). Designed to complement existing scales, the PDCS is the first to offer a holistic view of Parkinson's disease. See www.epda.eu.com/pdcs.

Advocacy

The EPDA actively engages with EU decision makers, partners and stakeholders to promote dialogue on policy gaps that negatively affect people with Parkinson's and their families, and to collectively advocate for long-lasting change. It undertakes a wide range of advocacy activities to raise disease awareness and educate politicians and policymakers at EU level of the challenges facing people with Parkinson's and their carers, and to raise the patient voice within EU policymaking.

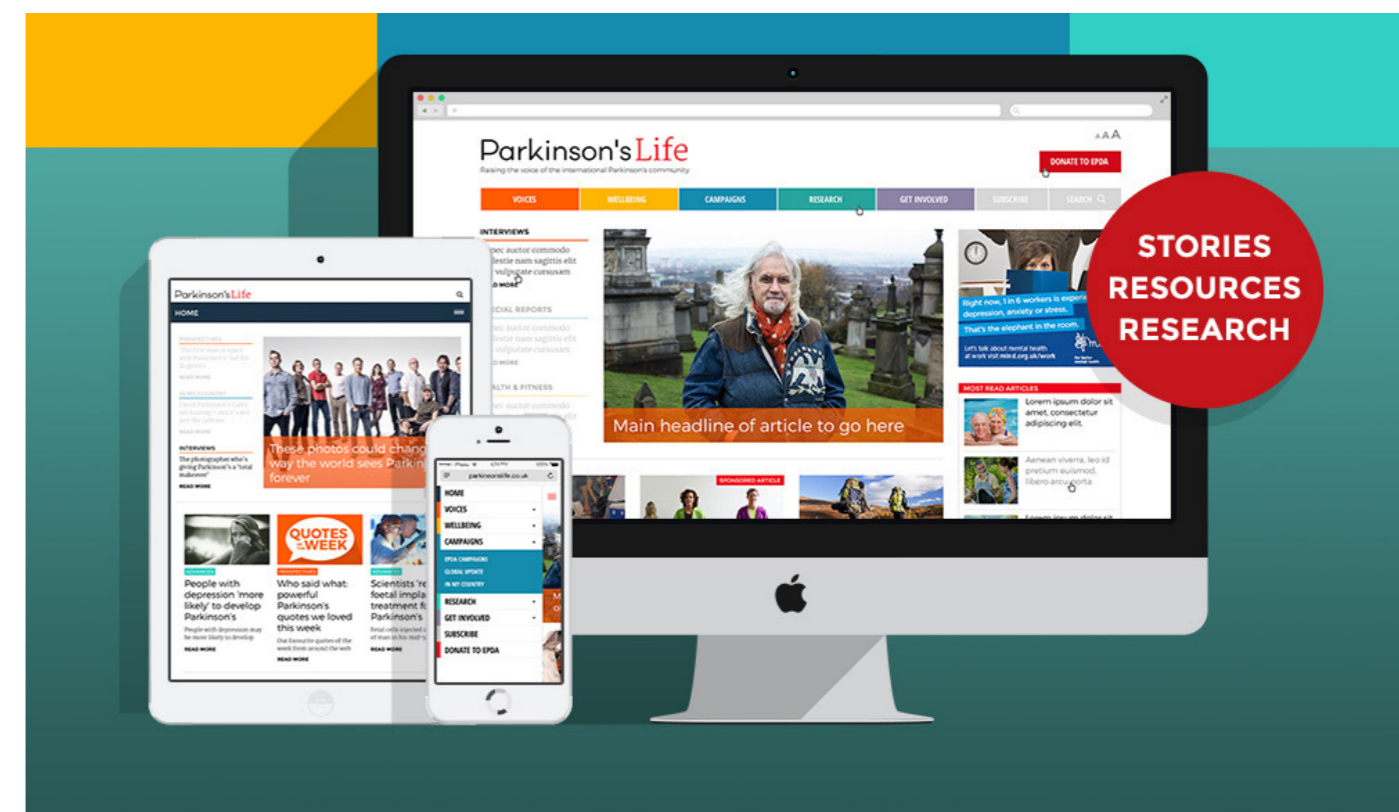
Data collection

Data collection is a vital part of the EPDA's work, with 26 years of experience in understanding people with Parkinson's and their families' unique journeys across Europe, and an extensive range of research projects since 1997. This can be found at www.epda.eu.com/datacollection.

Awareness raising

In 2017 and 2018, the EPDA and Parkinson's UK led a truly global awareness-raising Parkinson's campaign (#UniteForParkinsons). Together, the two bodies created an unprecedented global social media buzz on World Parkinson's Day (11 April), highlighting the need for everyone affected by Parkinson's to come together and speak with a powerful, united voice. In 2017, there were 9,000 hashtag uses from 89 countries and 33,000 social media engagements. In 2018, there were 17,000 hashtag uses from 97 countries, 18,000 video views and 880,000 social media engagements. Join the campaign at www.uniteforparkinsons.org.

Credits to www.epda.eu.com



First Day Sessions 6-12-2018

- 08:00 ■ *Registration and Refreshments*

- 09:00 ■ **Welcome to the University of West London**
Professor Anthony Woodman, Deputy Vice-Chancellor and Provost for Health, University of West London, United Kingdom
- 09:05 ■ **Presidential Address**
Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc), President and Chairman of Council, European Society for Person Centered Healthcare

Early Morning Session
FOCUS ON A NEW VISION FOR MENTAL HEALTHCARE, NON-CLINICAL PSYCHOSOCIAL MODELS OF CARE, AND THE PERSON-CENTERED CARE OF PATIENTS WITH DEMENTIA AND THEIR CARERS/FAMILY

- **Early Morning ChairPerson**
Professor Drozdstoj St. Stoyanov, Vice President (Eastern Europe), European Society for Person Centered Healthcare & Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Bulgaria
- 09:10 ■ **KEYNOTE 1**
New Vision for Mental Health: An Ecological Paradigm
Mr. Ray van der Poel, Head of Business & Development, Counselling and Psychotherapy Central Awarding Body, CPCAB Ltd
- 09:40 ■ **KEYNOTE 2**
Implementing and managing the non-clinical psychosocial model of person-centered community integrated care: barriers, tools and opportunities within our communities
Ms. Jane Teasdale, Principal and Director of Business Development, Mosaic Home Care Services & Community Resource Centres, Toronto, Ontario, Canada
- 10:10 ■ **The experience of being in the family of a person with early-stage dementia – a qualitative interview study**
Ms. Laila Mohrsen Busted, Senior Lecturer, Department of Nursing Education, University College Lillebaelt, Vejle, Denmark & Researcher, Health Sciences Research Center, University College Lillebaelt, Lillebaelt/Department of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark
- 10:30 ■ **Practical approaches to the provision of person-centered care for people living with dementia**
Dr. Juliette Brown, Consultant Psychiatrist, Community Mental Health Team (CMHT) for Older Adults, East London NHS Foundation Trust, London, UK
- 10:50 ■ **Panel Discussion with Delegate Participation**
With Panel Discussants Mr. Richard Oldfield, New Vision For Mental Health & Professor Victoria Tischler, Professor of Arts and Health & Head of the Dementia Care Centre, University of West London, UK

- 11:10 ■ *Morning Break and Refreshments*

Late Morning Session
FOCUS ON THE PHILOSOPHY OF PCC - REFLECTIONS ON EMPATHY, SHAME AND STIGMA, AND PATIENTS AND AGENTS

- **Late Morning ChairPerson**
Dr. Thomas Fröhlich, Vice President (Western Europe), European Society for Person Centered Healthcare, Heidelberg, Germany

- 11:40 ■ **Why every healthcare consultation needs a dose of empathy**
Dr. Jeremy Howick, Senior Research Associate, Department of Philosophy and Director of the Oxford Empathy Programme, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK
- 12:00 ■ **Shame and stigma – philosophical reflections**
Dr. Phil Hutchinson, Senior Lecturer in Applied Philosophical Psychology, Department of Health, Psychology and Social Care, Manchester Metropolitan University, England, UK
- 12:20 ■ **Patients and agents – or why we need a different narrative: a philosophical analysis**
Professor Michael Loughlin, Professor of Applied Philosophy & Co-Director, European Institute for Person Centred Health and Social Care, University of West London, UK
- 12:40 ■ **Panel Discussion with Delegate Participation**
With invited Panel Discussant Dr. Alexandra Pârvan, Department of Psychology and Communication Sciences, University of Pitești, Romania

- 13:00 ■ *Luncheon*

Early Afternoon Session
FOCUS ON MEASURING PERSON CENTERED CARE, the MAKEtoCARE INITIATIVE, SPIRITUAL AND RELIGIOUS CARE AND THE ETHICS OF HEALTHCARE CHAPLAINCY

- **Early Afternoon ChairPerson**
Professor Dr. Manuel Augusto Cardoso de Oliveira, Vice President (Southern Europe), European Society for Person Centered Healthcare; Professor Catedrático, Faculty of Sciences and Health, Fernando Pessoa University & Professor Emeritus of Surgery, University of Porto Medical School (rtd) / Former Head of the Department of Surgery, St. João Hospital, Porto, Portugal
- 13:50 ■ **Measuring and Improving the Person Centeredness and Quality of Care in Saudi Arabia**
Mr. Mohammed Aljuaid, PhD Student, Department of Primary Care and Public Health, Imperial College of London, London, UK & Lecturer, Department of Health Administration, King Saud University, Riyadh, Saudi Arabia
- 14:10 ■ **The MAKEtoCARE Initiative - developing original solutions, products and services, to ameliorate the daily experience of people facing diseases and disability**
Dr. Filippo Cipriani, Rare Disease Patient Advocacy Lead & Head of Open Innovation Projects, Sanofi Genzyme, Modena, Italy
- 14:30 ■ **Spiritual and religious care in clinical practice – an integral component of person-centered approaches**
Dr. Wendy Wigley, Head of School of Human and Social Sciences, University of West London, UK
- 14:50 ■ **Ethical questions in healthcare chaplaincy – learning to make informed decisions**
Dr. Pia Matthews, Senior Lecturer in Bioethics, Medical Law, Theology and Healthcare Ethics, St. Mary's Catholic University, Twickenham, London, UK
- 15:10 ■ **Panel Discussion with Delegate Participation**
With invited Panel Discussant Professor Emerita Colonel (Rtd) Marilyn A. Ray, Christine E. Lynn College of Nursing, Florida Atlantic University, United States of America & Honorary Distinguished Fellow, European Society for Person Centered Healthcare

- 15:30 ■ *Afternoon Break and Refreshments*

Late Afternoon Session
FOCUS ON RESILIENCE WITHIN PERSONS AND HEALTH SYSTEMS, PROFESSIONAL AND INSTITUTIONAL BURN OUT, AND THE MANAGEMENT OF AFFINITIES IN HEALTH INSTITUTIONS

Late Afternoon ChairPerson

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

- 16:00 ■ **Resilience for Health – An Emergent Property of the “Health Systems as a Whole”. Do we bounce back or move forward?**
 Dr. Joachim P. Sturmberg, Associate Professor of General Practice, School of Medicine and Public Health, Faculty of Health and Medicine University of Newcastle, Australia & Foundation President, International Society for Systems and Complexity Sciences for Health
- 16:20 ■ **Resilience, Health Perceptions, Stressors and Hospital Admissions – observations from the real world of clinical care of unstable health journeys in Monash Watch (MW), Victoria, Australia. The Health Links Chronic Care adult cohort**
 Dr. Carmel Martin, Associate Professor, Department of Medicine, Nursing and Allied Health, Monash Health, Victoria, Australia
- 16:40 ■ **Burn out across systems and persons**
 Professor Drozdstoj St. Stoyanov, Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Bulgaria & Vice Chair, Philosophy SIG, Royal College of Psychiatrists, UK
- 17:00 ■ **Management of affinities in health institutions**
 Professor Dr. Manuel Augusto Cardoso de Oliveira, Vice President (Southern Europe), European Society for Person Centered Healthcare; Professor Catedrático, Faculty of Sciences and Health, Fernando Pessoa University & Professor Emeritus of Surgery, University of Porto Medical School (rtd) / Former Head of the Department of Surgery, St. João Hospital, Porto, Portugal
- 17:20 ■ **Panel Discussion With Delegate Participation**
 With invited Panel Discussant Colonel Dr. Marcia Potter, Master Clinician, United States Air Force, United States of America
- 17:40 ■ **Closing Remarks**
 Professor Andrew Miles, Senior Vice President and Secretary General, European Society for Person Centered Healthcare
- 17:45 ■ *Close Of Day 1*
- 18:15 ■ **AWARDS CEREMONY OF THE EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE**
- 19:15 ■ **NETWORKING RECEPTION**
 (limited to event subscribers only)

Second Day Sessions 7-12-2018

08:00 ■ *Registration and Refreshments*

09:00 ■ **Welcome to Day Two**
 Professor Andrew Miles, Senior Vice President and Secretary General, European Society for Person Centered Healthcare & Editor-in-Chief, *European Journal for Person Centered Healthcare*

Early Morning Session
FOCUS ON MOTOR NEURONE DISEASE, HEALING HEALTHCARE THROUGH PERSON-CENTERED CARE, AND SHARED DECISION-MAKING – THE VALUES AGENDA

Early Morning ChairPerson

Professor Sir Jonathan Elliott Asbridge, Chief Patient Officer, Healthcare at Home UK; Deputy Chairman, Oxford Health NHS Foundation Trust & President and Chairman of Council, European Society for Person Centered Healthcare

09:10 ■ **KEYNOTE 1**
A person-centred approach to Motor Neurone Disease care encompassing quality of life, quality of care and quality of death
 Professor Samar Aoun, Professor of Palliative Care, Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria & The Perron Institute for Neurological and Translational Science, Perth, Western Australia, Australia

09:40 ■ **KEYNOTE 2**
On the application of Ray's Bureaucratic Caring Theory: 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, United States of America

Mid Morning Session
FOCUS ON SHARED DECISION-MAKING AND THE VALUES AGENDA: THE ROLE OF CULTURAL VALUES IN SHAPING MENTAL HEALTH PRACTICE

Mid Morning ChairPerson

Dr. Mathew Mercuri, Editor-in-Chief, *Journal of Evaluation in Clinical Practice*, Faculty of Medicine, McMaster University, Canada

10:10 ■ **KEYNOTE 3**
Shared decision-making: the values agenda, and the role of values-based practice in the development of person-centered care
 Professor Bill (KWM) Fulford, Emeritus Professor of Philosophy and Mental Health, University of Warwick, Founder Editor and Chair of the Advisory Board, *Philosophy, Psychiatry, & Psychology*, and Director of The Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford

10:40 ■ **The Balkan dissensus and balanced decision-making in values-based, person-centered care**
 Professor Drozdstoj St. Stoyanov, Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University Plovdiv & Vice Chair, Philosophy SIG, Royal College of Psychiatrists, UK

11:00 ■ **Panel Discussion with Delegate Participation**
 With invited Panel Discussants Dr. Abdi Sanati, Chairman, Philosophy SIG, Royal College of Psychiatrists & Professor Jack Dowie, Professor Emeritus of Health Impact Analysis, London School of Hygiene and Tropical Medicine; Honorary Professor, University of Sydney School of Public Health, Australia & Adjunct Professor, University of Southern Denmark

11:20 ■ *Morning Break and Refreshments*

Late Morning Session

FOCUS ON THE SUBJECTIVE EXPERIENCE OF PARKINSON'S DISEASE, NURSE CARING BEHAVIOURS, PATIENT AND PUBLIC INVOLVEMENT IN HEALTHCARE RESEARCH, AND PATIENT-REPORTED OUTCOMES

Late Morning ChairPerson

Dr. Wendy Wigley, Head of School of Human and Social Sciences, University of West London, UK

- 11:40 ■ **The subjective experience of Parkinson's disease: A qualitative study in 60 people with mild to moderate Parkinson's in 11 European countries**
Dr. Rowena K Merritt, Research Fellow, Centre for Health Services Studies, University of Kent, Canterbury, Kent, UK
- 12:00 ■ **Developing a new questionnaire to measure nurse caring behaviours: a mixed methods study**
Dr. Elisa Ambrosi, Assistant Professor, Department of Medical and Surgical Sciences, University of Bologna, Italy
- 12:20 ■ **A review of the nature and extent of patient and public involvement across *BMJ* journals**
Dr. Amy Price, Chief Executive Office, Empower2Go, Florida, United States of America & Senior Research Analyst, MedicineX, School of Medicine, Stanford University & The Patient Editor of Research and Evaluation at the *British Medical Journal* & Department of Continuing Education, University of Oxford, UK
- 12:40 ■ **Home-based service for enzyme replacement therapy in lysosomal storage disorders: patient reported outcomes**
Dr. Filippo Cipriani, Rare Disease Patient Advocacy Lead & Head of Open Innovation Projects, Sanofi Genzyme, Modena, Italy
- 13:00 ■ **Panel Discussion with Delegate Participation**
With invited Panel Discussant Professor Sir Jonathan Elliott Asbridge, Chief Patient Officer, Healthcare at Home UK & Deputy Chairman, Oxford Health NHS Foundation Trust, Oxford, UK

13:20 ■ *Luncheon*

Early Afternoon Session

FOCUS ON DANGERS TO PERSON-CENTERED DECISION-MAKING, PERSONALISED DECISION SUPPORT AT THE END OF LIFE, VALUES AND PREFERENCES IN PRACTICE POLICY AND DECISION-MAKING

Early Afternoon ChairPerson

Dr. Joachim P. Sturmborg, Associate Professor of General Practice, School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle, Australia & Foundation President, International Society for Systems and Complexity Sciences for Health

- 14:00 ■ **Traffic light risk classifications are a danger to person-centred decision making**
Profesor Jack Dowie, Professor Emeritus of Health Impact Analysis, London School of Hygiene and Tropical Medicine, Honorary Professor, University of Sydney School of Public Health & Adjunct Professor, University of Southern Denmark & Chairman ESPCH SIG on Health Impact Analysis
- 14:20 ■ **Incorporating uncertainty in personalised decision support: an end-of-life illustration (with live dialogue participation from Professor Jack Dowie as the 'dying patient')**
Dr. Mette Kjer Kalsoft, Odense University Hospital, Svendborg, Demark & University of Southern Denmark, Odense, Denmark
- 14:40 ■ **Defining the meaning, role and measurement of "values and preferences" in the development of practice guidelines: The case of GRADE**
Dr. Mathew Mercuri, Assistant Professor, Department of Medicine, Division of Emergency Medicine, McMaster University, Ontario, Canada & Editor-in-Chief, *Journal of Evaluation in Clinical Practice*

- 15:00 ■ **The use of goal-oriented deliberative fora for health policy and person-centred decision-making**
Dr. Phil Hutchinson, Senior Lecturer in Applied Philosophical Psychology, Department of Health, Psychology and Social Care, Manchester Metropolitan University, England, UK

- 15:20 ■ **Panel Discussion with Delegate Participation**
With invited Panel Discussant Professor Drozdstoj St. Stoyanov, Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Bulgaria

15:40 ■ *Afternoon Break and Refreshments*

Late Afternoon Session

FOCUS ON HORIZONS IN PERSON-CENTERED HEALTHCARE – MINIMIZING CLINICAL ERRORS, BIG DATA AND PRECISION MEDICINE, AND SELF-MANAGEMENT OPEN ONLINE TRIALS IN HEALTH

Late Afternoon ChairPerson

Dr. Carmel Martin, Associate Professor, Department of Medicine, Nursing and Allied Health, Monash Health, Victoria, Australia

- 16:00 ■ **Learning from significant medical events – a person-centered perspective from a systematic review of the literature**
Dr. Tristan Price, Research Fellow, Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), Faculty of Medicine and Dentistry, University of Plymouth, Plymouth, UK
- 16:20 ■ **Between data & dialogue: person-centred care in the era of genomic medicine**
Dr. Benjamin Chin-Yee, Resident Physician, Department of Medicine, Faculty of Medicine, University of Toronto, Canada
- 16:40 ■ **Self-Management Open Online Trials in Health (SMOOTH): Methods and public involvement survey of corresponding authors of existing online trials**
Dr. Amy Price, Chief Executive Office, Empower2Go, Florida, United States of America & Senior Research Analyst, MedicineX, School of Medicine, Stanford University & The Patient Editor of Research and Evaluation at the *British Medical Journal* & Department of Continuing Education, University of Oxford, UK
- 17:00 ■ **Panel Discussion with Delegate Participation**
Professor Mary Chambers, Professor of Mental Health Nursing; Director, Centre for Public Engagement & Associate Editor, *Health Expectations*, Joint Faculty of Health, Social Care and Education, St. George's University Hospital Campus, St. George's University of London, UK
- 17:20 ■ **Person-centered care – a nice idea, or a matter of design? Reflections on ESPCH5**
Dr. Joachim P Sturmborg, Foundation President, International Society for Systems and Complexity Sciences for Health, School of Medicine and Public Health, Faculty of Health and Medicine, University of Newcastle, Australia
- 17:30 ■ **President's Closing Remarks and Close of ESPCH5**
Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc), President and Chairman of Council, European Society for Person Centered Healthcare, London, UK

First Day Presentations 6-12-2018

KEYNOTE 1

09:10 New Vision for Mental Health: An Ecological Paradigm

Mr. Ray van der Poel, Head of Business & Development, Counselling and Psychotherapy Central Awarding Body, CPCAB Ltd

New Vision for Mental Health Project is the winner of the 2018 ESPCH President's Medal for Excellence in Person-Centered Healthcare

Ecology is the study of the inter-relationships within any given frame of reference. Within the "frame" of mental health, Mr. van der Poel proposes an ecological paradigm as the foundation of a new vision of mental healthcare in the 21st century, because, looking further than purely biophysical or psychosocial models, this ecological paradigm takes account of the widest set of inter-relationships, including those that relate more specifically to emotional, cultural, evolutionary, economic, environmental and existential or spiritual factors.

These inter-relationships form a complex web. Hence the model – and the field of ecology in general – is partly informed by the emerging field of *complexity science*. This contrasts with the more simplistic philosophy of science that still dominates mental healthcare.

The ecological paradigm of mental healthcare can be divided into three concentric layers with the person-in-connection at the centre:

- Layer 1: Practice (e.g. therapist and client)
- Layer 2: Community (e.g. primary mental healthcare system at local level)
- Layer 3: Society (e.g. national government policies)

These layers differentiate three broad categories of factors that contribute to mental health or ill-health, i.e. causality, with each person-in-connection containing additional contributing factors relating to their own psychological, social and developmental dimensions (their development over time). Importantly, the ecological mental healthcare paradigm shifts the focus towards understanding and working with complex causality. This is not, however, to deny the importance of symptoms, especially for the person's lived experience.

Each layer contains one or more of five major themes:

1. Layer 1: Practice (e.g. therapist and client):
 - Theme: Emotion-Focused Care
 - Theme: Collaborative Practice
2. Layer 2: Community (e.g. primary mental healthcare system at local level):
 - Theme: A Coherent System

3. Layer 3: Society (e.g. national government policies):
 - Theme: A Wellbeing Society
 - Theme: A Balanced Budget

These layers and themes are detailed during the presentation.

KEYNOTE 2

09:40 Implementing and managing the non-clinical psychosocial model of person-centered community integrated care: barriers, tools and opportunities within our communities

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

The psychosocial components of being, once considered clinically irrelevant, are recognised as having material impact on physical and mental well-being. Issues of social vulnerability, loneliness, social networks and community structure are slowly being drawn into the health care model.

How we engage at a meaningful level and how we address the wider dimensions of psychosocial health is not without problem of definition, organisation, funding, implementation and frame.

Fully addressing the psychosocial lies not just in meaningful conversation, or in the provision of interests and activities that satiate the hedonistic need. Just as important is the eudaimonic dimension, the opportunity for personal growth and meaning. Tying all these together requires rich social and community habitats that afford opportunities to generate vital social and community networks. Indeed, certain dynamics of social network theory necessitate meaningful interaction at the clinical level.

In "The Meaning of Me@": A Canadian blueprint for addressing the complex whole that is the person at the centre of the community-based homecare services model", Ms. Jane Teasdale discusses a working framework for addressing the non-clinical psychosocial for those living in place with complex care needs. Briefly, the model starts with knowing the person and meaningful conversation, then to opportunities for engaging in activities and interests, and then to a wider supporting community architecture.

In this presentation, Ms. Teasdale extends the model and addresses inter alia issues of holistic awareness, of organisation, of funding, of social prescribing and social networks, of the need to incorporate social and community objectives into the theory of the firm and of the risks of over institutionalisation of solutions. She will also address how social and community networks could be enhanced via community mapping and how

technology and cross sector collaboration could be used to address the psychosocial within the complex universe of diverse health care needs and personal preference.

10:10 The experience of being in the family of a person with early-stage dementia – a qualitative interview study

Ms. Laila Mohrsen Busted, Senior Lecturer, Department of Nursing Education, University College Lillebaelt, Vejle, Denmark & Researcher, Health Sciences Research Center, University College Lillebaelt, Lillebaelt/Department of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark

Research winning the 2018 ESPCH Prize for Qualitative Methods Research in Person-Centered Healthcare

A dementia diagnosis has a major effect on the lives of many people in addition to the patient. Persons with dementia often depend on their families to maintain their independence and well-being. When illness strikes one family member, it disrupts the entire family and has consequences for all family members. To improve caring for families with dementia, we need to better understand how family members experience being in the family of a person suffering from dementia.

Dr. Laila Mohrsen Busted presents a qualitative study exploring the experience of being in the family of a person suffering from early-stage dementia. The study was conducted with 17 family members to persons with dementia, through semi-structured interviews. The data was analysed using Braun and Clarke's model for thematic analysis. Through analysis and interpretation of the data, four themes were identified:

1. Living with a stranger in the family
2. Being trapped in a changed relation
3. Being short on time
4. Depending on each other in a new way within the family

These findings show that dementia illness has a large impact on relations within and across the family and relatives are forced to change their roles within the family.

The results of this study contribute to extending the knowledge about dementia and its impact on the family members by illustrating changes in the interactions within the family. Support from health care professionals may be beneficial in aiding family members to cope with the new situation within the family following the dementia diagnosis.

10:30 Practical approaches to the provision of person-centered care for people living with dementia

Dr. Juliette Brown, Consultant Psychiatrist, Community Mental Health Team (CMHT) for Older Adults, East London NHS Foundation Trust, London, UK

In this presentation, Dr Brown reviews the cultural and individual context of dementia, which includes associations with shame, fear and horror. She considers what person-centered care means in the context of both early and later dementia, and in relation to family, caregivers, and wider society. What does it take to hear from the person with dementia at every stage? A practical person-centered approach prioritises human responses ('being with') to technical solutions ('doing to'). It depends on the ability of caregivers to contain anxieties generated by not knowing. It promotes the continuance of attachments with individuals with dementia. Insights from clinical work with people with dementia and their carers are explored.

11:40 Why every healthcare consultation needs a dose of empathy

Dr. Jeremy Howick, Senior Research Associate, Department of Philosophy and Director of the Oxford Empathy Programme, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

In this presentation, Oxford researcher Dr. Jeremy Howick will explain how patients' health benefits when doctors take the time to express empathy. He has spent the last 10 years researching the ethics and effects of placebos and positive empathic communication, and he has conducted some of the key systematic reviews in the area which he will review. In the second part of his talk he will explain intimate relationship between empathy and person-centered care. He explains the hard science of empathy with stories from the past and present, the audience is guaranteed to be informed and entertained.

12:00 Shame and stigma – philosophical reflections

Dr. Phil Hutchinson, Senior Lecturer in Applied Philosophical Psychology, Department of Health, Psychology and Social Care, Manchester Metropolitan University, England, UK

In this presentation, Dr. Phil Hutchinson will draw upon philosophical discussion of emotion and shame, and will propose four insights that emerge from such philosophical reflection. Then, he will turn his attention to stigma and argue for two points: first, that discussion of stigma in abstraction from discussion of responses to stigma, such as shame responses, will always be partial. Unfortunately, much discussion of stigma has proceeded in precisely this way. Second, he will

propose The *Stigma Vector framework*, which serves as a framework for understanding stigma, while allowing researchers to provide the local content of stigma based on local ethnographic fieldwork. This approach also stands in contrast with much of the existing literature on stigma, which takes its task as being providing a theory or definition of stigma without drawing the distinction between the basic framework and the content, and which consequently has difficulty in capturing the cultural and subcultural specificity of stigma. Dr. Phil Hutchinson will then conclude by offering examples of how these insights and approaches might guide us in practically overcoming stigma in the healthcare setting and why this is necessarily person-centered.

12:20 Patients and agents – or why we need a different narrative: a philosophical analysis

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

The success of medicine in the treatment of patients brings with it new challenges. More people live on to suffer from functional, chronic or multifactorial diseases, and this has led to calls for more complex analyses of the determinants of health and illness.

While these factors do not require a radical paradigm shift, they do give us cause to develop a new narrative, to add to existing narratives that frame our thinking about medical care. The increased focus on lifestyle and shared decision making requires a new narrative of agency, to supplement the narrative of “the patient”. This narrative is conceptually linked to the developing philosophy of person-centered care.

The adoption of this narrative will have numerous benefits, helping practitioners work with patients to their mutual benefit, harnessing the patients’ motivation, shifting the focus from treatment to prevention and preventing unnecessary and harmful treatments that can come out of our preoccupation with the patient narrative. It will also help to shift research efforts, conceptual and empirical, from “treating” and “battling” diseases to understanding complex contributing factors and their interplay

13:50 Measuring and Improving the Person Centeredness and Quality of Care in Saudi Arabia

Mr. Mohammed Aljuaid, PhD Student, Department of Primary Care and Public Health, Imperial College of London, London, UK & Lecturer, Department of Health Administration, King Saud University, Riyadh, Saudi Arabia

Research winning the 2018 ESPCH Prize for Quantitative Methods Research in Person-Centered Healthcare

Introduction

The healthcare system in Saudi Arabia (SA) has been improving steadily over the last three decades, however, there is a need for further development in the quality of healthcare provision. Globally, there is an increasing need for person-centered care (PCC) rather than a disease-centered approach to healthcare. However, person-centeredness has received little attention within SA.

Aims

To explore the extent to which the provision of healthcare aligns with PCC in Saudi hospitals.

Methods

Quantitative survey research employing a comparative design included eight tertiary hospitals, four teaching hospitals funded by the Ministry of Education and four non-teaching hospitals funded by the Ministry of Health. A validated person-centered climate questionnaire (PCQ) was distributed to three distinct groups: patients, family members and hospital staff, results were analysed quantitatively.

Results

Completed questionnaire responses from 705 patients, 698 family members and 778 healthcare professionals were collated (response rate > 77%). Statistically significant differences identified in PCQ mean scores between respondents’ views in teaching and non-teaching hospitals, in relation to subscales safety, everydayness and hospitality/community. Participants in teaching hospitals reported a higher level of PCC compared to those in non-teaching hospitals. This study indicates that patients had a significantly higher (p <0.05) level of PCC (mean= 46.1, sd= 8.5) followed by family members and healthcare professionals, respectively. Overall findings indicated that healthcare environments lacked positive physical attributes and were not recognised as ‘homely’ environments.

Conclusion

A comprehensive, continuous quality assessment and improvement system in Saudi hospitals is essential to achieve high level of quality of healthcare. Physical environments e.g. layout, artwork, paintings and decoration need improvement to make healthcare settings more aligned to PCC.

14:10 The MAKEtoCARE Initiative - developing original solutions, products and services, to ameliorate the daily experience of people facing diseases and disability

Dr. Filippo Cipriani, Rare Disease Patient Advocacy Lead & Head of Open Innovation Projects, Sanofi Genzyme, Modena, Italy

MAKEtoCARE Initiative is the winner of the 2018 ESPCH Gold Medal for Excellence in Person-Centered Healthcare

MakeToCare is a Sanofi Genzyme initiative committed to encourage and facilitate the dissemination of innovative, useful solutions for the daily needs of people affected by any form of disability. Initially launched as a contest in Italy, now at the third edition, in partnership with the European Maker Faire, MakeToCare later developed in an original research pilot on how healthcare is rapidly changing and, above all, on the concept that patients and caregivers, together with new players such as makers and fablabs, are the driving force of such change.

The idea of developing a research took place in 2017 when Sanofi Genzyme asked the support and expertise of Polifactory and Fondazione Politecnico in the construction of a methodological framework to identify and consolidate the first repertoire of cases referring to the Italian context. The MakeToCare research explores the emerging ecosystem made up of innovative patients, independent researchers, research institutions, startups and new entrepreneurs, makers, and laboratories for digital manufacturing that work on the development of products or services capable of ameliorating daily life. The first mapping of the MakeToCare Ecosystem refers to the Italian context, with the identification of a first representative dataset of **120 innovative healthcare solutions** (products or services) developed by **188 subjects**. A second dataset and novel analyses - currently ongoing - will be presented.

Beyond observing and describing the current scenario and its evolution, MakeToCare is promoting a constructive debate at institutional, cultural, scientific and economic level on the future of collaborative and innovative Patient Advocacy.

14:30 Spiritual and religious care in clinical practice – an integral component of person-centered approaches

Dr. Wendy Wigley, Head of School of Human and Social Sciences, University of West London, UK

Spirituality is a phenomenon integral to health and wellbeing and a fundamental element of nursing care. Within the UK context of health care provision and service, meeting the varied spiritual needs of patients, visitors and indeed staff, is fundamental to the care the National Health Service (NHS) provides. Yet, in contemporary clinical nursing practice spirituality has become somehow ‘off-limits’, despite the recognition regarding the importance of spirituality by nursing theorists. Consequently, a conjectural void continues between the expectations of policy regarding the meeting of spiritual needs and those who receive, provide and teach spiritual nursing care.

The phenomenon that is spirituality, whether or not it exists, and what the constituents of spirituality are or how this phenomenon presents, either as religion or faith (or indeed neither); continually concerns those who provide ‘person-centered care’ particularly the nursing

profession. In this presentation, Dr. Wendy Wigley examines spirituality and spiritual being, through a variety of ‘lens’, and will go on to propose three main Basic Social Processes [BSPs]: *struggling, safeguarding and seeking* as concepts of the theory of ‘carrying hope’, along with a model of pastoral care to explain and create awareness of spirituality in those who are the providing and receiving of person-centered care.

14:50 Ethical questions in healthcare chaplaincy – learning to make informed decisions

Dr. Pia Matthews, Senior Lecturer in Bioethics, Medical Law, Theology and Healthcare Ethics, St. Mary’s Catholic University, Twickenham, London, UK

Winner of the 2018 ESPCH Book Prize for Person-Centered Healthcare Literature: *Matthews P. Ethical Questions in Healthcare Chaplaincy: Learning to Make Informed Decisions*. Philadelphia, PA: Jessica Kingsley Publishers; 2018

Healthcare practitioners are asked not only to be attentive to patients in their sickness by diagnosis and treatment, but also to be aware of the patient’s emotional and spiritual well-being. Once primarily the chaplain’s concern, spirituality and the personal dimension of the patient are now the concern of every practitioner. This person-centered care is often explained as enabling patients to participate in their own treatment in co-operation with practitioners: doing things with people rather than doing things to them. In planning care, practitioners are to see the patient as having particular needs, desires, values, and social situation. However, it is all too easy for person-centered care to become essentially a matter of enabling choice by providing information and gaining consent. Informing and ‘consenting’ the patient become the principle markers of patient-centred care. This of course falls down with patients who lack capacity. Healthcare chaplaincy can offer richer insights into person-centered care. The tasks of the healthcare chaplain can be summed up as see, judge, act: seeing involves grasping the situation in its complexity and establishing a genuine relationship with patients and their families; judging judges not the person but the situation and takes a positive attitude of basic acceptance regardless of what the patient does or says; acting always is from empathy, understanding the patient’s experience from the patient’s own frame of reference. Spiritual care is completely person-centered and it makes no assumptions about the person’s own personal convictions or life style. Rather than delivering person-centered care as something the healthcare professional does, the healthcare chaplain is person-centered. In person-centered care patients are valued and accepted as they are, as unique and individual human beings: their dignity is acknowledged first. Then the practitioner attempts to see things from the patient’s perspective.

16:00 Resilience for Health – An Emergent Property of the “Health Systems as a Whole”. Do we bounce back or move forward?

Dr. Joachim P. Sturmborg, Associate Professor of General Practice, School of Medicine and Public Health, Faculty of Health and Medicine University of Newcastle, Australia & Foundation President, International Society for Systems and Complexity Sciences for Health

Resilience has become a popular term, and its meaning varies widely depending on the context of its use. Its Latin origin, *resilire*, means “bouncing back”—should bouncing back be understood literally or rather metaphorically in the context of health, illness, disease, and disease? In this presentation, Dr. Sturmborg examines ecological, physiological, personal, and health system perspectives inherent in the concept of resilience. It emerges that regardless of the level of aggregation, resilience is a systems property—it is as much a property of each of the subsystems of network physiology, the person, and the health care delivery system as it is a property of the health system as a whole. Given the interdependencies between people, their internal and external environments, and the health service system, strengthening resilience, ie, the ability to positively adapt to challenges and changing circumstances, will require a broad-based public discourse: “How can we strengthen resilience and health for the benefit of people and society at large

16:20 Resilience, Health Perceptions, Stressors and Hospital Admissions – observations from the real world of clinical care of unstable health journeys in Monash Watch (MW), Victoria, Australia. The Health Links Chronic Care adult cohort

Dr. Carmel Martin, Associate Professor, Department of Medicine, Nursing and Allied Health, Monash Health, Victoria, Australia

Rationale, Aims and Objectives

Monash Watch (MW) aims to reduce avoidable hospitalisations in a cohort above a risk ‘threshold’ identified by Health Links Chronic Care (HLCC) algorithms using personal, diagnostic, and service data. MW conducted regular patient monitoring through outbound phone calls using Patient Journey Record System (PaJR). PaJR alerts are intended to act as a self-reported barometer of stressors, resilience and health status with more alerts per call indicating greater risk

Aims

To describe predictors of PaJR alerts (self-reported from outbound phone calls) and predictors of acute admissions based upon Theoretical Model for Static and Dynamic Indicators of Acute Admissions’.

Methods

Participants: HLCC cohort with predicted 3+ admissions/year in MW service arm for >40 days; n=244.

Baseline measures: Clinical Frailty Index(CFI); Connor Davis Resilience(CD-RISC): SF-12v2 Health Survey scores Mental (MSC) and Physical (PSC) and ICECAP-O. Dynamic measures: PaJR alerts/call in 10,869 MW records. Acute (non-surgical) admissions from Victorian Admitted Episode database.

Analysis: Logistic regression, correlations and timeseries homogeneity metrics using XLSTAT.

Findings

Baseline indicators were significantly correlated except SF-12_MCS. SF12-MSC, SF12-PSC and ICECAP-O best predicted PaJR alerts/call (ROC = 0.836). CFI best predicted acute admissions (ROC = 0.664), adding CD-RISC, SF-12_MCS, SF-12_PCS and ICECAP-O with 2-way interactions improved model (ROC = 0.702). PaJR alerts were higher ≤10 days preceding acute admissions and significantly correlated with admissions. Patterns in PaJR alerts in 4 case studies demonstrated dynamic variations signifying risk. Overall, all baseline indicators were explanatory supporting the theoretical model. Timing of PaJR alerts and acute admissions reflecting changing stressors, resilience and health status were not predicted from baseline indicators, but provided a trigger for service interventions.

Conclusion

Both static and dynamic indicators representing stressors, resilience and health status have the potential to inform threshold models of admission risk in ways that could be clinically useful.

16:40 Burn out across systems and persons: comparative studies on vulnerability and resilience

Professor Drozdostoj St. Stoyanov, Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Bulgaria & Vice Chair, Philosophy SIG, Royal College of Psychiatrists, UK

Burn Out is caused by dynamic global processes, changes in psychosocial context, and the vulnerability of the personality. Burn out has been, and continues to be a problem of modern society, in terms of psychological withdrawal, emotional exhaustion and reduced job performance. Burn out experience is experienced from – and is being enhanced by – organizational imbalances because of their contextual and complementary interactions in the “person-milieu” system. Formulated as a “loss of meaning” in its earlier descriptions and observed initially in the field of supporting professions, burn out is still reported on organizational and personal levels in various professional settings.

In this presentation, Professor Drozdostoj St. Stoyanov

will analyze and compare the degree of burnout among professional groups of health care providers and teachers through the results of a comparative study.

Further, there are delivered results from a pilot study of the relationship between individual components of emotional intelligence (Questionnaire of Shutte, Malouff, Hall, Haggerty, Cooper, Golden & Dornheim’s, adapted by Professor Stanislava Stoyanova for Bulgarian conditions), preferred coping strategies in the paradigm of Lazarus and burn out. Significant inverse correlations were determined between *Sharing emotions and empathy*, *Motivation for overcoming of difficulties and optimism*, *Total Score of the Emotional Intelligence*, and two of the dimensions of burn out *Emotional exhaustion* and *Dehumanization*. A significant positive relationship has been established between *Personal accomplishment* and three of the components of emotional intelligence, as well as positive correlation between *Personal accomplishment* and two of the constructive coping strategies – *Planful problem solving and Positive reappraisal*.

As a follow-up to the stress-diathesis approach and contribution to positive health resilience, these results support efforts in modeling potential resources to cope and the understanding of burn out as a systemic phenomenon.

17:00 Management of affinities in health institutions

Professor Dr. Manuel Augusto Cardoso de Oliveira, Vice President (Southern Europe), European Society for Person Centered Healthcare; Professor Catedrático, Faculty of Sciences and Health, Fernando Pessoa University & Professor Emeritus of Surgery, University of Porto Medical School (rt) / Former Head of the Department of Surgery, St. João Hospital, Porto, Portugal

Professor Cardoso de Oliveira’s insights in this presentation rests on decades of experience and sound relationships with persons in order to talk about the importance of them.

Chaos in healthcare systems is caused by different factors. Some of these factors are positive, such as, the dramatic progress in medical science, the explosion of medical knowledge and the exponential increase in diagnosis and treatment options. However, and we acknowledge that, some factors do exist in our healthcare systems that are negative and dysfunctional, such as fragmentation, polarization, destructive internal competition, erosion of public trust, excessive turnover, overuse of new technology, outdated mindsets, fear, and “too much management and not enough leadership”.

Therefore, we need to apply some actions in our healthcare systems relating to relational co-ordination, such as, identification of needy areas, identification of barriers, construction of new world system, improvement of organizational performance, enforcing incentives for change, and enhancing leadership culture.

In some cases, and due to traditional reasons, medical doctors were the last group to recognize the importance of a stronger interdisciplinary co-ordination due to teaching classic curricula in medical schools that lack very important concepts of relational co-ordination.

In what concerns relationships and communication, we need to have shared goals and not functional goals, shared knowledge and not specialized knowledge, and mutual respect and not lack of respect.

Systems of work with high performance comprehend teamwork, measure and reward team performance, proactively resolute conflicts, invest in leadership, design jobs for focus, create flexible job boundaries, create boundary spanners, facilitate connections through pathways, develop shared information systems, and partnership with suppliers. These factors contribute to better relational co-ordination resulting in better quality, better performance and more job satisfaction.

The affinities and performance in health institutions are disturbed by big reputations and big egos. In an organization, persons are the most important issue, hence the importance of social sciences to inspire a person-centered medicine.

Second Day Presentations 7-12-2018

KEYNOTE 1

09:10 A person-centred approach to Motor Neurone Disease care encompassing quality of life, quality of care and quality of death

Professor Samar Aoun, Professor of Palliative Care, Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria & The Perron Institute for Neurological and Translational Science, Perth, Western Australia, Australia

Winner of the 2018 ESPCH Vice President's Medal for Excellence in Person-Centered Healthcare

With no known cure and no effective treatment yet for Motor Neurone Disease (MND), this presentation brings the focus on quality of life, quality of care and quality of death, the three outcomes of a palliative approach to caring for people with MND (PwMND) and their family carers. A palliative approach emphasises patient - and family centered care that focuses on the person and not just the disease, the importance of therapeutic relationships between care providers and the patient and family, and clear communication throughout the illness trajectory, in particular about goals of care and advance care plans. A palliative approach needs to be integrated into the care plan for PwMND from the time of diagnosis, aiming to optimise their quality of life by relieving symptoms, providing emotional, psychological, and spiritual support pre-bereavement, minimising barriers to a good death, and supporting the family post-bereavement. However, these outcomes cannot be achieved without the following cornerstones of a palliative approach to MND care: the vital support of family carers, the involvement of MND Associations, the education and training of general health and community care practitioners, and the connection between the informal caring networks with the formal networks, as exemplified by Compassionate Communities policies and practices. Professor Samar Aoun in this presentation will cover a number of evidence-based initiatives from diagnosis to bereavement, that need to be implemented in standard practice to improve the person-centeredness of health and social care for PwMND and their family carers. The drive to find a cure should not take away from the fact that PwMND and their families still need to be supported physically and psychologically until then, through the continuum of care from diagnosis to bereavement.

KEYNOTE 2

09:40 On the application of Ray's Bureaucratic Caring Theory: 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, United States of America

Winner of the 2018 ESPCH Platinum Medal for Excellence in Person-Centered Healthcare

Focusing on the multiple domains of caring as explicated in Bureaucratic Caring Theory, Col (Dr.) Marcia Potter will lead the attendees 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.

KEYNOTE 3

10:10 Shared decision-making: the values agenda, and the role of values-based practice in the development of person-centered care

Professor Bill (KWM) Fulford, Emeritus Professor of Philosophy and Mental Health, University of Warwick, Founder Editor and Chair of the Advisory Board, *Philosophy, Psychiatry, & Psychology*, and Director of The Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford

Shared decision-making between clinician and patient is central to person-centered clinical care. This presentation will indicate the importance of values in shared decision-making and outline some of the work being developed to support clinicians and patients in bringing values more effectively into shared decision-making in the context of everyday clinical care.

The presentation will be in four short sections. Section 1, Values in Clinical Decision-Making, will use a brief interactive exercise to illustrate the importance of values (in the broad sense of 'what matters or is important to those concerned') alongside evidence in clinical decision-making. Section 2, Values-based Practice, will outline the main process elements of values-based practice and how these complement the processes of evidence-based practice in clinical decision-making. Section 3, the Montgomery Ruling, will describe the model of shared decision-making based on values and evidence required by the 2015 UK Supreme Court 'Montgomery' ruling as the basis of consent to treatment. Section 4, Implementation, will describe work currently underway between the Academy of Medical Royal Colleges, the NICE (National Institute for Health and Care Excellence) Shared Decision-making Collaborative, and the Collaborating Centre for Values-based Practice in Oxford, in support of implementation of the Montgomery model of shared decision-making. The presentation will conclude with a note on what the philosopher Isaiah Berlin called the 'challenge of pluralism' for work in this area.

10:40 The Balkan *dissensus* and balanced decision-making in values-based, person-centered care

Professor Drozdtoj St. Stoyanov, Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University Plovdiv & Vice Chair, Philosophy SIG, Royal College of Psychiatrists, UK

This presentation will focus on the potential for new philosophy of mental health arising from the uniquely pluralistic values of Bulgaria and other Balkan states reflecting their long periods of colonisation. Balkan people survived these periods by retaining their own values while at the same time evincing where necessary the values of their colonisers. Living at the edge of compromise in this way has left a legacy of values pluralism. Pluralism like monism carries its own challenges. But in a Balkan context we argue it is the basis for distinctively new contributions to that part of philosophy of mental health called values-based practice. An important strength but also a limitation of values-based practice is its basis in a particular kind of shared decision making called 'dissensus'. But dissensus depends critically on values pluralism whereas our default position in practice, as evidenced by experience at least in the UK, is monism.

Professor Stoyanov will illustrate the potential of Balkan cultural pluralism for two key challenges in contemporary mental health:

1. Preventing negative abuses of psychiatry
2. Promoting positive practice

Whether Balkan cultural pluralism will deliver on its potential in these and other areas remains to be tested. But developed like values-based practice itself, within the framework of mid-twentieth century ordinary language philosophy, it could add a key additional resource to the growing tool kit of methods for working with complex and conflicting values in health care.

11:40 The subjective experience of Parkinson's disease: A qualitative study in 60 people with mild to moderate Parkinson's in 11 European countries

Dr. Rowena K. Merritt, Research Fellow, Centre for Health Services Studies, University of Kent, Canterbury, Kent, UK

Team Winners of the 2018 ESPCH Silver Medal for Excellence in Person-Centered Healthcare

Dr. Rowena Merritt will present the findings of a qualitative study with people with Parkinson's (PwP) in 11 European countries. 60 PwP were interviewed. The presentation will focus on the key findings and the recommendations: PwP often delayed help-seeking due to lack of awareness of symptoms, and there was sometimes a delay in specialist referral. The diagnosis typically came

as a "shock", making PwP unable to absorb all the information, but having a diagnosis for the symptoms was sometimes described as a "relief". Prompt referral to a specialist, a clear and sensitively communicated diagnosis with reassurance about life expectancy, and a follow-up appointment with a PD nurse or other health care professionals a short interval after diagnosis were all positively viewed. Many reported worries and negative experiences with medications and wished for more time and information before initiating these. Reactions from family, friends, and work colleagues when communicating the diagnosis were typically positive. During ongoing care, longer appointments with specialists and provision of information from health care professionals, patient organisations, and self-help groups were considered important to many PwPs and helped them feel as if they could "take control" and manage their disease more effectively. Taking into account these findings has the potential to improve the experiences of PwP through improved communication, tailoring of appointments and information provision including self-help approaches.

12:00 Developing a new questionnaire to measure nurse caring behaviours: a mixed methods study

Dr. Elisa Ambrosi, Assistant Professor, Department of Medical and Surgical Sciences, University of Bologna, Italy

Research winning the 2018 ESPCH Prize for Mixed Methods Research in Person-Centered Healthcare

Background

Measuring nurse caring may provide empirical evidence to assist clinicians and administrators in making decisions. The most widely used measuring tools, as originally drafted or in all their different translations and adaptations, were developed in Anglo-Saxon countries. Even if they have been translated and validated in many languages, this could limit their applicability in other countries such as Italy.

Aim

The aim of the present study was to develop a new scale, called the CARE-Italy, grounded in the Italian culture, for measuring nurses' caring behaviours.

Methods

A mixed method approach was applied in developing the instrument. The item generation and scale development were performed through a qualitative phenomenological approach based on nurses' interviews and a focus group with a panel of experts. Then, the provisional instrument was administered to a convenience sample of 439 nurses and then questionnaire scaling and association analysis were performed. A dual scaling analysis of successive categories was performed to identify preferences on the rating scale. An item selection based on item-scale correlations and item weights was performed. Subjects' mean scores were computed and standardized in a 100-point scale.

Results

The 20 caring behaviours perceived by nurses to be the most important ones constitute the final version of the CARE-Italy questionnaire. They concern patients' surveillance, professional relationships with patients, satisfying patients' and family members' practical and psychological needs, team consultation and nurses' emotions.

Relational and paternalistic caring approaches according to Italian nurses seem to be suggested. The next step of the research project will be the validation process of the CARE-Italy questionnaire with a Likert scale measuring the occurrence of the 20 caring behaviours in daily practice.

12:20 A review of the nature and extent of patient and public involvement across BMJ journals

Dr. Amy Price, Chief Executive Office, Empower2Go, Florida, United States of America & Senior Research Analyst, MedicineX, School of Medicine, Stanford University & The Patient Editor of Research and Evaluation at the *British Medical Journal* & Department of Continuing Education, University of Oxford, UK

At the *British Medical Journal (BMJ)*, meaningful patient and public involvement is a core value that transcends vision to represent the work we do every day as a journal and this work defines who we are. Our journals are involving patients and members of the public as manuscript reviewers, co-authors, conference keynotes and editors. We have found patients with health conditions and their caregivers can become experts in their own right, reading research, visiting specialists, hearing differing opinions from peers and professionals, learning to cope with chronic or acute conditions, and building real life expertise on what it means to experience a cancer, a heart condition, diabetes, mental illness, or surgery. We ask our authors if and how they included patients in research papers and our clinical education sections feature patient and clinician teams. This talk will consider benefits, barriers and surprises on the way to involvement and we will share how some of journals have incorporated patient and public involvement in ways that work for them. The talk will be interactive with time for discussion. We invite you to come with questions and we look forward to learning together.

12:40 Home-based service for enzyme replacement therapy in lysosomal storage disorders: patient reported outcomes

Dr. Filippo Cipriani, Rare Disease Patient Advocacy Lead & Head of Open Innovation Projects, Sanofi Genzyme, Modena, Italy

Lysosomal storage diseases (LSDs) are a heterogeneous group of rare genetic disorders characterized by the progressive accumulation of various substrates within

the lysosomes. For affected patients, hospital-based enzyme replacement therapy (ERT), whenever available, represent the standard-of-care. Since LSDs are chronic conditions, treatment with ERT is life-long, with disease progression observed in cases of poor adherence or when infusions are regularly missed. The frequency of infusions, as well as the time to perform each infusion, might place a considerable burden on the life and personal finances of patients and caregivers. Fortunately, such therapies, without compromising on efficacy, can be safely offered in a domestic setting, if under the supervision of skilled personnel.

Via a telephone administered questionnaire study we investigated the level of patient satisfaction regarding the Italian TuTor program, a professional nursing service providing home-based ERT to patients with Gaucher's disease, Fabry disease or Mucopolysaccharidosis type 1. We shed light on patients' disease perception, presenting data from patient satisfaction questionnaires of the first 100 patients enrolled in the TuTor program covering the first 18 months of their experience of the home-based nursing service.

The home-based TuTor service is found to significantly improve patients' perception of quality of life, as well as provide a reduction in time and out-of-pocket costs associated with hospital-based ERT. Albeit beyond the scope of this research, also the NHS is taking advantage of treating patients at home; hospitals can free their capacity, cut their waiting list and improve their overall productivity.

Within the home-based TuTor programme, the majority of patients believed the service could benefit other ERT-eligible patients, on top of the time saving, due to the more personalized relationship established with a dedicated nurse, in their well known home setting.

14:00 Traffic light risk classifications are a danger to person-centred decision making

Profesor Jack Dowie, Professor Emeritus of Health Impact Analysis, London School of Hygiene and Tropical Medicine, Honorary Professor, University of Sydney School of Public Health & Adjunct Professor, University of Southern Denmark & Chairman ESPCH SIG on Health Impact Analysis

Guidelines for prevention and treatment often place persons in risk classes (e.g. low, moderate, high) on the basis of thresholds placed on a continuous metric for a single criterion (e.g. risk of developing a cancer). These 'traffic light' signals can lead to inferior decisions through their single criterion focus and lack of preference-sensitivity to the multiple criteria relevant to the person. It is arguably unethical to communicate to someone that they are at low, moderate, or high risk of cancer solely on the basis of the unpublished and often unknown preferences of the group that has set the classification thresholds. Any prior classification and labelling will

interfere with the individual's balanced processing of information on the performance of all treatment options on their multiple relevant criteria - including treatment side effects and burdens as well as main benefit. It will also jeopardise meeting the requirements for fully informed and preference-based consent to any subsequent action. Personalised decision support tools based on Multi-Criteria Decision Analysis can help fulfil these objectives, with apomediative (at home) e-decision support especially appealing because of its empowering and resource-saving potential. The individual's absolute risk score is required in these tools since any threshold-based risk classification will interfere with the coherence of the analysis across the multiple criteria

14:20 Incorporating uncertainty in personalised decision support: an end-oflife illustration (with live dialogue participation from Professor Jack Dowie as the 'dying patient')

Dr. Mette Kjer Kaltoft, Odense University Hospital, Svendborg, Demark & University of Southern Denmark, Odense, Denmark

A personalised decision support tool based on Multi-Criteria Decision Analysis is applied to an end-of-life decision involving the trading-off of average life expectation and the uncertainty surrounding it. Will Tremain must choose between Palliative Care offering less uncertainty but also a lower mean life expectancy than a surgical option. This presentation is in the form of a conversation

14:40 Defining the meaning, role and measurement of "values and preferences" in the development of practice guidelines: The case of GRADE

Dr. Mathew Mercuri, Assistant Professor, Department of Medicine, Division of Emergency Medicine, McMaster University, Ontario, Canada & Editor-in-Chief, *Journal of Evaluation in Clinical Practice*

Evidence Based Medicine (EBM) considers "values and preferences" to be a key component in determining how a patient's care will be managed, along with considerations of the research evidence about the effectiveness of potential treatments, resource implications, and context. However, how one defines, measures, and uses information regarding values and preferences to determine the best treatment option for a patient, when practicing EBM, is not clear - this may limit the extent to which practicing EBM can achieve "person-centered" care.

The GRADE framework was developed as an EBM means to produce clinical recommendations. The GRADE framework includes "values and preferences" as one of the components that determines treatment recommendation and how those recommendations

should be interpreted by stakeholders in practice. Thus, GRADE has the potential to close the gap in how to incorporate values and preferences into clinical practice, something that seems to have so far eluded EBM.

How the "values and preferences" component is conceptualized in the GRADE framework, and what impact that might have on individual patients receiving care consistent with GRADE derived recommendations has received little critical examination.

In this presentation, Dr. Mathew Mercuri will describe the role of values and preferences in the GRADE framework. The focus will be on three issues:

1. How values and preferences is defined in GRADE
2. How values and preferences is operationalized (e.g., whose values and preferences? How they should be measured) and integrated with other important components (e.g. clinical research) when making a recommendation
3. Whether recommendations developed using the GRADE framework are always appropriate for individual patients with respect to considering their own values and preferences (e.g. those recommendations lead to care that is consistent with individual patient values and preferences).

15:00 The use of goal-oriented deliberative fora for health policy and person-centred decision-making

Dr. Phil Hutchinson, Senior Lecturer in Applied Philosophical Psychology, Department of Health, Psychology and Social Care, Manchester Metropolitan University, England, UK

In this presentation, Dr. Phil Hutchinson will propose the idea of goal-oriented deliberative fora for health policy and person-centred decision-making.

Arriving at a healthcare policy decision involves the weighing of competing interests, value judgements and preferences, while also establishing the relevant facts. The decision should be one which is accepted as legitimate by all parties and provides optimal health outcomes. Dr. Hutchinson proposes that deliberative fora provide the best opportunity to achieve legitimacy and the optimality of the outcomes.

The deliberative forum has the following structure: professional, expert, and stake-holder 'witnesses' testify to a representative group of decision-makers. A set of questions are then provided to give structure to the decision-makers' deliberation: deliberation takes the form of a dialogue in which participants weigh up the data, evidence, testimony and moral considerations presented by the 'witnesses', in light of their own interests, values and preferences. The idea is that by the end of the forum the participants will have a better, more rational and less assumption-based understanding of and view on the topic under discussion in the forum,

because they will be able to offer reasons in support of that understanding. A forum for structured deliberation, therefore, provides us with a number of benefits: it allows us to mitigate against the distorting impact on our views of the *affect heuristic*, and it encourages the adoption of rationally-supported understanding and judgement in place of opinions, preferences and assumptions, which are more susceptible to bias and prejudice. Furthermore, the process of deliberation promotes deeper grasp of the views of one's interlocutors, and thereby increases the prospects of achieving outcomes acknowledged as legitimate.

16:00 Learning from significant medical events – a person-centered perspective from a systematic review of the literature

Dr. Tristan Price, Research Fellow, Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), Faculty of Medicine and Dentistry, University of Plymouth, Plymouth, UK

Winner of the 2018 ESPCH Bronze Medal for Excellence in Person-Centered Healthcare

Rationale, Aims and Objectives

Learning from significant medical events is a core component of quality and safety practice in healthcare worldwide. From a person-centered perspective it is imperative that significant event analysis is beneficial to both the medical staff who engage in the process, and the patients who are on the receiving end of medical care. If significant event analysis is to have such a positive impact, then it must work to improve the performance of doctors. However, the evidence that the analysis of significant events has a positive impact on doctor performance is relatively sparse. This presentation reports a systematic review into the impact of undertaking significant event analysis on medical performance.

Method

A systematic review using the following databases: PubMed, EMBASE, Medline, PsycINFO and the Cochrane Collaboration Library. Impact was defined according to a modified adaptation of the Kirkpatrick evaluation model. Selection and quality appraisal of studies was conducted by two reviewers, independently and blinded.

Results

Significant event analysis is reported to identify gaps in knowledge, improve teamwork and communication, and encourage reflection leading to improvements in practice. Time, resources and team dynamics were identified as factors that impacted on the effectiveness of significant event analysis. Significant event analysis may benefit from suspending existing hierarchies during the process itself, and external facilitation.

Conclusion

There is a lack of high quality evidence within the existing

literature to ascertain the effectiveness of significant event analysis in the medical context. Existing studies are largely based on self-reported measures, which may reinforce the importance of the discursive process for practitioners. Future research could be directed at identifying the pedagogical processes that lead to changes in performance as a result of engaging in significant event analysis.

16:20 Between data & dialogue: person-centred care in the era of genomic medicine

Dr. Benjamin Chin-Yee, Resident Physician, Department of Medicine, Faculty of Medicine, University of Toronto, Canada

Precision medicine fuelled by big data, such as genomics, is changing how clinicians make diagnoses, determine prognoses and develop new treatments. Although these developments hold promise, precision medicine remains a "disease-centered," not a "person-centered" epistemology. Using a case example, Dr. Benjamin Chin-Yee examines how genomic technologies and big data analytics are impacting patient care. He argues that genomic data not only underdetermine disease prognosis but fail to address fundamental questions arising in the clinical encounter. Precision medicine will not solve the problem that clinicians care for people, not diseases or genetic profiles. In this presentation, Dr. Chin-Yee discusses means of navigating the tensions between "disease-centered" and "person-centered" epistemologies engendered by the rise of precision medicine, explores the space between data and dialogue, and extracts lessons for clinicians on how to provide person-centered care in the era of genomic medicine.

16:40 Self-Management Open Online Trials in Health (SMOOTH): Methods and public involvement survey of corresponding authors of existing online trials

Dr. Amy Price, Chief Executive Office, Empower2Go, Florida, United States of America & Senior Research Analyst, MedicineX, School of Medicine, Stanford University & The Patient Editor of Research and Evaluation at the *British Medical Journal* & Department of Continuing Education, University of Oxford, UK

The growth of trials conducted over the internet has increased, but with little practical guidance for their conduct, and it is sometimes challenging for researchers to adapt the conventions used in face-to-face trials and maintain the validity of the work. The aim of this primary study was to systematically explore existing self-recruited online randomized trials of self-management interventions and analyze the trials to assess their strengths and weaknesses, the quality of reporting, and the involvement of lay persons as collaborators in the research. Dr. Amy Price reports that they have found the individual authors to be rich sources of nuanced and practical information a systematic review could not

capture. Authors report that detailed reporting of online methods and volunteer researcher involvement was hindered by role confusion between research volunteers and trial participants. Respondents were responsive to the development of protocol and reporting suggestions, but were not in favour of adopting complex new frameworks that require extensive time, training, space and funding. In this presentation, Dr. Amy Price combines the findings of the review with the insights of the authors.



Biographies of Conference Participants & 2018 ESPCH Award Winners



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

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.



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

Professor Sir Jonathan Asbridge DSc (hc) DHSc (hc), has a long and distinguished record of achievement within British 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 St. Bartholomew's and The Royal London Foundation NHS Trust as Chief Nurse and Executive Director of Quality, later to lead the Trust, one of the biggest and most complex in the UK, as Chief Executive. He was the Inaugural President of the UK Nursing and Midwifery Council with responsibility for the fitness for practice and regulation of the UK's 700,000 nurses

and midwives. He is a previous Deputy Chairman of the UK Council for Healthcare Regulatory Excellence and has acted as a Government 'Tsar' for Patient Experience in Emergency Care and for Patient and Public Involvement in Healthcare. Sir Jonathan has been involved in the development of several major NHS policies and conducted several formal Inquiries both in the UK and overseas. He was appointed Foundation Professor of Nursing at the University of Buckingham UK in 2010 and 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 invested with the Honour of Knighthood by Her Majesty Queen Elizabeth II for services to Healthcare on the occasion of The Sovereign's 80th Birthday in 2006.



Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc)
Senior Vice President and Secretary General, European Society for Person Centered Healthcare & Editor-in-Chief, *European Journal for Person Centered Healthcare*, Foundation Professor of Person Centered Health and Social Care & Co-Director: UWL European Institute for Person Centered Health and Social Care. Honorary Professor (Person Centered Care), Joint Faculty of Health, Social Care and Education, St. George's University Hospital Campus, University of London, UK.

Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc) is Professor of Person Centered

Health and Social Care and Co-Director of the European Institute for Person Centered Health and Social Care within the Office of the Vice Chancellor of 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) in late 2013. Professor Miles is Editor-in-Chief of the *European Journal for Person Centered Healthcare*, and Editor-in-Chief of the *Journal of Evaluation in Clinical Practice*.

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, Professor Miles 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 former World Health Organisation Senior Fellow, Faculty of Medicine, Imperial College London, UK. He is a Distinguished Academician of the National Academy of Sciences and Arts of Bulgaria, a Fellow of the New York Academy of Medicine USA, a Fellow of the Royal Society of Medicine UK, and a Fellow of the Royal Society of Public Health UK.

Professor Miles has published extensively within the peer reviewed medical and biomedical press. He is co-editor 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 125 clinical conferences and masterclasses in London as part of a major and long term contribution to British national postgraduate medical education. He has lectured, and lectures, widely in person-centered care across Europe and elsewhere, and is a sought after speaker.

Professor Miles is accredited with having changed the direction of the global EBM debate away from scientific 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.



Professor Drozdtoj St. Stoyanov MD PhD
Vice President (Eastern Europe), European Society for Person Centered Healthcare & Professor of Psychiatry, Department of Psychiatry and Medical Psychology, Medical University of Plovdiv, Bulgaria

Professor Drozdtoj Stoyanov received his MD from the Medical University of Sofia in 2002. He presented a PhD thesis (2005); was certified with the rank of Psychiatrist (2008) and awarded Postgraduate Certificate in Philosophy of Mental Health from the University of Central Lancashire, United Kingdom in October 2010.

Professor Stoyanov was tenured as Associate Professor in the Medical University of Plovdiv in 2008 and promoted to the academic position of Full Professor of Psychiatry and Medical Psychology in 2013. Head of the Neuropsychiatry and Brain Imaging Group at the Medical University of Plovdiv since 2015. On September 10th 2018 he defended successfully his thesis for Doctor of Sciences.

Professor Stoyanov was invited at the discretion of the Chair into the Philosophy Special Interest Group of the Royal College of Psychiatrists in 2007; appointed Vice Chair and member of its Executive Committee in 2012; Chair of Conceptual group in the Global Network for Diagnosis and Classification, World Psychiatric Association (2008). He is a Visiting Fellow in the Center for Philosophy of Science, University of Pittsburgh, USA (2009) and Project Partner

at the Collaborating Center for Values Based Practice in Health and Social Care, St.Catherine's College, University of Oxford (2015), Visiting Lecturer at the Universities of Basel, Copenhagen, Bergen and Vienna. International Distinguished Fellow, American Psychiatric Association (2017). Professor St. Stoyanov is Vice President (since 2014) of the European Society for Person Centered Healthcare, Vice President (since 2016) of the Bulgarian Academy of Sciences and Arts, and Associate Editor of the *European Journal of Person Centered Health Care*, Associate Editor, *Frontiers in Psychiatry*, Editorial board member, *Dialogues in Philosophy, Mental and Neurosciences*, *International Journal for Person Centered Medicine*, *Folia Medica* and others. Member Cognitive Neuroscience Advisory Board, Cambridge Scholars Publishing, UK- Author and co-author of more than 160 publications, cited about 400 times.

Team Winners of 2018 ESPCH President's Medal for Excellence in Person-Centered Healthcare for recognition of their teams work on The NEW VISION FOR MENTAL HEALTH Project



Mr. Richard Oldfield

Editor & Curator of New Vision For Mental Health & Consultant, Counselling and Psychotherapy Central Awarding Body, CPCAB Ltd

Mr. Richard Oldfield is the Editor & Curator of New Vision for Mental Health and a consultant for the Counselling & Psychotherapy Central Awarding Body (CPCAB), the only awarding body in Europe to specialise in the field of counselling & psychotherapy.

He has personal experience of caring for someone close suffering from mental ill-health. Within the mental health field, Mr. Oldfield is especially interested in the transliminal

and the possibilities for reconceptualising 'breakdowns' in potentially life-enhancing, albeit challenging ways. His interests range from mythology, history, cosmology and philosophy, through to ecology, anthropology, current affairs, politics, and, of course, the enormously wide field of mental health. On a completely tangential note, Mr. Oldfield has twice performed live as a singer on the main stage of the world's largest pop festival.



Mr. Ray van der Poel PGCE (PCET) BSc (Hons) PDHyp Dip Coun

Head of Business & Development, Counselling and Psychotherapy Central Awarding Body, CPCAB Ltd

Mr. Ray van der Poel is Head of Business and Development for the Counselling and Psychotherapy Central Awarding Body (CPCAB) which is the largest UK provider of counselling qualifications and the only awarding body in Europe to specialise in the field of counselling and psychotherapy. He has worked within educational management for many years and taught at various levels to a range of audiences. Currently overseeing the management of a video production team, Mr. van der Poel is enthusiastic about developing resources for counselling, psychotherapy and related healthcare projects.

Also, Mr. van der Poel has a wealth of experience as a therapist delivering both directive and person-centred interventions within the substance misuse field and in private practice. His special interest is in the use of therapeutic language and its impact on relationship and change; particularly with how relationships are formed within therapy. Over the years, Mr. van der Poel has also become interested in how non-counselling healthcare professionals build relationships with patients. He has a passion for encouraging the development of clients, staff, students and organisations and looks to achieve this through collaboration with others promoting both autonomy and empowerment.



Ms. Jane Teasdale

Principal Owner, Founder & 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. 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. 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.

Winner of the 2018 ESPCH Prize for Qualitative Methods Research in Person-Centered Healthcare



Ms. Laila Mohrsen Busted RN PhD student

Senior Lecturer, Department of Nursing Education, University College Lillebaelt, Vejle, Denmark & Researcher, Health Sciences Research Center, University College Lillebaelt, Lillebaelt/Department of Regional Health Research, Faculty of Health Sciences, University of Southern Denmark, Odense, Denmark

Ms. Laila Mohrsen Busted is a senior lecturer at the department of Nursing Education in Vejle, UCL University College in Denmark, where she teaches undergraduate and postgraduate students in family nursing science. Also, she is a Ph.D. student at University of Southern Denmark.

Her doctoral research is qualitative in nature and focuses on family-focused dementia care. She investigates both the personal experiences of people suffering early-onset dementia as well as the experiences of their family members during the early stage of dementia. This Ph.D. project takes a multidisciplinary approach in implementing family health conversations in dementia care in two Danish municipalities; an intervention, where health care professionals take care of the persons with dementia and their families, and is regarded from the point of view that illness is a family affair, especially that dementia is an illness affecting all family members in different ways. Currently, this intervention is being qualitatively evaluated, examining if family health conversations, as an early intervention for persons with dementia and their relatives, are deemed to be appropriate to reduce the burden that relatives and family members experience.



Dr. Juliette Brown BA MA MBBS MRC (Psych) PG Cert in Clinical Leadership
Consultant Psychiatrist, Community Mental Health Team (CMHT) for Older Adults, East London NHS Foundation Trust, London, UK

Dr. Juliette Brown is a consultant psychiatrist of adults and older adults in East London. She studied Literature, Gender, and Political Anthropology prior to Medicine. She was a Darzi Fellow in Clinical Leadership and worked with the academic health science network at UCL on advance care planning for people with dementia. She is a member of Association for Psychoanalytic Psychotherapy in the NHS and Clinical Network for Dementia Leadership Group, NHS England, and has research interests in the application of psychoanalytic theory, shared decision making, service improvement, and the cultural and philosophic basis of psychiatric illness and treatment. She is the author of *Self and identity over time: dementia*. (Brown, J. 2016. *J. Eval. Clin. Pract.*, doi: 10.1111/jep.12643) and a forthcoming chapter on psychoanalytic approaches to advance care planning.



Professor Victoria Tischler BSW MSocSc PhD CPsychol AFBPsS
Professor of Arts and Health & Head of the Dementia Care Centre, University of West London, UK

Professor Tischler is a Chartered Psychologist and an Associate Fellow of the British Psychological Society. She has a PhD in psychology from the University of Nottingham, where she worked for 12 years and retains an honorary position at its Medical School. Her research interests focus on creativity and mental health and multisensory approaches to dementia care. She is co-executive editor of the journal *Arts and Health* - an international journal for research, policy and practice. She serves on the scientific advisory board for Boots UK archive, and is a trustee for the charity Paintings in Hospitals.



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

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 practised 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 Prof. 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.



Dr. Jeremy Howick BA MSc PhD
Senior Research Associate, Department of Philosophy and Director of the Oxford Empathy Programme, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

An Oxford philosopher and medical researcher, Dr. Jeremy Howick has conducted groundbreaking studies about placebos and why we need unbiased experiments. He has degrees from Dartmouth College, the London School of Economics, and the University of Oxford. He has over 80 academic publications in top journals such as the *British Medical Journal*, *Annals of Internal Medicine*, and *The Lancet*. His textbook *The Philosophy of Evidence-Based Medicine* spearheaded a new sub-discipline. He collaborates about placebo treatments and the need for rigorous evidence with the National Institutes of Health in the United States, the National Institutes of Health Research in the United Kingdom, and the Canadian Institutes of Health Research in Canada, and Harvard University. He has won three teaching awards, appears regularly on television and has written for the *Times*, the *Huffington Post*, and *TheConversation*. He is the author of *Doctor You*, a book based on his own experience and research (which includes over 80 academic publications). He is also Director of the Oxford Empathy Programme at the University of Oxford. He was recently awarded the British Medical Association Dawkins and Strutt award to pursue research on the health benefits of empathic care.



Dr. Phil Hutchinson PhD
Senior Lecturer in Applied Philosophical Psychology, Department of Health, Psychology and Social Care, Manchester Metropolitan University, England, UK

Dr. Phil Hutchinson is currently pursuing three related research projects: 1) Shame, Stigma and Healthcare. This project has specific focus on shame and stigma in the clinical treatment and public health management of HIV, and is to be extended to healthcare in general. The project builds upon work begun in Phil's 2008 book *Shame and Philosophy*. 2) The Placebo Response. This project seeks to understand and explain the placebo response as medically significant *meaning* response. Drawing upon recent work in the philosophy of mind and new approaches to cognition, he proposes an alternative to the conditioned-response (behavioural) and expectancy-response (cognitive) explanations of placebo. 3) Non-representational approaches to mind and cognition. This project provides the philosophical foundations for projects 1 & 2, in providing a non-representational account of mind and cognition.

In addition to these three projects, Dr. Hutchinson is also interested in policy and decision making processes, which informs his work on goal-oriented deliberative fora and on a procedure for testing policy proposals: the Five Parameters Policy Test



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

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 policy-makers 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.

Winner of the 2018 ESPCH Essay Prize in Person-Centered Healthcare Literature for recognition of: Pârvan P. The mind electric: Challenges to clinical categories from a person-centered perspective and the possibilities of metaphysics and art for clinician, patient, and threatment. *Journal of Evaluation in Clinical Practice*. 2018; 24(5): 1065-1078.



Dr. Alexandra Pârvan BSc MA PhD

Department of Psychology and Communication Sciences, University of Pitești, Romania

Dr. Alexandra Pârvan is Lecturer in the Department of Psychology and Communication Sciences at the University of Pitești, Romania. She has degrees in Psychology (BSc), Philosophy (MA, PhD), and is licensed for independent practice in experiential counselling. She held post-doctoral fellowships in St Andrews (UK), Edinburgh (UK), Tübingen (Germany) and Princeton (USA), doing cross-disciplinary research in Augustinian Studies, philosophy of medicine and mental health, person-centred healthcare, with a focus on the metaphysics of evil/harm, violence and disease. Her work introduces the concept of "metaphysical care", arguing that non-reflective metaphysical assumptions

of both patients and clinicians influence treatment course and outcome, and thus metaphysical frameworks and views could usefully be employed in somatic and psychiatric contexts to ensure improved care. She takes an active interest in promoting humanities-informed education for clinicians through her teaching of future clinical psychologists and nurses, and through publishing medical poetry in medical research journals.

Professor Dr. Manuel Augusto Cardoso de Oliveira PhD

Vice President (Southern Europe), European Society for Person Centered Healthcare; Professor Catedrático, Faculty of Sciences and Health, Fernando Pessoa University & Professor Emeritus of Surgery, University of Porto Medical School (rtd) / Former Head of the Department of Surgery, St. João Hospital, Porto, Portugal

Professor Manuel Cardoso de Oliveira Biography Oliveira PhD, Professor Catedrático, Faculty of Sciences and Health, Fernando Pessoa University & Professor Emeritus of Surgery, School of Medicine and current Senior Researcher in the Institute of Molecular Pathology and

Immunology (IPATIMUP), University of Porto & Former Head of the Department of Surgery, St. João Hospital, Porto, Portugal & Vice President of European Society for Person Centered Healthcare representing Southern Europe, and a member of the Editorial Board of the *European Journal for Person Centered Healthcare*.

Professor Cardoso de Oliveira is an active member of numerous hospitals and university committees, a scholar of over 100 full scientific papers, hundreds of abstract publications, publication of congress acts, books and divulgation texts, a supervisor of Master Thesis and of PhD degree. He is currently engaged in an increasing number of partnerships with academic institutions, creating teaching/learning activities under various formats, running postgraduate courses in the Social Medicine Area, and a Chairman of numerous International Scientific Meetings in Portugal. He is founder and President of the Board of the Association for Patient Safety (APASD), Portugal, in which he is actively involved in the organization of its activities across Portugal and outside. He is also a founding member of the European Society of Endocrine Surgery, the Board of Endocrine Surgery at the European Union of Medical Specialists (UEMS), and the scientific association Portuguese Group of Medical-Surgical Endocrinology.

Winner of the 2018 ESPCH Prize for Quantitative Methods Research in Person-Centered Healthcare



Mr. Mohammed Aljuaid BSc MSc PhD Student

PhD Student, Department of Primary Care and Public Health, Imperial College of London, London, UK & Lecturer, Department of Health Administration, King Saud University, Riyadh, Saudi Arabia

Mr. Mohammed Aljuaid is a PhD candidate in the department of Primary Care and Public Health at Imperial College London and his doctoral studies are supported by King Saud University. His research focuses on a novel application of person-centred care within healthcare settings in Saudi Arabia, with a view to extending this concept to the Middle East region.

In 2011, Mr Aljuaid completed an MSc in Health Administration from the Faculty of Health Sciences, La Trobe University, Melbourne, Australia. Prior to this, in 2001, he completed a BSc in Quantitative Methods Research from the Faculty of Administrative Sciences, King Saud University, Saudi Arabia. He trained as a researcher (2012-2013) under the supervision of Professor Osman Galal, co-ordinator of Community Health Sciences at UCLA in the United States.

Mr. Aljuaid currently works as lecturer in the Department of Health Administration, King Saud University. Prior to this, he worked at the Saudi Ministry of Health in the Health Sciences College in Riyadh as a Teacher of Biostatistics. He is also a member of the WHO Collaborating Centre for Public Health Education and Training at Imperial College London.

Mr. Aljuaid has published two academic articles related to his doctoral thesis in the *British Medical Journal Open* and in the *Journal of Nursing Management* respectively. He has participated as speaker in three international conferences such as ISQua and International Forum on Quality and Safety in Healthcare.

Winner of 2018 ESPCH Gold Medal for Excellence in Person Centered Healthcare for recognition of his team's work on MAKEtoCARE Initiative



Dr. Filippo Cipriani BSc MSc PhD

Rare Disease Patient Advocacy Lead & Head of Open Innovation Projects, Sanofi Genzyme, Modena, Italy

Dr. Filippo Cipriani is currently Rare Disease Patient Advocacy Lead & Head of Open Innovation Projects for Sanofi Genzyme, where he previously covered multiple positions, at national and at European level, in the fields of Health Technology Assessments, Outcome Research, Pricing and Reimbursement and Market Access.

Over the years he developed a specific interest in the interconnection between science and society. In 2015, he developed **MAKEtoCARE**, a multistakeholder initiative on patients and caregivers bottom up and participative innovation.

Prior to Sanofi Genzyme, Dr. Filippo Cipriani spent over 6 years as research fellow for EMBL (Heidelberg, Germany) and Cancer Research UK (London, UK) before serving as Health Economist for the Emilia Romagna Regional Health and Social Agency (Bologna, Italy) and in GlaxoSmithkline (Verona, Italy). He holds a BSc in Industrial Biotechnology from the University of Bologna, a PhD in Molecular Genetics from the University College of London and a MSc in International Health Care Management, Economics and Policy (MIHMEP) from the L. Bocconi School of Management, Milan.



Dr. Wendy Wigley EN RGN DipHE BSC PGCAP DNP
Head of School of Human and Social Sciences, University of West London, UK

Dr. Wendy Wigley is Interim Head of School of Human and Social Sciences, University of West London and a Visiting Fellow of the School of Health Sciences, University of Southampton.

In nursing, Dr. Wendy Wigley has worked in Paediatrics, Neonatal Intensive Care, General Practice, Emergency Departments and as a Specialist Community Public Health Nurse (SCPHN) (health visiting) and Practice Teacher.

Dr. Wendy Wigley has wide experience in assessing health and social care needs and delivering and developing health and social care interventions. As a result, her clinical expertise is within quality community partnerships, needs assessments and risk management, especially when safeguarding children and vulnerable groups. Dr. Wendy Wigley's doctoral work used Glaserian grounded theory to explore and explain pre-registration nursing students' personal understanding of their own spirituality and the relationship between experiences in clinical practice and spiritual awareness.

As a result of this study and previous teaching experience linked to community children's and families teams, Dr. Wigley is keen to ensure that students are supported through higher education to gain meaningful and progressive experience of holistic complexity when working with individuals and communities. Dr. Wendy Wigley has expertise in teaching, supervision and curricula design at undergraduate, postgraduate and doctoral levels. Dr. Wendy Wigley's guiding ethos is to ensure that educational provision across health and social care is influenced by quality learning and teaching, that support and enhances the student experience, while meeting the workforce needs of care provider organisations across the statutory, private and voluntary sectors. Dr. Wendy Wigley is active in research recently as a co-author for an NIHR report, and currently an evaluation research of a Home Start Initiative.

In 2013, Dr. Wigley was awarded the title of Queens Nurse from the Queens Nursing Institute, for recognition of continuing commitment to improving standards of care in the community and to learning and leadership.

Winner of the 2018 ESPCH Book Prize in Person-Centered Healthcare Literature for recognition of:
Matthews P. *Ethical Questions in Healthcare Chaplaincy: Learning to Make Informed Decisions*. Philadelphia, PA: Jessica Kingsley Publishers; 2018.



Dr. Pia Matthews PhD MA MA Bth FHEA
Senior Lecturer in Bioethics, Medical Law, Theology and Healthcare Ethics, St. Mary's Catholic University, Twickenham, London, UK

Dr. Pia Matthews is a senior lecturer at St Mary's University, Twickenham and Director of Studies at St John's Catholic Seminary, Womersley, near Guildford. Dr. Matthews obtained a degree in Law from Trinity College, Cambridge. She then studied at St John's Seminary gaining a degree in Theology. Dr. Matthews followed further studies at St Mary's University Twickenham where she gained an MA in Bioethics and medical law. Her PhD thesis looked at the insights of theological and philosophical anthropology for bioethics. Dr. Matthews was appointed an expert by Pope Francis to the XIV Synod of Bishops in 2015. Dr. Matthews has written extensively in the area of disability, dementia, end of life issues and healthcare. She has also set up a foundation degree for healthcare practitioners, including chaplains, in ethics, theology, health and social care at St Mary's.



Professor Emerita Colonel (Rtd) Marilyn A. Ray RN BSN MSN MA PhD CTN-A FSfAA FAAN FESPCH (Hon) FNAP

Christine E. Lynn College of Nursing, Florida Atlantic University, United States of America & Honorary Distinguished Fellow, European Society for Person Centered Healthcare

Marilyn Anne (Dee) Ray is Professor Emeritus 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 Nursing with a specialty in 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 Christine E. Lynn Eminent Scholar, and Professorial positions at Florida Atlantic University and the University of Colorado, and Visiting Scholar, Virginia Commonwealth University. She is certified as an advanced Transcultural Nurse (CTN-A) and a transcultural nursing scholar. Her focus is in caring sciences, humanity sciences, and complexity sciences, and publishing widely with 5 books, many articles and chapters, and presenting nationally and internationally, and advancing Caring Science Inquiry methodology, and her Theories of Bureaucratic Caring and Transcultural Caring Dynamics in Nursing and Healthcare in healthcare inter-disciplinary environments. Her Theory of Bureaucratic Caring was featured as a model of caring with the academic leadership group of the American Association of Colleges of Nursing, and has been adopted as the structural framework and cornerstone for the interdisciplinary collaborative practice Person-Centered Caring Practice Model in the United States Air Force, Medical Service. Her *Transcultural Caring in Nursing and Healthcare* featuring her theory has been adopted by the publishing company, F. A. Davis Company, as the central transcultural caring book for undergraduate and graduate nursing education.

Professor Ray is a retired Colonel in the United States Air Force Reserve, Nurse Corps (USAFR NC), serving for 32 years. She is a veteran (alongside her late husband, James L. Droesbeke), contributing as a member of the Veterans Action League at FAU for research into veteran access to adequate healthcare. She also participates with the Military Officers Association of America. During her military career, Colonel Ray served as a flight nurse during the Vietnam conflict, followed by clinical nursing, USAF command positions in nursing education and administration in Denver, CO, Washington, DC and San Antonio, TX. She was a researcher and consultant in military hospitals, and aerospace nursing research, education and practice at the School of Aerospace Medicine. She attended the NASA Marshall Space Center for introduction into astronaut duties for the eventual development of nursing in space. She and her colleague, Dr. Marian Turkel were funded for almost 1 million dollars to study organizational caring with a focus on economic caring within military and civilian health care facilities by the TriService Nursing Research Program (Uniformed Services University of the Health Sciences), developed the Theory of Relational Caring Complexity, and received the national research award from the Military Surgeons Association of the United States. Presently, Colonel Ray is an advisor to the Surgeon General of the United States Air Force, Lieutenant General Dorothy Hogg with the assistance of Master Clinician, Colonel Marcia Potter, DNP, FNP, in the development of and education in the Person-Centered Caring Model using her Theory of Bureaucratic Caring for nursing and inter-professional practice.

Professor Ray has received numerous awards, such as: Transcultural Nursing Scholar Award, the University of Utah Distinguished Alumni Award, University of Colorado College of Nursing Alumni Lifetime Achievement Award, Lifetime Achievement status from Marquis Who's Who Biographers, Honorary Nurse Practitioner of Ontario, Fellow of the Society for Applied Anthropology, Fellow of the American Academy of Nursing, the Distinguished Fellowship in the European Society for Person-Centered Healthcare and the National Academies of Practice. Professor Ray also is an active member of the South Florida Haiti Project where she participates as a transcultural nursing advocate to ensure culturally responsive mental health research and practice in Haiti. Her Archives of Caring are housed in the Museum at Florida Atlantic University, Christine E. Lynn College of Nursing, Boca Raton, Florida



Dr. Joachim P. Sturmberg MBBS DRACOG MFM FRACGP PhD

Associate Professor of General Practice, School of Medicine and Public Health, Faculty of Health and Medicine University of Newcastle, Australia & Foundation President, International Society for Systems and Complexity Sciences for Health

For almost 30 years Dr. Joachim Sturmberg is practicing family medicine at Wamberal Surgery, Wamberal, Australia. He is the Foundation President of the *International Society for Systems and Complexity Sciences for Health*, and he remains actively involved in the Royal Australian College of General Practitioners as well as co-leading the special interest groups in complexity in WONCA, ESPCH and NAPCRG. He has been instrumental in initiating the *International Conferences for Systems and Complexity Sciences for Health*.

His research interests relate to the application of systems and complexity principles to health care delivery, health policy and health systems organisation. He has been invited to speak on these topics in Europe and North America, he has published extensively on these topics in peer-reviewed journals and has contributed several book chapters on these topics. Current research collaboration focuses on the nature of multimorbidity from an interconnected physiological perspective, and the study of aging as reflected in heart rate variability. Selected Bibliography:

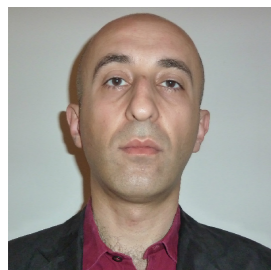
- Sturmberg JP. *Health System Redesign*. Springer 2017
- Sturmberg JP and Martin CM (eds). *Handbook of Systems and Complexity in Health*. Springer 2013



Dr. Carmel Martin MBBS PhD MRCGP FRACGP FAFPHM

Adjunct Associate Professor, Department of Medicine, Nursing and Allied Health, Monash University, Melbourne, Australia & Senior Medical Advisor, Community Health, Monash Health, Dandenong, Victoria, Australia

An Australian medical graduate from the University of Queensland, Dr. Martin completed a Masters in Community Medicine at the London School of Hygiene, University of London and a PhD in Epidemiology and Population Health at the Australian National University. Dr. Martin is in active clinical practice as a general practitioner. Her research in Australia, Canada and Ireland has focused on reforms to primary health care related to chronic care and complex systems. Her interests, research and implementation and evaluation cover a wide range of systems-based interventions, underpinned by complex adaptive systems theory and social constructionist perspectives. A particular focus is to improve chronic illness trajectories. This involves modelling and predicting illness and wellness, resilience, tipping points and deteriorations using complex systems theory and IT systems. She is the Joint Editor in Chief of the *Handbook on Systems and Complexity in Health* (Springer Verlag), Joint Associate Editor of the Forum on Systems and Complexity in Health in the *Journal of Evaluation in Clinical Practice* (Wiley), and Joined Chair of the ESPCH SIG on Complexity Theory, Non-Linearity and PCH, with Associate Professor Dr. Joachim Sturmberg, University of Newcastle.



Dr. Abdi Sanati, Chairman MD FRCPsych
Philosophy SIG, Royal College of Psychiatrists

Dr Abdi Sanati is a consultant psychiatrist working for East London NHS Foundation Trust. He completed his basic medical degree in Tehran University and had higher training in psychiatry in the UK. In 2004, he became a member of the Royal College of Psychiatrists, and in 2010 he became a full time consultant. In 2016, he was awarded fellowship of the Royal College of Psychiatrists. He is currently the chair of the Philosophy Special Interest Group of the Royal College of Psychiatrists. Since 2011 he has been a co-editor of the Philosophy Special Interest Group's newsletter. His research interests include delusions, epistemic injustice and ethics.

Winner of the 2018 ESPCH Platinum Medal for Excellence in Person-Centered Healthcare



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, United States of America

Colonel 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.

Winner of 2018 ESPCH Vice President's Medal for Excellence in Person-Centered Healthcare



Professor Samar Aoun BSc(Hons) MPH PhD

Professor of Palliative Care, Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Melbourne, Victoria & The Perron Institute for Neurological and Translational Science, Perth, Western Australia, Australia

Samar Aoun is Professor of Palliative Care, Palliative Care Unit, School of Psychology and Public Health, La Trobe University, Victoria and the Perron Institute for Neurological and Translational Science, Western Australia. She is a palliative care researcher with a public health approach and a focus on under-served population groups such as people with Motor Neurone Disease (MND), Dementia, terminally ill people who live alone and family carers before and after bereavement. Professor Aoun strongly advocates for a person-centered health and social care. Her research programs on supporting family caregivers at end of life and the public health approach to bereavement care have informed policy and practice at the national and international levels. Her recent work on social models in bereavement support has provided empirical evidence to strengthen the Compassionate Communities movement in bereavement support.

Professor Aoun is a member of the editorial advisory board of *Palliative Medicine*, a member of an expert advisory group for the development of best practice guidelines in bereavement care in Europe and a member of the reference group on Public Health Palliative Care of the European Association of Palliative Care. Professor Aoun has established and chaired the West Australian Country Health Services Ethics Committee for 23 years. She has served on National Health and Medical Research Council committees: the Australian Health Ethics Committee, and the Prevention and Community Health Committee. Professor Samar Aoun is currently the Vice-President of the MND Association in WA and Director on MND Australia Board. She was awarded the Centenary Medal in 2003 from the Prime Minister of Australia for her work in rural health and community development; the Paul Harris Fellow in 2008 from Rotary International; and the Eleanor Mounsher Medal in 2016 in recognition of outstanding commitment, dedication and service to people living with MND and their families.

Honorary Distinguished Fellowship of the ESPCH



Dr. Mathew Mercuri BKin MSc PhD

Editor-in-Chief, *Journal of Evaluation in Clinical Practice* & Assistant Professor, Faculty of Medicine, McMaster University, Canada

Dr. Mathew Mercuri completed his PhD in Health Research Methods at McMaster University (Hamilton, Canada), and a postdoctoral fellowship in the Department of Medicine at Columbia University (New York, USA). He is currently an Assistant Professor in the Department of Medicine at McMaster University and a Lecturer in the prestigious Vic One program at the University of Toronto (Toronto, Canada). Dr Mercuri has significant

experience in health services research, where his past work examined the organization of healthcare services, issues around ionizing radiation exposure from medical imaging, and methodological issues in the study of medical practice variations.

In addition, Dr. Mercuri holds positions as a Graduate Fellow at the Institute for the History and Philosophy of Science and Technology (University of Toronto) and a Research Associate at the African Centre for Epistemology and Philosophy of Science (University of Johannesburg). His current academic interests focus on issues related to how to determine that a healthcare intervention is effective for improving patient care, and how this information can be used to support decisions on the provision of healthcare services. Dr. Mercuri has recently been named the new Editor-in-Chief of the *Journal of Evaluation in Clinical Practice*, which he will take over from Professor Andrew Miles in January 2019.



Professor Bill (KWM) Fulford PhD

Emeritus Professor of Philosophy and Mental Health, University of Warwick, Founder Editor and Chair of the Advisory Board, *Philosophy, Psychiatry, & Psychology*, and Director of The Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford

KWM (Bill) Fulford is a Fellow of St Catherine's College and Member of the Philosophy Faculty, University of Oxford; and Emeritus Professor of Philosophy and Mental Health, University of Warwick Medical School. He is Director of the *Collaborating Centre for Values-*

based Practice at St Catherine's College (valuesbasedpractice.org). His previous posts include Honorary Consultant Psychiatrist, University of Oxford, and Special Adviser for Values-Based Practice in the Department of Health. Besides values-based practice, Bill has led on a number of academic and administrative developments in the philosophy of psychiatry. His publications include *Moral Theory and Medical Practice*, *Essential Values-based Practice*, *The Oxford Textbook of Philosophy and Psychiatry*, and *The Oxford Handbook of Philosophy and Psychiatry*. He is also Lead Editor for the Oxford book series *International Perspectives in Philosophy and Psychiatry* and Founder Editor and Chair of the Advisory Board of the international journal *Philosophy, Psychiatry, & Psychology* (PPP). The recently endowed Oxford tutorial post in philosophy of mind with special relevance to psychiatry and cognitive neuroscience has been named the Fulford Clarendon Lecturer and Fellowship in recognition of his contributions to the field.



Dr. Amy Price PhD

Chief Executive Office, Empower2Go, Florida, United States of America & Senior Research Analyst, MedicineX, School of Medicine, Stanford University & The Patient Editor of Research and Evaluation at the *British Medical Journal* & Department of 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. Dr. Amy's experience has shown her that shared knowledge, interdisciplinary

collaboration, and evidence based research will shape and develop the future. She serves as a *BMJ* editor and as a senior research advisor with MedicineX, Department of Anesthesiology Stanford University.



Professor Jack Dowie MA (NZ) PhD (ANU)

Professor Emeritus of Health Impact Analysis, London School of Hygiene and Tropical Medicine; Honorary Professor, University of Sydney School of Public Health, Australia & Adjunct Professor, University of Southern Denmark & Chairman ESPCH SIG on Health Impact Analysis

Professor Jack Dowie took up the newly-created chair in Health Impact Analysis at the London School of Hygiene and Tropical Medicine in 2000, leaving the Open University where he had been a member of the Faculty of Social Sciences since 1976. While at the OU, he designed and ran the multi-media courses on RISK (from the late seventies) and PROFESSIONAL JUDGMENT AND DECISION MAKING (from the late eighties). His early qualifications were in history and economics at the University of Canterbury, New Zealand and he went on to merge these disciplines in doctoral work (at the Australian National University) and subsequent lecturing in economic development and economic history (at ANU, Kent and Durham). What had been side interests in accidents, gambling and health, it eventually took over and led to full time involvement with risk and judgment in health decision making and to involvement with both clinical decision analysis and cost-effectiveness analysis in

healthcare. Professor Jack Dowie was a founder member of the Health Economists Study Group and the Society for the Study of Gambling. He recently completed ten years of service as a member of the Appraisals Committee of the then National Institute for Clinical Excellence (NICE). Professor Dowie had formally retired in 2003, but remains active in the School, and also as an Adjunct Professor in the Department of Public Health, University of Southern Denmark, and he is a Honorary Professor in the University of Sydney School of Public Health. His research is mainly in connection with the software implementation of Multi-Criteria Decision Analysis, called Annalisa, which he developed. Annalisa is designed to facilitate more equal balancing of intuition and analysis in health decision making, whether it be in the person-centred settings of screening or clinical consultation, or the citizen-centred setting of health and non-health sector policies, programmes and projects. The decision support tools built in Annalisa provide personalised decision support based on individual preferences as well as evidence and expertise. Professor Jack Dowie was recently honoured to receive the Gold Medal of the European Society for Person Centered Healthcare for his work in this area.



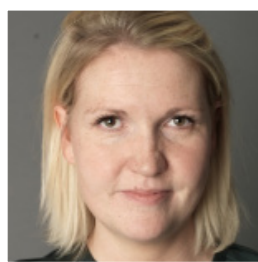
Dr. Mette Kjer Kaltoft PhD

Odense University Hospital, Svendborg, Denmark & University of Southern Denmark, Odense, Denmark

Dr. Mette Kjer Kaltoft obtained her PhD in 2015 with the thesis *Towards improved decision quality in person-centred 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.

Team Winners of 2018 ESPCH Silver Medal for Excellence in Person-Centered Healthcare, for recognition of their work in Parkinson's Disease, and for recognition of their teams' work at the European Parkinson's Disease Association, EPDA



Dr. Rowena K Merritt D.Phil

Research Fellow, Centre for Health Services Studies, University of Kent, Canterbury, Kent, UK

Dr. Rowena Merritt is the Head of Research at The National Social Marketing Centre (NSMC), UK, & Affiliate Professor at the University of South Florida and a Research Fellow at the University of Kent. Dr. Merritt has over ten years of experience conducting research and evaluating behaviour change projects. In her position at The NSMC, Dr. Rowena Merritt managed England's first multi-trial application of social marketing involving ten learning demonstration sites across England, each focused on a different topic or audience. Dr Merritt also worked with national stakeholders to manage the implementation of the

Department of Health's national social marketing strategy. In recent years, Dr. Rowena Merritt developed a number of HIV prevention programmes and conducted formative research in Laos and the Philippines to support the implementation of the WHO Regional Action Plan. Dr. Merritt's Doctorate, gained in 2006, explores the use of social marketing techniques to improve clinical outcomes for depressed patients.



Professor Anette Schrag FRCP MD PhD

Honorary Consultant Neurologist & Professor of Clinical Neurosciences at University College London, UK

Professor Anette Schrag is a Professor of Clinical Neurosciences at University College London and an Honorary Consultant Neurologist at the Royal Free, University College London and Luton and Dunstable Hospital Trusts. She is also an Honorary Professor at Queen Mary University London. She was trained at the University Hospital in Berlin and the Institute of Neurology at Queen Square in London both as a neurologist and a psychiatrist. Her research has focused on clinical aspects of Parkinson's disease to improve the diagnosis, assessment and clinical management of patients, including the psychiatric, cognitive and other non-motor aspects of Parkinson's. She has pioneered a patient-centred approach in assessing outcomes of clinical trials in Parkinson's disease

and the inclusion and development of patient-oriented outcome measures in this field. Professor Schrag led and participated in numerous clinical trials in Parkinson's disease, and co-authored European guidelines on the diagnosis of Parkinson's disease. She chaired and participated in several committees of the International Parkinson's and Movement Disorders Society, is a Steering Committee Member of the MDS Non-motor Symptoms Group, is a Board member of the British Neuropsychiatric Association and a member of the Association of British Neurologists' Movement Disorders Special Interest Group. She has served on the Parkinson's UK Research Advisory Board and is the Lead of the North London UK Parkinson's Excellence Network. She has a close relationship with the European Parkinson's Disease Association, including the development and analysis of results of a Europe-wide study on the healthcare experiences of people with Parkinson's. Her current research programme includes collaborative studies on the Care of Late Stage Parkinsonism, an Antidepressant Trial for patients with Parkinson's, on Predicting risk of Parkinson's in the population, and on Personalising Care for people with Parkinson's.



Dr. Sarah Hotham PhD C.Psychol

Research Fellow, Centre for Health Services Studies, University of Kent, UK

Dr. Sarah Hotham is a Chartered Psychologist and Research Fellow at the Centre for Health Services Studies, University of Kent, with 10 years of experience in developing and implementing applied health projects. She has extensive knowledge and expertise in the areas of health behaviour change, with a specific focus on physical activity, evaluation methodologies, and delivering training to healthcare professionals. Dr. Sarah Hotham has received research funding awards from The Big Lottery, London Sport, Local Authority

Public Health teams, NHS Trusts and CCGs. Dr. Sarah Hotham is currently Principal Investigator for a number of projects exploring the impact of behaviour change techniques on obesity and physical activity and the role of the voluntary sector in delivering health and social care. She also leads a local evaluation - 'Ageless Thanet' - of a five year Big Lottery-funded programme to reduce social isolation and loneliness.



Mr. Dominic Graham

Interim Secretary General, European Parkinson's Disease Association (EPDA)

Although he has worked much more consistently with the EPDA since 2012, Mr. Graham's relationship with the EPDA and Parkinson's disease dates back to 2000 when he had attended an EPDA congress in Vienna as a trainee journalist. He is currently the Interim Secretary General, and he will become Operations Director in January supporting the newly appointed Secretary General. He is involved in all areas of the EPDA's activities, ranging from strategy and project management to fundraising and campaigns. In addition to his work with the EPDA, Mr. Dominic Graham's background is as a freelance journalism consultant with roles varying from writing, editing and magazine production, to project management, strategic planning and delivery.

Winner of the 2018 ESPCH Prize for Mixed Methods Research in Person-Centered Healthcare



Dr. Elisa Ambrosi BSN MSN PhD

Assistant Professor, Department of Medical and Surgical Sciences, University of Bologna, Italy

Dr. Elisa Ambrosi is Senior Assistant Professor at the School of Medicine of the University of Bologna. She is qualified as an Associate Professor of Nursing. She completed a PhD in Education at the University of Verona (Italy) with a thesis on caring perceptions and behaviors amongst nursing students, as they progressed through their nurse education.

As a doctoral student, she spent a quarter at University of California, Los Angeles studying Advance Qualitative Research Methodology. She lectures in Evidence Based Nursing and Qualitative Research Methodology both at undergraduate and graduate courses. She is a member of the Italian Society of Nursing Sciences and an Associate Editor of the international journal *BMC Nursing*. She has published extensively on caring in nursing, has co-authored a book and has organized and presided an International conference on nurses' caring gestures and thoughts. In addition, her research interests are focused on nursing sensitive outcomes and workforce issues.

Winner of the 2018 ESPCH Bronze Medal for Excellence in Person-Centered Healthcare for recognition of his work in Patient Safety and Regulation of Clinical Practice

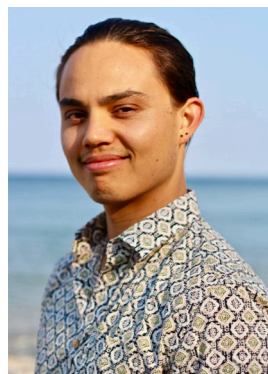


Dr. Tristan Price BSc MSc PhD PGCE PGCPSE

Research Fellow, Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA), Faculty of Medicine and Dentistry, University of Plymouth, Plymouth, UK

Dr Tristan Price is a Research Fellow in the Collaboration for the Advancement of Medical Education Research and Assessment (CAMERA) at the University of Plymouth. He came to medical education research from a background in teaching in both the secondary and higher education sectors. Dr. Tristan Price has a particular interest in research on educational and behaviour change interventions, and he is currently working on a large

NIHR-funded review into doctor remediation. His previous research includes a number of systematic reviews on topics related to remediation, doctor performance and medical licensing, as well as primary qualitative research on the organisational impacts of medical revalidation.



Dr. Benjamin Chin-Yee MA MD

Resident Physician, Department of Medicine, Faculty of Medicine, University of Toronto, Canada

Dr. Benjamin Chin-Yee is an internal medicine resident at the University of Toronto, where he also completed his MD and MA in the history and philosophy of science. His research spans a range of disciplines, from bioethics to the history and philosophy of medicine. He is particularly interested in the ethics of the patient-physician relationship and how to integrate evidence-based and precision medicine to provide individualized, person-centered care. His current work explores the philosophical implications of big data and genomic medicine in clinical practice. He has authored a number of articles and book chapters, which have been recognized with local and international awards, including the 2016 Essay Prize from the European Society for Person Centered Healthcare. He has served as guest editor for the *Journal of Evaluation in Clinical Practice* and *Studies in History and Philosophy of Biological and Biomedical Sciences*.

Winner of the 2018 ESPCH Young Reseracher Prize in Person-Centered Healthcare Research



Ms. Kristina Stoyanova BA MSc.Ed

PhD Student, Department of Psychology, South West University "Neofit Rilski", Blagoevgrad, Bulgaria

Ms. Kristina Stoyanova is a supporter of person-centered approach to education, and has preferred research interests in the fields of organizational psychology, social psychology, experimental psychology, neuropsychology, and neurosciences in general. Outside of psychology, her research interests extend in the direction of counseling, psychoanalysis (especially in the spirit of the Yungian school), affinity to the Neo-Reichian psychotherapeutic school, and psychodrama.

Ms. Stoyanova holds a Bachelor Degree in Psychology (2006) and Master's of School Psychology (2012), from South West University "Neofit Rilski", Blagoevgrad, Bulgaria, and currently she is continuing her post-graduate research studies at the Department of Psychology of the same University, where she is undertaking training in the Doctoral degree program "Pedagogical and age psychology". She has studied the relationship between burn out and the psychological types of university lecturers (Yung's paradigm), and her dissertation explores the relationship between burn out, emotional intelligence and coping strategies of teachers in support for her believe in. Also, in within the same context she published:

- Stoyanova K. Interview With Drozdostoy Stoyanov About Burn-Out. *Psychological Thought*. 2018; 11(1):45-51
- Stoyanova K. A Neo-Reichian Reading of Burn-out – talk with Madlen Algaferi. *Psychological Thought*. 2018; 11(2): 234-241
- Stoyanova, K. The Concept "Emotional Intelligence" in the ideas of Moncef Gittuni. In the "National Scientific and Practical Conference on Psychology, Psychology – theory and practice", Varna. *Psychoanalysis publication*: 2017; 25-33



Professor Mary Chambers Dip.N (Lond) RCNT RNT PhD BEd(Hons) PgCert RMN RGN

Professor of Mental Health Nursing; Director, Centre for Public Engagement & Associate Editor, Health Expectations, Joint Faculty of Health, Social Care and Education, St. George's University Hospital Campus, St. George's University of London, UK

Mary Chambers is Professor of Mental Health Nursing and Director of the Centre for Public Engagement, Faculty of Health, Social Care and Education, Kingston University and St George's, University of London. Throughout her career, she has held a number of clinical, managerial and academic positions including coordinator of the Northern Ireland Centre for Health Informatics. She is involved in a number of research projects locally and internationally. Professor Cahmbers is a fellow of both the Royal Society of Medicine and

the European Academy of Nurse Scientists, and an expert panel member of HORATIO, the European Association for Psychiatric Nurses, and a member of the Institute of Leadership and Management. Mary is also Associate Editor to *Health Expectations*.

Outcomes of her work with respect to PPI in both these areas have had impact nationally and internationally. Integral to this work has been the coproduction and delivery of education programmes, as well as PPI at all stages of the research process.

Winner of the 2018 ESPCH Young Teacher Prize in Person-Centered Healthcare Education



Mr. Alexander Silverstein

Diabetes Education & Engagement Lead, NHS North West London Collaboration of CCGs

Mr. Alaxenader Silverstein is an international patient advocate, NHS employee and self-employed consultant. He worked for the charity Diabetes UK before becoming the first President of the International Diabetes Federation's (IDF) Young Leaders in Diabetes programme. In his role, Mr. Silverstein led 200 young adults from 102 different countries to deliver projects with their national diabetes charities. In 2014, he launched the national campaign HelloOURaimis, with Dr Kate Granger, to build a partnership model of care between patients and healthcare professionals. This has been taken up by a number of organisations across the NHS to deliver person-centred care, shared goal setting and care planning. He also worked with the NHS London Clinical Senate to create a self-care

commissioning framework for young adults called "Made in London". He currently works for the NHS, as part of a diabetes transformation programme across North West London. His role is to support over 350,000 people learn about diabetes in a way that suits them by 2021. This includes the use of tools, such as apps, lay-educators and community champions and e-learning, whilst also developing a mechanism for people with diabetes and Healthcare professionals to access training, support, medical records and behaviour change tools through a single website. He is also a member of the *British Medical Journal's* patient panel. Mr. Alexander Silverstein is passionate about ensuring that no matter where someone lives they receive the Equipment, Education, Empathy and Engagement opportunities to be a partner in their care.



European Society for Person Centered Healthcare

December 2018

www.pchealthcare.org.uk