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ESPCH-4

The Fourth Annual Conference and Awards Ceremony

THE EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE

26 & 27 October 2017
Westminster Cathedral Hall London, UK

Programme Brochure

PREFACE

FOURTH ANNUAL CONFERENCE AND AWARDS CEREMONY EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE (ESPCH4)

Dear Conference Delegates, Speakers, Chairmen and Friends

We are delighted that it has proved possible for you to be in London with us for the Fourth Annual Conference and Awards Ceremony of the European Society for Person Centered Healthcare. ESPCH4 builds on the highly successful *First* (3 & 4 July 2014, Madrid), *Second* (18 & 19 June, 2015, Madrid) and *Third* (29 & 30 September 2016, London) annual conferences and award ceremonies of the Society. As in previous years, the ESPCH has secured the involvement of a wide range of distinguished clinicians and scientists from across the globe, with prominent representation from the United Kingdom, Germany, France, Italy, Denmark, Romania, from the United States of America, from Canada and from Australia. The Society is privileged to be able to work with such a stellar line up of accomplished colleagues in our joint endeavour to contribute to the progressive understanding and implementation of person-centeredness across health and social care systems internationally.

The Society is most grateful to His Eminence, The Cardinal Archbishop of Westminster, for the use of the Cathedral Hall as this year's venue for the annual meeting and awards ceremony of the Society. Westminster Cathedral Hall was designed by the British architect John Francis Bentley and represents some of his finest work. When completed in 1902 it was originally known as Chapter Hall and was used for liturgical services until the Cathedral itself was permanently opened on Christmas Eve 1903. It retains the exquisite Edwardian features of its original design. For sure, it is a fitting venue for the Society's 2017 Annual Meeting, enabling presenters and delegates to access a highly central conference venue with minimal difficulty.

For all those of you who have travelled to London from abroad, we welcome you to this great and historic city and wish you the most pleasant of stays.

ESPCH4 – Day One
Introduction

ESPCH4 has been organized over two days and eight individual sessions. Following the *Opening Welcome* from Professor Andrew Miles (London UK), the President and Chairman of Council of the Society, Professor Sir Jonathan Asbridge DSc (*hc*) DHSc (*hc*) (Oxford and London, UK), will deliver the *Presidential Address*.

Sessions 1 & 2
Sessions One and Two are focussed on the relationship between the distinctive theses of person-centered healthcare (PCH) and evidence-based medicine (EBM), exploring how these initially differing systems of thought can be seen as having moved closer together in their respective visions of what exactly constitutes an authentic health and social care. Session One is chaired by Dr. Mark Tonelli (Seattle USA & Cambridge UK). The first KeyNote presentation will be delivered by Professor Bee Wee (Oxford, UK) who will describe how the Ambitions Framework is informing a UK National Blueprint for Palliative and End-of-Life care which focusses relentlessly on the person of the patient and not primarily 'the system'. The second KeyNote presentation will be delivered by Dr. Benjamin Djulbegovic (California, USA), who will consider the crucial role of patient values and preferences in clinical-decision making and how various 'bridges' are being built between PCH and EBM. Following the keynote presentations, Professor Andrew Miles (London, UK) will provide a brief overview of the recently published EBM Manifesto for the purposes of conference discussion, followed by Dr. Peter Wyer's (New York, USA) presentation focussing on the epistemologies of PCH and EBM. Professor Michael Loughlin, Chairman of the ESPCH Special Interest Group on Health Philosophy, will join the ensuing panel as an invited Panel Discussant.

Session Two is chaired by Dr. Sandra Tanenbaum (Ohio, USA). The first presentation of the session is delivered by Dr. Mark Tonelli (Seattle, USA) who, continuing the theme of epistemology, will consider whether precision/personalized medicine can avoid the errors of EBM. The theme of genomic medicine continues in the presentation which follows by Dr. Hilary Burton (Cambridge UK) which examines the concept of person-centered disease prevention. The presentations which follow examine key themes of EBM and PCH. Dr. Mathew Mercuri (Ontario, Canada) reflects on EBM, PCH and variations in clinical practice, with James Marcum (Texas, USA) comparing and contrasting the EBM and PCH theses. Dr. Peter Wyer (New York, USA) will join the ensuing panel as an invited Panel Discussant.

Sessions 3 & 4
Following luncheon, the Conference moves to Sessions Three and Four which have as their respective foci the growing patient and public involvement in healthcare practice and research, the use of motivational interviewing, cancer care, and person-centered care implementation. Session Three is chaired by Professor Mary Chambers (London UK). The first presentation is given by Dr. Amy Price (Florida USA & Oxford UK) and focusses on patient and public involvement in the design of clinical trials, providing an overview of systematic reviews of the subject area. Dr. Price's presentation is followed by Professor Brendan McCormack's (Scotland UK) delivery which describes the development of person-centered educational programmes at both the Master's and Doctor's levels. Following Professor McCormack's presentation, Dr. Amy Price returns to the platform to describe the bridge between evidence, methods and ethics in research co-production. Dr. Metter Kjer Kaltoft (Denmark) will join the ensuing panel as an invited Panel Discussant.

Session Four of the Conference, the concluding Session of Day One, is chaired by Dr. Benjamin Djulbegovic (California, USA). The first presentation is given by Dr. Lauren Copeland (Wales UK) and focusses on person-centered approaches to motivational interviewing as part of strategies to effect behavioural change. Following Dr. Copeland's delivery, Dr. Alan Haycox (Liverpool, UK) addresses the economic aspects of cancer care with reference to the maxim of curing sometimes, but caring always. Following Dr. Haycox's presentation, Professor Alan Gillies (Lancashire UK & Romania) continues the theme of cancer care, presenting a person-centered approach to moving cancer care from a focus on the acute episode to that of a long-term condition. The concluding presentation of the Conference will be delivered by Dr. Derek Mitchell (Kent UK), focusing on the barriers to PCH implementation. Professor Diana Slade (Canberra, Australia) will join the ensuing panel as an invited Panel Discussant.

ESPCH4 – Awards Ceremony and Reception

Following the Close of Day One of the Conference, the President of the Society will confer the 2017 Awards. The winner of this year's Presidential Medal is Professor Bee Wee (Oxford UK), with the Senior Vice Presidential Medal being awarded to Dr. Benjamin

Djulbegovic (California USA). The Platinum Medal of the Society is awarded to Professor Diana Slade (Canberra, Australia) and the Gold Medal to Ms. Jane Teasdale (Ontario, Canada). The Silver Medal of the Society is awarded jointly to Dr. Derek Pheby (Buckingham UK), Dr. Lorenzo Lorusso (Pavia Italy), Dr. Lara Gitto (Rome, Italy) and Dr. Elenka Brenna (Rome, Italy) for team-based research. The Bronze Medal of the Society is awarded to Ms. Bernadette Brady (Canberra, Australia). The Book Prize is awarded to Professor Brendan McCormack (Edinburgh, Scotland) and the Essay Prize to Dr. Mathew Mercuri (Ontario, Canada). The Young Researcher prize is awarded to Ms. Karishma Jivraj (London UK). There were no winners of the 2017 Young Teacher prize. A formal Reception within the Cathedral Hall will follow the conferment of the awards.

ESPCH4 – Day Two

Sessions 5 & 6

Day Two of the Conference is opened by Professor Andrew Miles (London UK) and commences with Sessions Five and Six which have as their respective foci the lived experience of illness and evidence-informed, person-centered guideline development. Session Five is chaired by Dr. Thomas Fröhlich (Germany). The first KeyNote lecture will be delivered by Professor Emerita Colonel Marilyn Ray (Florida, USA) and presents a phenomenological perspective in focusing on the lived experience of illness as the starting point for inquiry, reflection and interpretation by the clinical professions. Dr. Ray's presentation is followed by the second KeyNote, to be delivered by Professor Diana Slade (Australia). Professor Slade's presentation focusses on clinical communication skills and processes, specifically how better bedside handover can be achieved through the training of nurses in interactional and informational skills as part of a person-centered approach. Continuing the theme of communication, Dr. Elizabeth Rider (Massachusetts, USA) presents a 10-year perspective on relational learning and how this method can enhance faculty teaching of communication skills and relational capacities. The final presentation of the session is delivered by Ms. Bernadette Brady (Australia) and focusses on the building of better relationships within emergency care settings. Professor Sir Jonathan Asbridge (Oxford and London UK) will join the ensuing panel as an invited Panel Discussant.

Session 6 is chaired by Dr. Peter Wyer (New York, USA), with a focus on evidence-informed, person-centered clinical decision-making. As part of this session, the first presentation is delivered by Dr. Benjamin Djulbegovic (California, USA) and draws from the 'Great Rationality Debate' in discussing the many faces of rationality in medicine and their implications for a person-centered clinical decision-making model. Following Dr. Djulbegovic's presentation, we move to the presentation by Professor Jack Dowie (London UK and Denmark) and to his review of *MyDecisionEngagement*, a formative, preference-sensitive and dually personalized measure for person-centered care. Next, Dr. Mette Kjer Kaltoft (Demark) describes a bone health decision support tool of use in the avoidance of invasive medicine when constituting person-centered bone health models of care. The final delivery of the morning is given by Dr. Amy Price (Florida USA & Oxford UK) who considers the codification of the principles of person-centeredness into research co-production. Dr. Shashi Seshia (Saskatchewan, Canada) will join the ensuing panel as an invited Panel Discussant.

Sessions 7 & 8

Following luncheon, the Conference moves to Sessions Seven and Eight which have as their respective foci health policy, home-based person-centered care, concepts of personhood and person-centered patient safety and complex clinical cases. Session Seven is chaired by Professor Emerita Colonel Marilyn Ray (Florida, USA) and begins with a focus by Dr. Sandra Tanenbaum (Ohio, USA) on current health policies emerging in the United States and their implication for the development and provision of person-centered care. Following Dr. Tanenbaum's presentation, Professor Didier Vinot (Lyon, France) will consider the problem of assessment of value of relationship in person-centered healthcare organisations. Following Professor Didier's delivery, the Conference moves to consider current progress in healthcare provision at home, the first presentation discussing the Healthcare at Home Model delivered by Ms. Wendy Gee (London UK) and the second delivered by Ms. Jane Teasdale (Ontario, Canada). Dr. Elisa Chelle (Lyon, France) will join the ensuing panel as an invited Panel Discussant.

Session Eight, the final session of the Conference, is chaired by Professor Andrew Miles (London UK) and commences with a presentation examining a centered context of personhood by Dr. Thomas Fröhlich (Heidelberg, Germany). Following Dr. Fröhlich's delivery, Dr. Shashi Seshia (Saskatchewan, Canada) presents a discussion on how Reason's model of clinical safety can be expanded to embrace person-centered principles. Following Dr. Seshia's delivery, Dr. Derek Pheby (Buckingham UK) and Dr. Lorenzo Lorusso (Pavia, Italy) will focus on the care and costs of ME/CFS within the context of a person-centered health and social care framework. Dr. Lara Gitto (Rome, Italy) will join the ensuing panel as an invited Panel Discussant.

Following the Panel Discussion for Session Eight, the President and Chairman of Council, Professor Sir Jonathan Elliott Asbridge and the Senior Vice President/Secretary General of the Society, will jointly close the Conference.

ESPCH4 – Resulting Publications and Society Membership

The presentations delivered at ESPCH4 will in the majority of cases be written up into formal academic papers and published within Volume 6 (2018) of the *European Journal for Person Centered Healthcare*, the official journal of the Society, thereby affording international access to presented work. The Society welcomes applications for membership at any of the available grades of membership – Distinguished Fellow, Fellow, Member, Associate and Student. Applications may be made via the ESPCH Website or by writing to Professor Andrew Miles: andrew.miles@pchealthcare .org.uk

Forthcoming ESPCH projects

As part of the implementation of Year 5 of the Society's 10 Year Strategic Plan, the Society will, in 2018, begin the organization of a large number of illness/condition-specific conferences and practice guidelines development across a wide variety of chronic illnesses, designed to assist colleagues in increasing the person-centeredness of care within individual clinical practice and health systems. Multi-stakeholder involvement in these initiatives will be a cardinal feature of the programme and sponsorship opportunities are available to interested organisations. Further details of the projects will be made available via the Society's Website and Journal in December 2017 and may be discussed also with Professor Andrew Miles: andrew.miles@pchealthcare .org.uk

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

Professor Sir Jonathan Asbridge DSc (*hc*) DHSc (*hc*)
President & Chairman of Council

	Day One 26 October 2017
08.00	**REGISTRATION AND REFRESHMENTS**
09.00	**Welcome to ESPCH4, Westminster, London, UK** Professor Andrew Miles 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* / Editor-in-Chief, *Journal of Evaluation in Clinical Practice*
09.05	**Presidential Address** Professor Sir Jonathan Asbridge DSc (*hc*), DHSc (*hc*), President and Chairman of Council, European Society for Person Centered Healthcare

	Session 1 Early Morning Session
	FOCUS ON PERSON-CENTERED HEALTHCARE AND EVIDENCE-BASED MEDICINE – ADVANCING THE DIALOGUE - I
	Early Morning Chairman Dr. Mark Tonelli, Professor of Medicine, Division of Pulmonary and Critical Care Medicine & Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, USA & Visiting Fellow, Clare College, Cambridge, UK
09.10	**KEYNOTE 1. Focussing relentlessly on the person, not the system – the Ambitions Framework as the UK National Blueprint for Palliative and End-of-Life Care** Professor Bee Wee, National Clinical Director for End of Life Care, NHS England & Consultant in Palliative Medicine, Sir Michael Sobell House, Oxford University Hospitals NHS Foundation Trust, Oxford, UK
09.35	**KEYNOTE 2. The crucial role of patient values and preferences in clinical decision-making: bridging the gap between EBM and PCH** Dr. Benjamin Djulbegovic, Professor of Oncology & Director of Research, Department of Supportive Medicine & Department of Hematology, City of Hope, Duarte, California, USA
10.00	**Evidence Based Medicine - a manifesto for better healthcare** Professor Andrew Miles MSc MPhil PhD DSc (*hc*), Centre for Public Engagement, Joint Faculty of Health, Social Care and Education, Kingston University and St. George's University of London, St. George's University Hospital Campus, London
10.20	**The Tree of Wisdom: Maintaining Epistemological Health Within the Emerging Evidence-free Environment** Dr. Peter C. Wyer, Associate Clinical Professor of Medicine, Columbia University College of Physicians and Surgeons NY & Chairman, Section on Evidence Based Health Care at the New York Academy of Medicine, New York, USA
10.40	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Professor Michael Loughlin, Manchester, UK)**

11.00	**BREAK AND REFRESHMENTS**

	Session 2. Late Morning Session
	FOCUS ON PERSON-CENTERED HEALTHCARE AND EVIDENCE-BASED MEDICINE – ADVANCING THE DIALOGUE - II
	Late Morning Chairman Dr. Sandra Tanenbaum, Professor, Health Services Management and Policy, College of Public Health, Ohio State University, Ohio, USA
11.30	**Substituting genomics for clinical epidemiology: can precision/personalized medicine avoid the errors of EBM?** Dr. Mark Tonelli, Professor of Medicine, Division of Pulmonary and Critical Care Medicine & Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, USA & Visiting Fellow, Clare College, Cambridge, UK
11.50	**Person-centered disease prevention: from populations to individuals** Dr. Hilary Burton, Senior Public Health Consultant and Immediate Past Director, PHG Foundation, Cambridge, UK
12.10	**Reflecting on Evidence-Based Medicine, Person Centered Care and Practice Variations** Dr. Mathew Mercuri, Assistant Professor, Division of Emergency Medicine, McMaster University & Hamilton General Hospital, Ontario, Canada
12.30	**Mapping similarities and differences to progress mutual understanding and dialogue – a comparison and contrast of EBM and PCH** Dr. James Marcum, Professor, Department of Philosophy & Director, Medical Humanities Program, Baylor University, Texas, USA
12.50	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Dr. Peter Wyer, NY, USA)**

13.10	**LUNCHEON**

	Session 3. Early Afternoon Session
	FOCUS ON PATIENT AND PUBLIC INVOLVEMENT AND CLINICIAN EDUCATION IN PERSON-CENTERED HEALTHCARE
	Early Afternoon Chairman Professor Mary Chambers, Professor of Mental Health Nursing & Director, Centre for Public Engagement, Joint Facilty of Health, Social Care and Education, Kingston University and St. George's University of London, UK
14.00	**Patient and Public Involvement in the Design of Clinical Trials: An Overview of Systematic Reviews** Dr. Amy Price, Chief Executive Officer Empower2Go Florida, USA & Research Fellow, *British Medical Journal* Department of Continuing Education, University of Oxford, UK
14.25	**Person-centeredness in the Curriculum: developments, opportunities and lessons learned** Professor Brendan McCormack, Head of the Division of Nursing and Associate Director, Centre for Person-centred Practice Research, School of Health Sciences, Queen Margaret University, East Lothian, Scotland, UK
14.50	**The bridge between evidence, methods and ethics in research co-production** Dr. Amy Price, Chief Executive Officer Empower2Go Florida, USA & Research Fellow, *British Medical Journal* Department of Continuing Education, University of Oxford, UK
15.10	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Dr. Mette Kjer Kaltoft, Denmark)**

15.30	**BREAK AND REFRESHMENTS**

	Session 4. Late Afternoon Session
	FOCUS ON MOTIVATIONAL INTERVIEWING, CANCER CARE AND THE EXPERIENCE OF ILLNESS
	Late Afternoon Chairman Dr. Benjamin Djulbegovic, Professor of Oncology & Director of Research, Department of Supportive Medicine & Department of Hematology, City of Hope, Duarte, California, USA
16.00	**Introduction to Motivational Interviewing - a person-centered approach to health behaviour change** Dr. Lauren Copeland, Research Associate, PRIME Centre Wales, Division of Population Medicine, Cardiff University, Cardiff, Wales, UK
16.20	**To cure sometimes but to care always. Economic perspectives and lessons for cancer care** Dr. Alan Haycox, Reader in Health Economics, School of Management, University of Liverpool, UK
16.40	**Moving cancer from acute episode to long term condition: a person-centered approach** Professor Alan Gillies, Professor of Information Management, UCLAN; Director, Register of Cancer Survivorship Professionals Ltd and Doctor *Honoris Causa*, University of Medicine and Pharmacy, Cluj, Napoca, Romania
17.00	**From Persons to Patients – the barriers to person-centered healthcare** Dr Derek Mitchell, Fellow, England Centre for Practice Development, Canterbury Christchurch University, Kent, UK
17.20	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Dr. Harold E. Longmaid III, Massachusetts, USA)**
17.40	**Concluding Address and Close of Day One** Professor Andrew Miles 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* / Editor-in-Chief, *Journal of Evaluation in Clinical Practice*
18.15	**THE 2017 ANNUAL AWARDS CEREMONY AND CONFERENCE RECEPTION OF THE EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE** ***(Ticket Holders Only)***

	Day Two 27 October 2017
08.00	**REGISTRATION AND COFFEE**
09.00	**WELCOME TO DAY 2** Professor Andrew Miles 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* / Editor-in-Chief, *Journal of Evaluation in Clinical Practice*
	Session 5. Early Morning Session
	FOCUS ON LIVED EXPERIENCE OF ILLNESS, CLINICAL COMMUNICATIONAND BUILDING RELATIONSHIPS
	Early Morning Chairman Dr. Thomas Fröhlich, Physician, Heidelberg, Germany & Vice President (Western Europe), European Society for Person Centered Healthcare
09.10	**KEYNOTE 1. Human Science: Lived Experience as the Starting Point for Inquiry, Reflection and Interpretation in the Caring Professions** Colonel (Rtd) Professor Emerita Marilyn Ray, Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, Florida, USA
09.35	**KEYNOTE 2. Better bedside handover communication: training nurses in the interactional and informational skills of well-structured patient-centred handovers** Professor Diana M. Slade, Professor of Applied Linguistics and Director, Institute for Communication in Healthcare, Australian National Univerity, Canberra, Australia
10.00	**Relational Learning: Enhancing Faculty Teaching of Communication Skills and Relational Capacities – A 10 Year Perspective** Dr. Elizabeth Rider, Director of Academic Programs & Director, Faculty Education Fellowship in Medical Humanism and Professionalism, Institute for Professionalism and Ethical Practice, Harvard Medical School, Boston, USA
10.20	**Seek first to understand - building better relationships in an Emergency Department** Ms.Bernadette Brady, Director, Partnering with Patients, Canberra, Australia & Former Director, Patient and Family Centered Care, ACT Health, Canberra, Australia
10.40	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Professor Sir Jonathan Asbridge, Oxford and London UK)**

11.00	**BREAK AND REFRESHMENTS**

	Session 6. Late Morning Session
	FOCUS ON EVIDENCE-INFORMED, PERSON-CENTERED CLINICAL DECISION-MAKING
	Late Morning Chairman Dr. Peter Wyer, Associate Clinical Professor of Medicine, Columbia University College of Physicians and Surgeons NY & Chairman, Section on Evidence Based Health Care at the New York Academy of Medicine, New York, USA
11.30	**The Great Rationality Debate - the many faces of rationality in medicine and in person-centered clinical decision-making** Dr. Benjamin Djulbegovic, Professor of Oncology & Director of Research, Department of Supportive Medicine & Department of Hematology, City of Hope, Duarte, California, USA
11.50	***MyDecisionEngagement*: a formative, preference-sensitive, dually-personalised measure for person-centered care** Professor Jack Dowie, Emeritus Professor of Health Impact Analysis, Department of Social & Environmental Health Research, Faculty of Public Health & Policy, London School of Hygiene and Tropical Medicine, London
12.10	**A bone health decision support tool - avoiding invasive medicine in person-centered bone health** Dr. Mette Kjer Kaltoft, Odense University Hospital, Svenborg, Denmark & University of Southern Denmark, Odense, Denmark
12.30	**Person-centered clinical practice guidelines** Dr. Amy Price, Chief Executive Officer Empower2Go Florida, USA & Research Fellow, *British Medical Journal* Department of Continuing Education, University of Oxford, UK
12.50	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Dr. Shashi Seshia, Canada)**

13.10	**LUNCHEON**

	Session 7.Early Afternoon Session
	FOCUS ON HEALTH POLICY, VALUE AND COMMUNITY-BASED PROVISION OF PERSON-CENTERED MODELS OF HEALTHCARE
	Early Afternoon Chairman Colonel (Rtd) Professor Emerita Marilyn Ray, Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, Florida, USA
13.50	**Current U.S. Health Policy and the Future of Person-Centered Care** Dr Sandra Tanenbaum, Professor, Health Services Management and Policy, College of Public Health, Ohio State University, Ohio, USA
14.10	**The problem of assessment of value of relationship in Patient Centered Healthcare Organizations** Professor Didier Vinot, Co-Director, Chair 'Values of Patient-Centered Care' and Vice President for Economic and Social Affairs and Heritage, University of Lyon 3, France
14.30	**Homecare: the person-centred approach** Ms. Wendy Gee, Director of Nursing, Healthcare at Home Ltd, Newcastle-upon-Tyne, UK
14.50	**"The Meaning of Me ®" a Canadian blue print for addressing the complex whole that is the person at the centre of the community based homecare services model** Ms. Jane Teasdale, Director, Business Development & Community Relations and Principal Owner Mosaic Home Care Services Inc. and Community Resource Centres, Toronto, Ontario, Canada
15.10	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Dr. Elisa Chelle, France)**

15.30	**BREAK AND REFRESHMENTS**

	Session 8. Late Afternoon Session
	FOCUS ON CONCEPTS OF PERSONHOOD, PATIENT SAFETY AND COMPLEX CLINICAL SCENARIOS
	Late Afternoon Chairman Professor Andrew Miles 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* / Editor-in-Chief, *Journal of Evaluation in Clinical Practice*
16.00	**A centered concept of personhood** Dr. Thomas Fröhlich, Physician, Heidelberg, Germany & Vice President (Western Europe), European Society for Person Centered Healthcare
16.20	**Gating the holes in the Swiss cheese: expanding Professor Reason's model for Person-Centered Healthcare** Dr. Shashi S. Seshia, Clinical Professor,Department of Paediatrics, Division of Paediatric Neurology, University of Saskatchewen, Saskatoon, Saskatchewen, Canada
16.45	**The care and costs of ME/CFS: the EUROMENE initiative** Dr. Lorenzo Lorusso, Consultant Neurologist, Pavia, Italy; Dr. Derek Pheby, Visiting Professor of Epidemiology, Buckinghamshire New University, High Wycombe, England, UK; Dr. Lara Gitto, Health Economist & Researcher, CEIS EEHTA (Economic Evaluation and Health Technology Assessment), Univeristy di Roma "Tor Vergata", Rome, Italy & Dr. John Cullinan, JE Cairnes School of Business & Economics, National University of Ireland (NUI), Galway, Republic of Ireland
17.20	**PANEL DISCUSSION WITH DELEGATE PARTICIPATION (with invited Panel Discussant Dr. Lara Gitto, Rome, Italy)**
17.40	**Closing Remarks** Professor Sir Jonathan Asbridge DSc (*hc*), DHSc (*hc*), President and Chairman of Council, European Society for Person Centered Healthcare
17.50	**CLOSE OF THE FOURTH ANNUAL CONFERENCE OF THE ESPCH** Professor Andrew Miles 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* / Editor-in-Chief, *Journal of Evaluation in Clinical Practice*
18.30	**MEETING OF COUNCIL OF THE EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE (*Members of Council and invited observers only)***

Abstracts for Presentations Day 1 26 October 2017

09.10 KEYNOTE 1. Focussing relentlessly on the person, not the system – the Ambitions Framework as the UK National Blueprint for Palliative and End-of-Life Care

Professor Bee Wee, National Clinical Director for End of Life Care, NHS England & Consultant in Palliative Medicine, Sir Michael Sobell House, Oxford University Hospitals NHS Foundation Trust, Oxford, UK

In this presentation, I shall describe why and how the Ambitions for Palliative and End of Life Care came about, as a national framework for local action in England. The belief in, and practice of, person centred holistic care has always been fundamental to palliative care. But as more and more people become involved in supporting and delivering palliative and end of life care, and as the systems in which we all work and live come under increasing pressure, there is a danger that the person becomes lost in the system. I will explain how the ethos and language which permeate the Ambitions Framework help to send across a strong national signal about the centrality of the individual, and those important to them. Instead of a pathway depicting a 'typical' patient journey, the Ambitions Framework sets out foundations and building blocks that are needed to build person centred outcomes for each individual. We need to be relentless in focusing on the person, and in ensuring that the health and care system, and wider society, supports rather than hinders this focus.

09.35 KEYNOTE 2. The crucial role of patient values and preferences in clinical decision-making: bridging the gap between EBM and PCH

Dr. Benjamin Djulbegovic, Professor of Oncology & Director of Research, Department of Supportive Medicine & Department of Hematology, City of Hope, Duarte, California, USA

At its core, clinical medicine is characterized by decision-making under conditions of uncertainty. Many factors affect decision-making, chief of which is having (reliable) research evidence. Evidence, however, is necessary but not sufficient for optimal decision-making. Both EBM and PCH insist that consulting patients' values and preferences (V&P) is *conditio sine qua non* for modern practice of medicine. This requirement is, however, normative, derived from the right-based ethics. Research during last two decades has convincingly demonstrated that people have difficulties figuring out what they really want, that their V&Ps are unstable, context-dependent and easily manipulated. As a result, today's PCH is characterized by a normative-descriptive gap, which raises the important questions for the future of clinical medicine and the role of physicians. This, among other things raises, an uncomfortable question about paternalism in modern practice of medicine: are V&P are absolute or there is a role for paternalism in modern healthcare?

10.00 Evidence Based Medicine - a manifesto for better healthcare

Professor Andrew Miles MSc MPhil PhD DSc (*hc*), Centre for Public Engagement, Joint Faculty of Health, Social Care and Education, Kingston University and St. George's University of London, St. George's University Hospital Campus, London

This presentation aims to summarise, for the purposes of discussion, the key tenets of the 'EBM Manifesto', debated at the Oxford Conference 'Evidence Live' in mid-June 2017 and which was subsequently published with the *British Medical Journal* in August earlier this year (2017) under the title '*Evidence based medicine manifesto for better healthcare. A response to systematic bias, wastage, error and fraud in research underpinning patient care*'. The article to which I refer, authored by Carl Heneghan, Kamal Mahtani, Ben Goldacre, Fiona Godlee, Helen Macdonald and Duncan Jarvies, is brief, spanning only some three published pages, although it importantly includes two boxes which, taken together, illustrate the problems with the 'E' of EBM. Yet even when we have a *reliable* and *acceptable* 'E' for EBM, how do we use it when we are confronted with the very particular personal circumstances of the unique individual clinical 'case' - where 'reliable scientific evidence' may collide, for example, with the patient's own values and preferences? The question remains as it always was – how is scientific evidence to be integrated with all of the other forms of knowledge of immediate relevance to the person, who, having become ill, presents, asking for help? The essence of clinical practice remains, perhaps, as it was in 1927 and 1928, when Francis Peabody spoke of, indeed described, in *JAMA*, the essences of the 'care of the patient' and 'the soul of the clinic'. This recent Manifesto, then, appears strong on a dogmatic insistence on an essential primacy of scientific knowledge within the consultation, and weak on how science is to be methodologically integrated alongside other sources of knowledge in order to ensure that patients' real life concerns are attended to. For sure, a strong concern for the development, dissemination and implementation of better (scientific) evidence for better healthcare is to be applauded. But the Manifesto leaves unanswered the question of how such knowledge it is be integrated into real life clinical decision-making if patients' multiple concerns are to be taken properly and comprehensively into full account. It might therefore be asked: 'Is this a Manifesto aimed at satisfying the theoretical interests and concerns of clinical scientists, or is it a Manifesto aimed at assisting the experience and coping of patients with their illnesses and those of the clinicians who aim to serve these patients well? Remedies to poor science are outlined by the Manifesto, but methods to use the resulting science in the care of the patient and the soul of the clinic are undescribed.

10.20 The Tree of Wisdom: Maintaining Epistemological Health Within the Emerging Evidence-free Environment

Dr. Peter C. Wyer, Associate Clinical Professor of Medicine, Columbia University College of Physicians and Surgeons NY & Chairman, Section on Evidence Based Health Care at the New York Academy of Medicine, New York, USA

Criticisms and defenses of evidence-based medicine (EBM) continue to proliferate but have neither resulted in a coherent body of discourse nor a successful demonstration of how research evidence can constitute a viable "basis" for maximizing the health of individuals and communities. In the wake of the recent US presidential election, such exchanges have been generated within a climate in which ostensibly factual information is subject to rejection as "fake news" even as maliciously fake news proliferates via nefarious electronic outlets. Within this setting, the integrity of information from clinical research is being questioned as a result of ongoing revelations of fraud and subterfuge on the part of research sponsors, leading to claims that EBM has failed and is in a state of crisis. Even as EBM advocates express alienation from their only presumed source of truth, it has become clear that a positivist conceptual framework is incapable of remedying such a state of crisis. Failed attempts at such a remedy have taken the form of proposals to redefine elements of the healthcare process as "EBM", subjugating patient experience, perspectives and participation to elements of an expanded "hierarchy of evidence" based upon research design. Such proposals have not been put in actionable form and appear destined to collapse under their own weight. Other attempts have posed, in different ways, rationalist solutions to the dilemmas created by a dominant positivist framework. A more compelling approach would entail adoption of a social sciences orientation to the issues of person centeredness, attentiveness to the patient experience, maximization of the value of research and inclusiveness of stakeholder engagement in all aspects of the healthcare system. Specifically, a social constructivist epistemology corrects many, if not all, weaknesses of the positivist-rationalist juggernaut.

11.30 Substituting genomics for clinical epidemiology: can precision/personalized medicine avoid the errors of EBM?

Dr. Mark Tonelli, Professor of Medicine, Division of Pulmonary and Critical Care Medicine & Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, USA & Visiting Fellow, Clare College, Cambridge, UK

While precision/personalized medicine (PM) aims to incorporate individual variability in genes, in environment and in lifestyle into individualized prevention, diagnosis and treatment strategies, to date the progress in PM has been related to personalized genetic profiling. Even this relatively narrow focus on genomics has required PM to expand beyond population-based methodologies in order to individualize care. More than half of the genetic variation in individuals is associated with extremely rare variants, where allele frequency does not allow for standard population studies in order to assess medical relevance. As such, precision medicine has moved beyond standard tools of epidemiology to develop and incorporate mechanistic reasoning and methodologies into clinical decision making. This has lead to improvements in risk assessment, diagnostics and therapeutics for a limited number of disorders. While this epistemic inclusivity represents an improvement from evidence-based medicine, PM will need to embrace an even broader collection of methods and knowledge, including those from the social sciences, in order to achieve the goal of truly personalized care.

11.50 Person-centered disease prevention: from populations to individuals

Dr. Hilary Burton, Senior Public Health Consultant and Immediate Past Director, PHG Foundation, Cambridge, UK

In this presentation I will explore some of the complexities of person centred healthcare in the context of the increased potential for personalised prevention enabled by new genomic and other biomedical and digital technologies.

Genomics and other biomedical and digital technologies offer unprecedented opportunities for individuals to find out about their risk of disease or detect its onset early – making it possible to prevent disease or ameliorate the effects. Increasingly, these opportunities create a new dimension for prevention. In the future personalised prevention will sit alongside the current major public health prevention programmes aimed at populations. Genomic technologies may be used to assess individual risk with the aim of offering an intervention appropriate to that risk. This is most critical in the case of single gene disorders where risk of future disease may be extremely high and effective treatments are available. But increasingly it will include measurement of so-called susceptibility variants, where a combination of many variants (possibly more than 100) is used to assess risk of common chronic diseases such as heart disease or cancer; the population can then be stratified according to risk and preventive options tailored to the risk level. This has the theoretical advantage of minimising the harm that can arise from unnecessary testing, or treatments for low risk people who have little opportunity to benefit. Interventions can also be focused on those at highest risk, in the hope that this group may be more motivated to change their lifestyle or comply with treatment. Ultimately, this will be more cost effective for the health system.

Whereas genomic tests would largely be provided by the health sector, individuals are nowadays accessing information about their health from wider sources: in the future we can envisage a range of biomarkers being available via wearable sensors such as Fitbits, sensors around the house or new technologies such as AliveCor, which can provide detailed 24 hour ECG monitoring.

But using this information for prevention may be quite complex. In genomics people may have the opportunity to find out about potential for a wide range of disease, some of it very rare and all of it quite uncertain. The vast majority of physicians will be unprepared to help them interpret test results. Yet the stakes are high: knowledge of risk may suggest interventions that are invasive and potentially harmful. At the individual level, getting decisions wrong could be costly on many dimensions, whereas for health systems there is the question of how to deal with increased demand and how to optimise benefit for the whole population.

How do we ensure that person-centred care is enhanced in this new complex and uncertain environment? Central to person-centred healthcare is the principle of shared decision-making: decision making that is informed, takes into account values and preferences and enhances patient autonomy, independence and empowerment. Issues to be addressed will include the imbalance of knowledge and experience, how to help patients understand what is important to them, how to provide a sympathetic and caring presence and maintaining compassion in healthcare.

12.10 Reflecting on Evidence-Based Medicine, Person Centered Care and Practice Variations

Dr. Mathew Mercuri, Assistant Professor, Division of Emergency Medicine, McMaster University & Hamilton General Hospital, Ontario, Canada

Healthcare services are typically provided at the level of the individual patient. What the individual patient seeks is something that will address his or her health care needs. Hence we cannot assume that the individual will accept (or should acquire) what works on average at the level of the population. One reason is that for any therapeutic intervention there is no guarantee that it will be effective for everyone (i.e., success is uncertain and the final outcome for any individual is also uncertain). This is problematic because health is not a transferable good, hence individuals cannot be compensated if they acted based on what is good for the population. Another reason is that individual patients may differ from the population (or each other) in their values, preferences and circumstances and thus value the potential consequences of an intervention differently.

There is concern among both service providers and patients that the current state of individual patient care is not optimal. Over the past few decades, three movements have received a great deal of attention by healthcare researchers and stakeholders: Evidence Based Medicine (EBM), Person Centred Medicine (PCM) and Small Area Variations (SAV). These movements each claim to provide a means for improving care to individual patients. However, each has its own challenges in meeting this claim. For EBM, the challenge stems from its commitment to clinical trials as evidence of therapeutic effectiveness. Clinical trials offer information on the average effect of a therapy among those patients participating in the trial. How such information is useful for managing the care of individual patients is not clear. Furthermore, although EBM recognizes patient preferences, values and the clinical context as important factors in individual patient management, it is not clear how each of these are defined, measured and integrated with trial evidence when determining how to manage the care of an individual patient. PCM offers an intriguing alternative to EBM in that it both recognizes that the individual patient should be the focus of health care service delivery, and that the kind of evidence we need for effective delivery should be sought at the level of the individual patient. However, how we acquire such evidence is not clear at this time. The usefulness of SAV for individual patient care is premised on the belief that observed variations reflect that some patients are not receiving the care they need - eliminating those variations should result in improved care for individual patients. However, SAV methods are not sensitive to individual patient preferences, values and circumstances and thus, do not discriminate between warranted and unwarranted variations. This is problematic in that eliminating variation that is warranted may not be in the best interest of the individual patient.

Although PCM offers perhaps the best way forward, we are currently without an answer on how to optimize the care for an individual patient, nor is there a magical answer on how to move forward. We believe that only by acknowledging the problems can we find an answer.

12.30 Mapping similarities and differences to progress mutual understanding and dialogue – a comparison and contrast of EBM and PCH

Dr. James Marcum, Professor, Department of Philosophy & Director, Medical Humanities Program, Baylor University, Texas, USA

Evidence-based medicine (EBM) and person-centered healthcare (PCH) are often seen as opposing approaches to clinical practice. And yet both offer advantages to providing quality healthcare. In this presentation, both approaches to clinical practice are analyzed philosophically by comparing their foundational principles. The presentation's goal is to determine whether a common ground exists in which they might be integrated and how best to operationalize an integrated approach, both clinically and pedagogically.

To that end, the principles undergirding both EBM and PCH are enumerated and then integrated by shifting the emphasis from EBM to PCH. Rather than focusing on clinical decisions and recommendations, as for EBM's GRADE approach to healthcare, the focus is on the person - whether patient or clinician - for the delivery of quality healthcare. In this way, PCH provides the optimal starting point for EBM. In terms of operationalizing the two approaches to clinical practice, Miles and Asbridge propose a dynamic 4-step model towards that end, which also serves as an impetus to incorporate an integrated approach to EBM and PCH into the medical education.

In sum, EBM and PCH can be integrated but only through enfolding EBM into PCH, particularly with a well-formed notion of the person.

Finally, the root of modern healthcare must be a person's, whether patient's or clinician's, dignity. For the goal of PCH is to relieve suffering associated with illness, whether that involves curing a disease or not, and not to add to the suffering associated with illness.

14.00 Patient and Public Involvement in the Design of Clinical Trials: An Overview of Systematic Reviews

Dr. Amy Price, Chief Executive Officer Empower2Go Florida, USA & Research Fellow, *British Medical Journal* Department of Continuing Education, University of Oxford, UK

Background: Funders encourage lay-volunteer inclusion in research. There is controversy and resistance, given concerns of role confusion, exploratory methods and limited evidence about what value lay-volunteers bring to research. This overview explores these areas.

Methods: Eleven databases were searched without date or language restrictions for systematic reviews of public involvement (PPI) in clinical trials design. This systematic overview of PPI included 27 reviews from which areas of good and bad practice were identified. Strengths, weaknesses, opportunities and threats of PPI were explored through use of meta-narrative analysis.

Results: Inclusion criteria was met by 27 reviews ranging in quality from high (n=7), medium (n=14) to low (n=6) reviews. Reviews were assessed using Cerqual, Nice-H, CASP for qualitative research and CASP for systematic reviews. Four reviews report risk of bias. Public involvement roles were primarily in agenda setting, steering committees, ethical review, protocol development, and piloting. Research summaries, follow-up, and dissemination contained PPI, with lesser involvement in data collection, analysis, or manuscript authoring. Trialists report difficulty in finding, retaining, and reimbursing volunteers. Respectful inclusion, role recognition, mutual flexibility, advance planning and sound methods were reported as facilitating public involvement in research. Public involvement was reported to have increased the quantity and quality of patient relevant priorities and outcomes, enrollment, funding, design, implementation and dissemination. Challenges identified include lack of clarity within common language, roles and research boundaries; while logistical needs include extra time, training and funding, Researchers report struggling to report involvement and avoid tokenism.

Conclusions: Involving patients and the public in clinical trials design, can be beneficial but requires resources, preparation, training, flexibility and time. Issues to address include reporting deficits for risk of bias, study quality and conflicts of interests. We need to address these tensions and improve dissemination strategies to increase PPI and health literacy.

14.25 Person-centeredness in the Curriculum: developments, opportunities and lessons learned

Professor Brendan McCormack, Head of the Division of Nursing and Associate Director, Centre for Person-centred Practice Research, School of Health Sciences, Queen Margaret University, East Lothian, Scotland, UK

Person-centredness and person-centred practice is now a common discourse in health care generally. Significant developments have occurred in Scotland, across the UK and internationally in the development of person-centred healthcare services. However, a similar pace of development has not been evident in education programmes or in Higher Education Institutions. It remains the case that there are few examples of person-centred curricula and at best most have 'the person-centred course' as a part of the curriculum. O'Donnell *et al*. have demonstrated in a systematic review, that this situation is challenging to the way that (in this case) new nurses are prepared for the realities of working in a person-centred way in practice. The curriculum is more than the particular programme itself and inclusive notions of curricula pay attention to the total learning and academic milieu within which staff and students interact. To that end Waddington argues that Universities lack compassion in their structures and processes. This is an issue that we at The Division of Nursing Queen Margaret University have been addressing over the past 3 years. A key part of this work has been creating an academic environment that 'lives' person-centered values and compassion in all aspects of our work. This paper will present the results of this 3-year collaborative research project that has focused on generating a person-cenetred academic environment. It will illustrate the processes used and outcomes achieved thus far, drawing on 3 rounds of stakeholder evaluation data. The challenges of establishing the framework and embedding it in practice will also be highlighted. The ongoing programme of work will be outlined, so that all aspects of the curriculum culture are truly 'lived' rather than 'espoused'.

14.50 The bridge between evidence, methods and ethics in research co-production

Dr. Amy Price, Chief Executive Officer Empower2Go Florida, USA & Research Fellow, *British Medical Journal* Department of Continuing Education, University of Oxford, UK

Introduction: Evidence-based medicine (EBM) introduced in 1991 marks the relationship between medical evidence and clinical practice. In EBM, evidence acts as a neutral arbiter between competing views. EBM enjoys exponential growth on par with innovations such as antibiotics and anesthesia, however it has not escaped external controversy or internal debate. EBM asserts the trustworthiness of available evidence can determine the confidence we place in the relevant evidence. Crucially evidence is dynamic and comes in gradation of its relationship to the "truth"- high quality evidence is considered closer to the truth than lower quality evidence. The global reach of the concept of EBM implies it is commensurable or common across languages.

Objective: To investigate how the term "Evidence" is interpreted across languages and to explore the value of a common definition for the word evidence across languages and cultures.

Method: To assess how "evidence" is translated across 90 languages, we used Google Translator to translate the term evidence. After obtaining translation of the term "evidence"; we reversed translation to assess variation in how the term "evidence was denoted. We confirmed reliability of the "Google translation" by polling EBM colleagues for whom these languages were their mother tongue.

Results: We found languages carry distinctly different terms from the meaning of "evidence" in English. In 79/90 or 88% of languages, evidence and proof were used interchangeably and interpreted as "proof, law or terms that disallow grading of evidence quality and minimize the importance of critical appraisal.

Conclusions: Most languages translate "evidence" as a proof – a distinct concept that assumes certainty in arriving at "conclusion" than what English word "evidence" presumes. The concepts of medical evidence and, thus, EBM are arguably shaped by translation. Adopting the term "evidence" within a language does not retain or assure that the concept of EBM is commensurable or common across languages. When it is stated practice and policy are evidence-based, we benefit from the clarification of what is meant by evidence.

16.00 Introduction to Motivational Interviewing - a person-centered approach to health behaviour change

Dr. Lauren Copeland, Research Associate, Division of Population Medicine, Cardiff University, Cardiff, Wales, UK

Motivational Interviewing is an intervention designed to enhance a patient's motivation for change and adherence to treatment. "It is a collaborative, goal-oriented style of communication which pays particular attention to the language of change. It is designed to strengthen personal motivation for and commitment to a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion" (Miller & Rollnick, 2012). There are four key processes that happen within Motivational Interviewing counselling sessions; engaging, evoking, focusing and planning.

There have been a number of reviews examining at the effectiveness of Motivational Interviewing in relation to health outcomes, which have found that it can have a positive and statistically significant change in health outcomes such as cholesterol level, body weight and HIV viral load.

This talk will provide you with a brief overview of Motivational Interviewing and the techniques involved in delivering it.

16.20 To cure sometimes but to care always. Economic perspectives and lessons for cancer care

Dr. Alan Haycox, Reader in Health Economics, School of Management, University of Liverpool, UK

Archie Cochrane-effectiveness and efficiency: Health Economics has come a long way in a comparatively short period-not always without controversy !. In this short period perhaps the greatest controversies have revolved around the tools used by health economists to evaluate health service 'outcome'. Every clinician will repeat the mantra that 'every patient is different' and hence the aim of encompassing every patient within the same outcome parameter is obviously reductionist nonsense-however unfortunately such 'reductionism' is absolutely required if we are to generate comparisons of the clinical and cost effectiveness of the health benefits provided to patients as a consequence of their treatment. The simple (simplistic?) health economic approach of concentrating on the two elements of 'outcome' that are of greatest importance to patients (quality and quantity of life) has succeeded both in focussing healthcare resource allocation on outcome (rather than on input or process measures) and also in distilling the complex debate concerning how output can best be measured into a focus on optimising the quality and quantity of life of patients.

Given such controversies how can it be sensible to extend the approach to end of life care when longevity can be measure in weeks and quality of life is normally symptom driven and severely compromised. However, generating patient centred end of life care is crucial as I hope the following two real life examples adequately emphasise.

The unplanned journey- a ‘Bad’ Death: Ann was admitted to the hospice for pain control. She was a 32 year old lady who had been diagnosed with pancreatic cancer and had ascites which impacted on her ability to mobilise. Ann was unemployed and lived with her partner John who she had been in a relationship with for 2 yrs. Both Ann and John identified themselves as drug users. Other than the ‘sisters of mercy’ Ann received no other visitors as she had fallen out with her sisters due to her chaotic lifestyle.Ann’s pain was identified as ‘total pain’ and as a consequence was very hard to control. Ann was commenced on a pain chart on admission and this was completed every time she had breakthrough pain. No matter how many times pain relief was administered Ann’s pain was never any better and the scoring never went down. As a result John would get verbally aggressive with the staff, shouting that we weren’t quick enough with the pain relief and we weren’t doing enough to help her.Staff were upset and consequently we ensured that no one would care for Ann consecutive days. Although the staff weren’t directly caring for Ann support for team members was still required.Ann deteriorated quite quickly, was commenced on the LCP and John was called in and notified that Ann had entered the dying phase. Obviously he was very upset and verbally abusive; as a result we called in his key worker who did come in. Ann died with John lying next to her on the bed. After Ann’s death staff talked to John and he was very remorseful about how he had directed his anger to staff saying that he knew we were doing our best and was very reproachful. He came back the next day for what little possessions Ann had and was again very happy with how staff had cared for Ann

As this to us had been a ‘bad death’ as Ann’s pain had never really been controlled it was important for staff to ‘reflect’ on care given and what if anything would we change for future practice. This is also a way for staff to acknowledge what team members have done well and is a very positive experience for all the team.

The planned journey- a ‘Good’ Death: Bill was admitted to the hospice for terminal care from the community as his family were struggling to manage at home and Bill no longer wanted to be a burden to his loving family. Bill had lung cancer and was in the dying phase when admitted so went directly into a side room. Bills wife and his sister were present when staff went over the LCP. Bill was agitated and had a bit of pain and was commenced on a syringe driver. Bill had spoken to his wife about not wanting the ‘kids’ to be there when he passed away. He had all that he wanted which was her with him and so we set up a camp bed in the room and his wife made a ‘table’ (as it was Christmas) for the kids to come in a have their ‘goodies’.

Bill was very settled and all symptoms were well managed. Bill spent Christmas day with his family and died peacefully with his wife at his bedside early hours Boxing Day. The children had been referred to the children’s counsellor and had done memory boxes *for* their dad.

16.40 Moving cancer from acute episode to long term condition: a person-centered approach

Professor Alan Gillies, Professor of Information Management, UCLAN; Director, Register of Cancer Survivorship Professionals Ltd and Doctor *Honoris Causa*, University of Medicine and Pharmacy, Cluj, Napoca, Romania

In 2011, Cancer Research reports that for the first time the overall 10-year cancer survivorship rate in the UK exceeded 50%. This single figure hides a significant degree of complexity, nevertheless it suggests that for many of the commonest cancers the majority of patients will survive, and treatments after initial interventions should focus on dealing with these cancers as a long-term condition.

Therefore, the publication of the 2011 MacMillan report *“The importance of physical activity for people living with and beyond cancer”* which has proved to be highly influential was very timely.

In spite of its influence, this report and its headline conclusions also hide a significant degree of complexity. In 2014, Warrington Health Plus commissioned an evaluation report from this author for their “*We are positive about cancer”* cancer rehabilitation programme built around exercise, but including other support activities.

The literature review carried out for this evaluation concluded that “Many studies are small” and that:

“A common theme is that in order to gain significant benefits, the programmes need to be tailored for the patients, and the articles highlight differences according to age, gender, ethnicity, cancer type, cancer stage, therefore generalizable conclusions are difficult to establish."

The evaluation found that patients valued the exercise programmes but also belonging to a group, the opportunity to share experiences, and the information provided.

The evaluation demonstrated the need to meet the needs of patients living with cancer. Along with other local evaluations, it showed that support groups can have a major impact on patient well-being through a range of mechanisms including appropriate exercise programmes. However, there is a shortage of appropriately equipped professionals, and the author has established a professional register to support the development of a suitably equipped professional community.

17.00 From Persons to Patients – the barriers to person-centered healthcare

Dr Derek Mitchell, Fellow, England Centre for Practice Development, Canterbury Christchurch University, Kent, UK

From Persons to Patients: Something happens to us when we go and see a doctor or some other kind of healthcare professional. We go along as an independent thinking person who has made a decision to seek help with a health problem. We enter the room as an autonomous subject and leave as a patient. What is it that happens during this brief encounter? What is it about the nature of the encounter that changes us from being a person to being a patient?

How do we become Patients?: First, the doctor really does know better. Second there are the biological and normative understandings of illness which predominate in healthcare systems. In both cases we are depersonalised by the treatment we receive, treated as machines that have gone wrong rather than persons with a life of our own. Third there is medical technology, increasingly present in modern healthcare systems and which brings considerable benefits to all of us when we are ill. However, the use of medical technology goes a long way to depersonalise both sides of the healthcare encounter. Fourth there is the sheer complexity of the process of diagnosis and treatment and the multiplicity of people who we will meet. In healthcare we live in an age of strangers. We are passed on, through a bewildering stream of Others who we do not know and who we may never meet again. Fifth there is the curative impulse. Doctors are trained to cure patients, or more accurately to cure their ills. Those of us who visit doctors accept this too, we go looking for a cure. This jointly held impulse quickly overrides our sense of personal autonomy and whatever sense the doctor may have of us as a person with our own life to lead.

All five of these factors make person centred healthcare more difficult and contribute to the surrender of autonomy, dignity and respect that happens all too often when we become patients, but understanding is half the battle towards overcoming the tendency.

Abstracts for Presentations Day 2 27 October 2017

09.10 KEYNOTE 1. Human Science: Lived Experience as the Starting Point for Inquiry, Reflection and Interpretation in the Caring Professions

Colonel (Rtd) Professor Emerita Marilyn Ray, Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, Florida, USA

Caring in the health professions is a way of life, a journey of compassion, an aesthetic act and a human science. Inquiring about the meaning of caring touches the heart and translates through the soul/grace, the intensity of "speaking together", the reception and internalization of different forms of meaning-making within us. Human science inquiry in the health professions attempts to capture the primacy of practice - the meaning-giving methods of everyday life of the professional practitioner. Human science is a phenomenological-hermeneutic enterprise with unique approaches that seek to describe and understand foundations of thought, of consciousness, of the being of the human being, and of culture. This presentation will focus on central philosophical foundations and processes of caring inquiry incorporating phases illuminating intentionality, dialogic experiencing, reflecting, interpreting and theorizing, comparing, and transforming to facilitate revelation of the hidden meanings of the "compassionate we."

09.35 KEYNOTE 2. Better bedside handover communication: training nurses in the interactional and informational skills of well-structured patient-centred handovers

Professor Diana M. Slade, Professor of Applied Linguistics and Director, Institute for Communication in Healthcare, Australian National University, Canberra, Australia

Clinical handover – the transfer between clinicians of responsibility and accountability for patients and their care – is a pivotal, high-risk communicative event in hospital practice. Studies focusing on critical incidents, mortality, risk and patient harm in hospitals have highlighted ineffective communication – including incomplete and unstructured clinical handovers – as a major contributing factor. In Australia, as internationally, Health Departments and hospital management have responded by introducing standardised handover communication protocols and more recently by mandating that the shift-to-shift handovers, wherever possible are conducted at the bedside and thereby involving the patient in discussions about their care.

This presentation presents discourse analyses of spoken clinical handovers from a three-year study of handover communication in Australian public hospitals. The translational research involved staff interviews and ethnographic observations combined with detailed language analyses of audio and video recorded ward-to-ward and shift handovers to identify the features of effective and less effective handovers.

We found that most of the clinicians delivering the handovers focussed exclusively on the transfer of information and that such a focus constrained their ability to shape effective handovers. In the case of bedside handovers, the nurses deployed communication styles that excluded and objectified patients. We argue that handover communication must be conceptualised as inherently interactive and that attempts to describe, model and teach handover practice must recognise both the informational and interactive, interpersonal communication strategies.

We will show how we used professionally re-enacted videos, explicit communication strategies and scaffolded role plays to support nurses to adopt more effective interactional and informational styles in bedside handovers. The impact and positive evaluations of the training suggest that research-based communication training is a vital component in improving patient inclusion and satisfaction during clinical handovers.

10.00 Relational Learning: Enhancing Faculty Teaching of Communication Skills and Relational Capacities – A 10 Year Perspective

Dr. Elizabeth Rider, Director of Academic Programs & Director, Faculty Education Fellowship in Medical Humanism and Professionalism, Institute for Professionalism and Ethical Practice, Harvard Medical School, Boston, USA

Relationships in healthcare are based on attention to values and skillful communication that makes those values visible. These capacities are anchored in self-reflection, respect and humility. A clinician's humanistic capacities - including the capacity for self-awareness, empathy, "presence" for self and others, and to mind one's own behavior - are significantly associated with patients' perceptions of the quality of care. Establishing beneficial relationships with patients and families requires healthcare professionals to be continually aware of their own values and communication.

Studies show that good communication grounded by values and patient engagement improves health outcomes, patient safety, and patient and clinician satisfaction. Yet, these human aspects of care do not receive the emphasis necessary to make them central to every healthcare encounter. In today's corporate driven, technology focused healthcare environment, physician-patient and clinician-patient relationships have deteriorated.

At the same time, clinicians often note insufficient preparation to teach interpersonal and communication skills, especially for challenging conversations and interactions. *Difficult Conversations in Healthcare: Teaching and Practice*, an interprofessional, international faculty development course now in its 12th year, teaches educational methods and strategies for implementing relationship-centered learning across a variety of healthcare settings. Participants learn various teaching approaches, and engage in an evidence-based interprofessional relational learning model - the Program to Enhance Relational and Communication Skills (PERCS) that incorporates realistic enactments using professional actors (simulation), collaborative learning, reflection and patient/family perspectives.

The relational learning model promotes relationship-centered, interprofessional learning by integrating patient and family perspectives and the moral and relational aspects of care, creating safety for learning, honoring multiple perspectives, and valuing reflection and self discovery. It is designed to prepare clinicians to engage in challenging conversations, such as conveying a bad diagnosis, making difficult end of life decisions, addressing adverse medical outcomes and others.

Data gathered over 10 years will be used to give a 'snapshot' of the model's learning outcomes. A 4-year analysis of participants' reports of "the most important thing learned" will also be shared.

This presentation will briefly describe the application of relational learning to develop two faculty education and leadership fellowships designed to further enhance relational competency in clinical and education leaders at Boston Children's Hospital, Harvard Medical School. Finally, we will take a brief look at the *International Charter for Human Values in Healthcare* and it's use as a foundational framework for relational teaching and learning.

10.20 Seek first to understand - building better relationships in an Emergency Department

Ms.Bernadette Brady, Director, Partnering with Patients, Canberra, Australia & Former Director, Patient and Family Centered Care, ACT Health, Canberra, Australia

While clinicians understand their own roles within healthcare, there is little understanding of the roles of other health professionals nor the emotions felt by those seeking care.
This presentation will explore the thinking behind a research pilot project aimed at building that understanding. It was hypothesized that:

1. Empathy increases after listening to empathic audio recordings

2. Employees self-reported empathy increases after listening to non-employees empathic audio recordings

3. Non-employee self-reported empathy increases after listening to employees empathic audio recordings.

An intervention consisting of audio clips concerning the experiences of the people of an Emergency Department (patients, families and staff) of a regional hospital in a capital city, was completed in 2009. Stories were gathered from 10 patients and/or families, 2 allied health staff, 2 medical staff, 2 wards persons/porters, 4 nursing staff and 2 administration staff; all asked the same question. Staff stories were then shared with other staff and ED visitors. Visitor stories were shared with other visitors and staff. Empathy scores were measured before and after sharing the stories. Participants indicated that after listening to a story, 93.2% felt they had a better understanding of the situation experienced by staff, patients, visitors or significant others in the ED. Furthermore, 88.3% of participants indicated that their empathy towards the people of the ED had increased after listening to a story.

The Intensive Care Unit at the same hospital are interested and looking to establish a similar set of recordings to increase empathy. The Hospital is also planning to establish a group of trained volunteers to interview staff and patients on a weekly basis and provide those stories for sharing. A grant has been applied for to enable the audio or visual capturing and recording of those stories. It is hoped that the improvement in empathy noted in the ED, will follow through to these areas as well.

11.30 The Great Rationality Debate - the many faces of rationality in medicine and in person-centered clinical decision-making

Dr. Benjamin Djulbegovic, Professor of Oncology & Director of Research, Department of Supportive Medicine & Department of Hematology, City of Hope, Duarte, California, USA

It has been estimated that more than 30% of healthcare costs are wasted on inappropriate care. This suboptimal care is increasingly connected to the quality of medical decisions. It has been estimated that personal decisions are the leading cause of death, and 80% of healthcare expenditures result from physicians' decisions. Therefore, improving healthcare necessitates improving medical decisions, i.e., making decisions (more) rational.

However, exactly characterizes rational decision-making? "The Great Rationality Debate"—a debate about most optimal course of our reasoning, decision-making, and actions—has permeated the fields of philosophy, economics, and psychology for decades but remains a neglected topic in clinical literature, despite of its obvious importance. We draw on writings from "The Great Rationality Debate" to identify core ingredients of rationality commonly encountered across various theoretical models.

We showed that what is "rational "behavior under one rationality theory may be irrational under the other theory. We also showed that context is of paramount importance to rationality and that no one model of rationality can possibly fit all contexts. We suggest that in context-poor situations, such as policy decision-making, normative theories based on expected utility informed by best research evidence may provide the optimal approach to medical decision-making, whereas in the context-rich circumstances other types of rationality, informed by human cognitive architecture and driven by intuition and emotions such as the aim to minimize regret, may provide better solution to the problem at hand. The choice of theory under which we operate is important as it determines both policy and our individual decision-making. Finally, we demonstrated practical implications of "The Great Rationality Debate" for today's health care which is dominated both by under-and over-use of health care services.

11.50 *MyDecisionEngagement*: a formative, preference-sensitive, dually-personalised measure for person-centered care

Professor Jack Dowie, Emeritus Professor of Health Impact Analysis, Department of Social & Environmental Health Research, Faculty of Public Health & Policy, London School of Hygiene and Tropical Medicine, London

The reasons behind the slow movement to person-centred *decision making* - a prerequisite of person centred *care* – are conventionally allocated to one of three groups: the unwillingness or inability of health professionals to engage, the unwillingness or inability of persons-as patients to engage, and, as context, the characteristics of the social and institutional setting, notably guidelines and resourcing. Without diminishing their possible importance, we draw attention to what is, in our *opinion*, a less detected and questioned source of the slow pace of the movement to person-centred *decision making* – a prerequisite of person-centred *care*: the inappropriate pursuit of scientific rigour, and the complexities associated with it.

The use of 'scientism' as a term of abuse is well-established, but, as with all other '-isms', so is the wide variety of definitions and interpretations that the terms evokes. We do not wish to enter this debate, rather identify and illustrate in the presentation some practices that are hindering progress towards person-centred care, and which might warrant the use of the term. And also to show our attempts to address them in our own decision support tools. In attacking these aspects of 'scientism' we in no way intend to diminish the value of the appropriate use of scientific methods. Nor to let the opposite phenomenon of 'practicism' off the hook ('my clinical expertise and experience means I don't need any analytical or empirical support in dealing with my unique individual patient"). However, the consequences of the latter hubris are relatively well documented and discussed, so we focus on the more hidden and less questioned obstacle of 'scientism'.

We identify six examples of 'scientism' specifically relevant to decision making in, and decision support for, the individual case. Elaborations will be provided in the presentation.

- Impractical or Inapplicable Methods
- Improper Measurement
- Irrelevant Comparators
- Invisible Preference-based and Informed Consent
- Ignoring Clinical Significance
- Inconceivable Resourcing

Our conclusion is that the rewards system in healthcare research leads to levels of scientific rigour and complexity that increasingly go beyond the point where person-centred care can benefit, and can actually harm it, encouraging a reversion to 'practicism'.
We have an obligation to say how our own work in developing and delivering decision support tools eliminates or reduces at least some of these undesirable phenomena. Examples using the Annalisa template will be drawn on.

12.10 A bone health decision support tool - avoiding invasive medicine in person-centered bone health

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

Background: Funded by a national call for developing a decision support tool (DST) incorporating the preferences of the individual citizen/ patient, we report first findings of a current study that invites those coming for a first bone (DXA) scan at a university hospital outpatient clinic to prepare for the upcoming consultation about the result with their health care provider.
Aim: To explore how Multi-Criteria Decision Analysis (MCDA)-based support, implemented online, can be integrated with current practice for enhanced health-e-decision literacy.
Methods: Iterative action research cycles of development, testing and adjusting the DST 'My bone health'. A pre-post design of mixed methods introduces a formative construct of MyDecisionQuality (MDQ) as the primary outcome for an informed consent process.
In the post baseline phase, the interactive DST for bone health, implemented in the Annalisa® template added the Preparation for Decision Making instrument. A 'save for

Later' feature allows for weblogging of results and access to a 'preliminary opinion' during a subsequent consultation about DXA result. The three criteria in the aid, with data sources are: *Fracture in next 10 years (F10)*: person-specific fracture risk from Frax multiplied by generic effectiveness data from Network Meta-Analysis (with a check against local experts). *Treatment Side Effects (TSE)*; local experts (% of patients terminating treatment due to side effects) *Treatment Burden (TB)*; assessed early in tool for different frequency, mode, and place of delivery) and performance ratings of 17 options to enhance bone health, and a 'do nothing /watchful waiting'. A network meta-analysis was supplemented by an elicitation survey among members of the national bone society. The Frax estimates were adjusting for self-rated dose of steroids i.e. one of the risk factors of the Frax algorithm embedded in the DST.

Status and preliminary results: Initial findings from the baseline e-survey N=30 and intervention onsite N=30 are presented. Data will later be supplemented with interviews in the next phase of the intervention. Contrary to fears of demand for restricted options due to possible local restrictions, the average criteria weights (of 43%F10, 37%TSE, 20%TB) imply that less than 50% weight is being given to the (avoid fracture) criterion on which all guidelines are based. The 'do nothing' and fall prevention options obtained the highest scores in the early analyses.

The next phase will invite those coming for a DXA to prepare for their upcoming consultation via a safe bridge to an embedded app into the Electronic Health Record in the region. This will constitute apomediation via citizen access to a website linking to the national e-health portal 'patient handbook', as well as teaching tools. The outlined project has experienced considerable interoperability issues as well as challenging the current culture, despite such change being in demand by official bodies.

12.30 Person-centered research co-production

Dr. Amy Price, Chief Executive Officer Empower2Go Florida, USA & Research Fellow, *British Medical Journal* Department of Continuing Education, University of Oxford, UK

Background Statement: Research Co-Production is research with everyone, citizens included, in the design and production of the research process. The purpose is to introduce an atmosphere of trust and respect with the plan to explore a shared health culture to identify problems in research that matter most and to share solutions. This session asks you to be part of the answer

Methods: *Four Problems to Solve*

Informed consent: The tensions are between readability and the need for a robust legal document.

Shared research data: Consequences of unfettered access and multiple data collectors.

Open Peer Review: Bad manners or meanness in peer review, needs for anonymity.

Inadvertent Deception: Assumptions based on partial knowledge.

Following a short presentation, we will work in small groups. In groups of 3-4 you will be given scenarios with two problems to solve. Your assignment is to make the best of a less than ideal situation and to craft a plan for the future.

Conclusion: Your solutions will be shared with the large groups and discussed again. Following this we will post how our solutions differed or were the same as what people actually did. Those of you who would like to co-author an article for the journal sharing our solutions please volunteer. Let's make research better together!

13.50 Current U.S. Health Policy and the Future of Person-Centered Care

Dr Sandra Tanenbaum, Professor, Health Services Management and Policy, College of Public Health, Ohio State University, Ohio, USA

Current US health policy is contested and consensual. This is not new to American health care, as the last seventy years have seen on the one hand, conflict between those who would expand access to health services and those who would restrict it, and on the other, a popular pursuit of biomedical research and the interventions it spawns. During the last year, US health policy has repeated this dynamic, with multiple unsuccessful attempts to repeal the Affordable Care Act (ACA) as well as (near) unanimous passage of the 21st Century Cures Act. This paper reports on each half of the conflict-consensus dynamic and considers which, if any, aspects of these current US health policies might lead to more (or less) person-centered care. Attention will be drawn especially to access to health care under the ACA and the use of "real-world evidence" under the Cures Act. The former allows more Americans to receive more of the care they need. The latter challenges evidence-based medicine's evidence hierarchy, where randomized controlled trials (RCTs) are considered superior to other ways of knowing, even for the care of individual persons. The paper describes the current discussion of what sorts of evidence are appropriate to a drug and device regulatory regime. It remarks on the claims to person-centeredness by proponents and opponents of both bills and on potential dilemmas posed when aspects of person-centeredness conflict.

14.10 The problem of assessment of value of relationship in Patient Centered Healthcare Organizations

Professor Didier Vinot, Co-Director, Chair 'Values of Patient-Centered Care' and Vice President for Economic and Social Affairs and Heritage, University of Lyon 3, France

Evaluating added value in healthcare systems appears as a necessary and objective process. Yet, measuring tools are not neutral. We argue that they do not measure a performance that was already there, but construct the very notion of performance. Economic evaluation confers an undisputed value to care by breaking it down into technical components and matching them with single costs. From this standpoint, the intangible part of care (what can't be measured) is left aside.

The quality of relationships is one component of what we call "intangible care". A humanitarian approach can, for instance, enhance the capabilities (Amartya Sen, Martha Nussbaum) of the patient. How these capabilities can in turn count as an added value to care? Drawing from a management science perspective, we argue that taking relational value into consideration is essential for medical practice, and for the patient in the first place. Should we find an adequate measuring tool, government authorities could scale it into public policy schemes, and healthcare institutions into organizational patterns.

This theoretical presentation outlines the difficulties of grasping the economic value of the non-technical dimension of care. Essential to person-centered care, it is nonetheless considered a secondary aspect by managers and policymakers. We analyze the reason for this discredit as the impossibility to put it into numbers. The French case, a hospital-centered health care system, is used to illustrate a few structural hurdles. We then explore the possibility of designing a measuring tool that could assign economic value to the relational dimension of care.

14.30 Homecare: the person-centred approach

Ms. Wendy Gee, Director of Nursing, Healthcare at Home Ltd, Newcastle-upon-Tyne,UK

NHS England's chief executive, Simon Stevens, recently stated that focus must be put on care in the community and in the home to tackle the huge deficits facing NHS trusts.

Traditionally, decisions about treatment and care solutions for patients were made by the healthcare professional - the nurse, the pharmacist, the doctor. In contrast, person-centred care focuses on empowering and enabling the patient to take an active role in their own health and care as equal partner in the decision-making process.

When people play a more collaborative role in managing their health and care, they are less likely to use emergency hospital services. They are also more likely to stick to their treatment plans and take their medicine correctly; more likely to engage in positive health behaviours; and health service staff performance and morale are improved.

Joining up services between hospital and home brings many benefits for patients and the health service, improving adherence and health outcomes, streamlining processes, reducing time in hospital and offering data and real-world evidence so that clinicians and the pharmaceutical industry can improve treatments and prove value.

Healthcare at Home specialises in person-centred care and bringing clinical services directly to people in their own homes.

14.50 "The Meaning of Me ®" a Canadian blue print for addressing the complex whole that is the person at the centre of the community based homecare services model

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

Mosaic's blue print for Person Centred Care extends the notion that care based services should be implemented collaboratively with the individual and their families to one that also embraces the voice and the rich habitat of the mind and the being of the person being cared for. It is one that is also especially sensitive to the importance of community, the person's place in the community and the wider dynamic that encompasses a person's many dimensions of being. In this sense the model is one that delivers personal support and medical care along well defined client centered protocols differentiated by a fluid organic relationship core. Not only is the client front and centre in the relationship but the care provider itself develops a wider set of relationships with the community.

At a fundamental level, the "Meaning of Me®" is a conversational framework that becomes an interactive journey between all those involved in the care relationship. It differs in many meaningful respects from other similarly framed interventions paying attention to, as Daniel Kahneman would say, the remembering self and the experiencing self: to remember, to create to positive experience. It is also a framework very much aware of the dynamics of interaction and the processes required to provide the necessary creative space and loop back to the client. At one level, it is simple and easy to execute, but it is through the doors that it opens that the potential lies.

Much of the inspiration for the development of the model came from the Joseph Rowntree Foundation report, A Better Life-What Older People with High Support Needs Value (Jeanne Katz *et al*., 2011).

The talk will discuss how the service model is framed and delivered, how it interacts with the person being cared for and how an organisation can tailor specific services that interact with the greater focus on the person. It will also address key organisational platforms needed to deliver care within the complex whole. The talk will also address issues of costs and funding for such services as barriers to the development of holistic services and how these could possibly be addressed.

The community based model for care that places the individual front and centre in the relationship, while also preserving the necessary duality of professionalism and the personal is a complex one. As the growing literature and, indeed, much of the empirical work confirms, a failure to embrace the many inputs that impact both physical and mental wellbeing is expensive not just financially but costly for society as a whole, and at times devastating for the individual.

16.00 A centered concept of personhood

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

The aim of our research is to provide an overarching concept of science embedded in a concept of humanities. The resulting theory is rooted in philosophy, more specifically in the Aristotelian differentiation of *actus et potentia*, or *energeia* and *dynamis* and in the work of the former Heidelberg Biologists and philosophers J. J. von Uexküll and Helmuth Plessner.

Issuing personhood, we state that, whatever we gave a name, from now on is accompanied by this name. Constant accompaniment can be conceptualised as a cloth that changes an unclothed item into a dressed one. The cloth acts as an interface intermediating and interconnecting an enclosed inside with its non-inside. Using words is applying interfaces placed between us and the dressed content.

Explicit, tacit, immunological and genetical forms of knowing act the same way, serving as an intermediating conceptual interface between us and the item functional ly 'wrapped' in our tacit knowing.

Our world, as far as we physically, emotionally and mentally interact with it, thus consists of items that have been processed and equipped with an intermediating functional layer allowing for a selective, targeted approach. For the rest of the world, except religious approaches, we have no name and no tacit knowing, and no intermediating device allowing an individualising access.

With the words and our tacit knowing being an integral part of us, we beyond infancy exist as also consisting of them. And by virtue of simple facticity, being made of qualitative material, we also exist as physically based features with a both temporal and spatial rootedness. Being rooted, in turn, implies a corresponding centeredness, establishing and maintaining a unique perspective emerging from the point of view of this material.

As characteristic for all living beings, we also are equipped with a device that by enclosing, filtering, attributing, anticipating and intermediating guarantees our operational, synchronic and sequential consistency and coherence, with the timing produced by our 'inner clock' and the functional positioning enacted in encounters with our '*Umwelt*' (Uexküll).

The filtering done by putting an intermediating net over non-self items is based on a transient composition of agents that need not be spatially positioned as a net. They emerge from sets of functions, with underlying agents being elements of sets that need not be disjunct from each other. In formal terms, the envelopes wrapped around focused sets of incoming processes perform an anticipatory *focusing 'vectorial indexing procedure'*, or *VIP***,** with each vector pointing from inside to outside, or vice versa, and from present to an anticipated next present. They do so in functional analogy to the work of the skin as our physical border. Such functional analogies are common in Biology, like a fly's eye as a functional analogue of a human eye, both realising the potential (*dynamis*) 'ability to see'. Consequently, the centered concept of personhood must be derived from an identification of underlying potentials, their inherent timing and positioning and the inter- mediating function of an anticipating *focusing VIP*, realised as stable or transiently produced enveloping, mutually embodying networks.

16.20 Gating the holes in the Swiss cheese: expanding Professor Reason's model for Person-Centered Healthcare

Dr. Shashi S. Seshia, Clinical Professor,Department of Paediatrics, Division of Paediatric Neurology, University of Saskatchewen, Saskatoon, Saskatchewen, Canada

Introduction: The principles of person-centered healthcare (PCHC) have been discussed in several international forums. Patient safety can be defined as "prevention of (healthcare-associated) harm caused by errors of commission or omission," and implicitly incorporates the goal of ensuring the best possible outcome for every individual: patient safety is person-centered. Although patient safety has improved steadily, harm remains a major global healthcare challenge. To date, efforts to improve atient safety have focused on hospital settings rather than across the continuum of care. Better understanding of the complex covert cognitive factors influencing healthcare-related decisions and organizational cultures could lead to more rational approaches, and thereby to further improvements in PCHC not only in hospitals but throughout the spectrum of care.

Hypothesis: A model integrating the concepts underlying Reason's Swiss cheese theory and the cognitive-affective biases plus cascade has the potential to advance the understanding of cognitive-affective processes that underlie decisions and organizational cultures.

Methods: Thematic analysis and overview, qualitative information from several sources and disciplines being used to support argumentation.

Results-Discussion: In the integrated model, the Swiss cheese slices represent dynamic cognitive-affective gates: Reason's successive layers of defence. Like firewalls and antivirus programs, cognitive-affective gates allow the passage of rational decisions. Erroneous decisions are blocked and consequences minimized by being constantly mindful, and activating additional cognitive defenses when necessary i.e., through dynamic cognitive-affective gating. Conversely, gates can be breached (i.e., 'holes' created) by one or more elements of cognitive-affective biases plus and other error-catalyzing factors at one or more levels of organizations, teams and professionals. There are far reaching downstream consequences when error catalyzing factors such as unsound decisions or erroneous information are made or circulated by those with authority or influence. Informed shared decision making is an often overlooked yet crucial dynamic cognitive-affective gate (layer of defence) in the care of each individual.

The integrated model addresses the complex covert cognitive phenomena that underlie decisions influencing patient safety. The model can also provide an evidence-informed framework for developing and evaluating strategies to optimize organizational, team and individual cultures and decisions.

Limitations: The concept is abstract, the model 'virtual,' and the best supportive evidence qualitative and indirect.

Conclusions: The integrated cognitive-affective-gated Swiss cheese model may help enhance rational decision making across the continuum of healthcare, thereby enhancing PCHC globally.

16.45 The care and costs of ME/CFS

Dr. Lorenzo Lorusso, Consultant Neurologist, Pavia, Italy and Dr. Derek Pheby, Visiting Professor of Epidemiology, Buckinghamshire New University, High Wycombe, England, UK

ME/CFS is a seriously disabling condition that may affect two million people in Europe, as well as family members and others. The European ME/CFS Research Network (EUROMENE), a research collaboration involving research institutions in 18 European countries, is endeavouring to enhance research capability in this area, in order to ameliorate the lives of sufferers and those around them. EUROMENE has six working groups, four for research groups (epidemiology, biomarkers, socio-economics, clinical research/diagnostic criteria), and two administrative (short-term scientific missions, workshops and conferences; dissemination).

Working Group 3 (socio-economics), with 10 participants from 6 European countries, has a series of tasks entirely within the field of health economics, and an overall objective to estimate the burden of ME/CFS to society and provide long-term trend estimates for societal impact. As a start, a literature review was undertaken, to review the current state-of-the-art. Initial literature searches were undertaken by Derek Pheby and Xia Wang, and a report prepared by Lara Gitto and Elenka Brenna. The review summarised ME/CFS as a condition of chronic weakness, of sufficient duration and severity to impair functioning, not alleviated by rest, and associated with lower quality of life, higher health care utilisation, and considerable cost implications. Most common in women, the peak age of onset is 20-40. Prevalence is between 0.2% - 2.6%, depending on which of many case definitions has been employed.

The literature review focused on publications applying economic evaluation techniques. A chronological approach was used, to identify possible evolution in research studies, and both direct (i.e. healthcares) and indirect (loss of productivity) costs were considered. The main findings were of general agreement on the cost-effectiveness of primary care, but no consensus on what constituted the most cost effective therapy. Authors agreed on the usefulness of self-management in improving both self-esteem and physical energy. Only cognitive behaviour therapy (CBT) showed evidence of prolonged beneficial effects. A major problem in carrying out economic analysis is that many patients remain undiagnosed. The disease has nevertheless significant cost implications, but this information is difficult to capture. Variations in prevalence may be due to natural variation between populations, but also reflects differences in diagnostic criteria and in the propensity of doctors to diagnose ME/CFS. Pan-European agreement on case definitions and research methodologies was necessary, and emphasis on early diagnosis, indirect costs, including work incapacity and productivity loss and costs of informal caregiving, and lower quality of life. Generating Europe-wide comparative information on the burden of ME/CFS is problematic because of differences in health care provision and funding, levels of economic development, degree of recognition of ME/CFS as a genuine clinical entity, and case definitions, as well as exchange rate variations.

Following the review, possible research priorities include comparative reviews of cost-of-illness studies, and of the comparability of case definitions, pilot studies of the cost implications of patient journeys in different countries to test and validate a data collection methodology, and a proposed study of prevalence and costs in Latvia, which could possibly be replicated in other small jurisdictions.

Biographies of Participants

Professor Sir Jonathan Asbridge DSc (*hc*) DHSc (*hc*)

Professor Sir Jonathan Asbridge DSc (hc) has a long and distinguished record of achievement within healthcare system organisation, accreditation, re-configuration and regulation. Gaining appointment to the positions of Chief Nurse of the Oxford University and Cambridge University Teaching Hospitals very 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 appointed by HM Secretary of State for Health as 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 and has held Secretary of State appointments as a Government Tsar for Patient Experience in Emergency Care and as a Government Tsar for Patient and Public Involvement in Healthcare. He is a previous Deputy Chairman of the UK Council for Healthcare Regulatory Excellence. 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. Sir Jonathan was awarded a second honorary doctorate for services to healthcare by Anglia Ruskin University, Cambridge, in 2016. Sir Jonathan is currently National Clinical Director for Healthcare at Home.

Bernadette Brady

Bernadette Brady worked as a registered nurse and midwife for 24 years. More recently she has worked independently, providing advice and assistance to organisations seeking to become more person centred. Throughout her career Bernadette has learnt and been more aware that the language of health is not necessarily the language of those using the service. Advocacy of patients and their supporters has always been important to her.

From 2006 to 2013 Bernadette was the Director, Patient and Family Centred, ACT Health. During her time in this role Bernadette instigated gathering patient's stories to inform the health department of gaps in service. It was in gathering those stories that she realised the need to also gather staff stories to understand the constraints they faced in their daily work. In listening to all these stories it became evident that staff and patients often approached the same interaction from very different perspectives but those perspectives were not always recognised or accommodated.

During the 1990s Bernadette was awarded a Community Award and Government award for her work with women experiencing pregnancy loss. More recently she won an ACT Government Leadership award and was an ACT Telstra Woman of the Year finalis.

When the team, of which she had been part was disbanded, Bernadette set out to work independently and continues to gather information on how patients/consumers, and health staff interact.

Hilary Burton

Dr Hilary Burton is former director and now public health consultant at the PHG Foundation and vice president at Hughes Hall Cambridge. The PHG Foundation is a not for profit organisation with a special focus on how genomic and other technologies can provide more effective personalised healthcare and improve population health. Qualified in medicine at Oxford University, Hilary subsequently trained in public health in the Eastern Region and worked as a consultant in Cambridge.

Since 1997 at the PHG Foundation Hilary has focused on the genomics context for population health, and, in particular, has led national work on the implementation of new technologies in mainstream UK health services. As a member of the Royal Colleges' Joint Committee on Medical Genetics, she was the main author of a report looking at the service implications of introducing genomics across a wide range of clinical specialties. In pursuing this further she is currently chairman of a national RCP Working Group, which aims to promote increased awareness and competence in genomics amongst UK physicians

At PHG Foundation, Hilary is leading a programme entitled *‘My Healthy Future’*, which aims to set out for policymakers a vision for personalised healthcare where individuals use new technologies and access information about themselves, their health and risk of disease to optimise their health. Through background analysis and a series of conversations and workshops, we will be examining opportunities arising from these new technologies and describing the issues for individuals, society and healthcare providers. We will examine the perspectives for people across four life stages where their health needs and personal approaches to health may differ– pregnancy, teen years, the ‘healthy’ adult and older age. Importantly we will also take a number of cross cutting themes; among them will be the interface between increasingly technologically driven healthcare and the provision of person centred healthcare.

Elisa Chelle PhD

Elisa Chelle received a PhD in political science from Sciences Po Grenoble, France. Her dissertation was on conditional social policy, with a comparative perspective between France and the United States. Her ongoing work concerns the transformations of health insurance, the politics of health policy, and, most recently, animal-assisted therapies. She is a postdoctoral fellow at the University of Lyon (Chair ”Values of patient-centered care”) and an affiliated member of the Laboratory for Interdisciplinary Evaluation of Public Policies at Sciences Po, Paris.

Lauren Copeland PhD

I am a Research Associate in the division of population medicine. My research interest lie in understanding how counselling techniques can help improve mental and physical outcomes. I am also interested in understanding behaviour change. My previous research has been focused on: the mechanisms within motivational interviewing in relation to weight loss maintenance outcomes, a novel peer-support intervention using motivational interviewing for breastfeeding maintenance and developing a measure of focusing within a motivational interviewing session

Mary Chambers PhD

Mary 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.

During her career she has held a variety of clinical, managerial and academic positions including coordinator of the Northern Ireland Centre for Health Informatics. She is a fellow of the Royal Society of Medicine, the European Academy of Nurse Scientists and a member of the Institute of Leadership and Management.

Mary has a well-established record of patient and public involvement (PPI) in education and research and is involved in a number of research projects locally, nationally and internationally. Outcomes of her PPI research work have had impact nationally and internationally. Integral to this work has been the co-production and delivery of education programmes as well as PPI at all stages of the research process.

Benjamin Djulbegovic MD PhD

Benjamin Djulbegovic is a Professor of the City of Hope, Duarte, California. Dr. Djulbegovic’s main academic and research interest lies in attempts to optimize clinical research and practice of medicine by understanding both nature of *medical evidence and decision-making*. The role of uncertainty and rationality in science and clinical medicine has been one of the common themes across his work, particularly evident on his analysis of equipoise and role of regret. As of October of 2017, he has published 308 papers in peer-review journals, 190 abstracts and two books. His work has been published in all major scientific and medical journals including *Nature, Lancet, JAMA, New England Journal of Medicine, etc*. He has also widely taught on these subjects and received numerous awards related to his work. During last two decades Dr. Djulbegovic has enjoyed continuous external funding by both US federal and private entities related to his fields of interest.

Jack Dowie MA (NZ) PhD (ANU)

I 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 I had been a member of the Faculty of Social Sciences since 1976. While at the OU I designed and ran the multi-media distance-learning courses on RISK (from the late seventies) and PROFESSIONAL JUDGMENT AND DECISION MAKING (from the late eighties). My early qualifications were in history and economics at the University of Canterbury, New Zealand and I 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 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 health care. I was a founder member of the Health Economists Study Group and the Society for the Study of Gambling. I recently completed ten years’ service as a member of the Appraisals Committee of the then National Institute for Clinical Excellence (NICE). I formally retired in 2003 but remain active in the School and am also Adjunct Professor in the Department of Public Health, University of Southern Denmark and Honorary Professor in the

University of Sydney School of Public Health. My research is mainly in connection with the software implementation of Multi-Criteria Decision Analysis I developed, called Annalisa. 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 it provide personalised decision support based on individual preferences as well as evidence and expertise. I was recently honoured to receive the Gold Medal of the European Society for Person Centered Healthcare.

Thomas Fröhlich MD PhD

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, being profoundly influenced by the teaching of Ulrich Wahn and Wolfgang Rebien. From 1973-1976 and 1986 – 1987, he worked at the Max Planck Institute for Medical Research, Heidelberg, conducting research in 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 (Reinhold Haux), Hospital of Internal Medicine and Psychosomatics, Heidelberg University (Gerd Rudolf) and Psychosomatic Medicine, Klinikum rechts der Isar, Munich Technical University, with Peter Henningsen. Dr. Fröhlich has been awarded research grants to develop understanding in his field and 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. He is currently developing 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 in beta-version.

Wendy Gee

Wendy was appointed Director of Nursing at Healthcare at Home in 2016, previously holding roles responsible for Clinical Service Design and Head of Primary Care Nursing and is an experienced nurse manager. In the Director of Nursing role, Wendy has responsibility for management of 700 nurses and the development and implementation of branded clinical person-centred behaviours across the clinical organisation, including schedulers and drivers. Wendy has particular expertise in Long Term Conditions, Respiratory medicine, Diabetes and CHD.

Wendy qualified in 1979 and trained at Sunderland Royal Infirmary, undertaking several community-based roles in District Nursing, progressing from a District Nursing Sister role to Practice Nursing, before joining an independent healthcare provider in 2001.

Wendy began her career in homecare in 2005 with Healthcare at Home where she developed a passion for delivering person-centred care, and ensuring that patients and clinicians understand the value and importance of this approach. Wendy is committed to enhancing patient care and transforming the way people access healthcare.

Healthcare at Home partner with public, pharmaceutical and private providers to deliver services that are essential for sustainable healthcare. Over 25 years they have consistently delivered the highest standard of clinical care.

Alan Gillies MA (Oxon) PhD

Alan Gillies has been Professor of Information Management at UCLAN since 1994, the first sixteen years as a full-time academic, the last seven as an honorary professor, enabling him to apply his expertise in advising policy-makers, evaluation studies, and commercial technology start-ups. He has maintained his links as medical academic links as Doctor Honoris Causa at the University of Medicine and Pharmacy, Cluj-Napoca, Romania.

He has experience of working in both clinical and commercial business sectors. His interest in teaching and learning led to him establishing the first MSc in Health Informatics in the UK to be delivered by (blended) online learning, and the first in any subject in his University. This programme was professionally accredited by the NHS and led to the commissioning of a foundation degree programme, as well as a European Masters in Health Research Methods with partners in Romania, France and Italy. He now develops a wide range of novel academic and professional learning programmes from a blended advanced paediatric nursing Masters programme to informal skills development courses for 18 to 25-year olds delivered through 2-minute training videos on mobile devices at campusforlife.com and the 99pskillshop.com

He combines his academic roles with managing AGLC (Alan Gillies Learning Consultancy) Ltd, and acting as Development Director at Care Aware International Ltd and the Register of Cancer Survivorship Professionals.

Since leaving full time academia, he has also:

- been Editor of Clinical Governance: an International Journal.
- acted as a Member of CQC National Information Governance Committee
- acted as advisor to the Regulatory Delivery, part of the Department for Business, Energy & Industrial Strategy.
- operated as Director of Informatics and Evaluation at Hope Street Centre CIC in Liverpool.
- evaluated the Warrington “We are positive about cancer” project
- developed an online tool for the support and dissemination of HIV nursing standards for the NHIVNA
- been Development Director at Perform Learn Develop Ltd and Global Pharmaceutical Applications Limited.

More information is available at aglc.co.uk and alangillies.com

Lara Gitto PhD

Lara Gitto is Research Assistant at the Faculty of Economics of the University of Rome "Tor Vergata. She is qualified as an Associate Professor of Public Economics.

She holds a PhD in Public Economics at the University of Catania (Italy) with a thesis on the quality of hospital care, the Master in Health Economics at the University of Messina and the Master of Science in International Business and Economic Integration at the University of Reading (UK). She graduated in Law at the University of Messina (Italy).

During the last three years she has been lecturer of "Microeconomics" and “Health Economics” at undergraduate and graduate courses, and coordinator of research projects in Health Economics and Management.

She is a member of national and international research groups on economic evaluation in health and quality of life for chronic diseases, including "Managing the Transition to SPMS - ManTra", coordinated by Besta Neurological Institute, Milan; "Development and validation of a tool for patient-reported assessment of cancer related financial toxicity", coordinated by the Istituto Pascale, Naples; COST Action 15111 - EUROMENE on Chronic Fatigue Syndrome (CFS/ME), EU Framework, Horizon 2020 Program.

She has been a member of the Scientific Board of the Italian Association of Health Economics (AIES) and is currently auditor of the Association. She is a member of other scientific societies, such as: International Health Economics Association (IHEA), International Society for Pharmacoeconomics and Outcomes Research (ISPOR), European Society for Patient Adherence, Compliance and Persistence (ESPACOMP), Italian Institute for Quality of Life (AIQUAV).

She is author of more than one hundred of studies published in international and national journals and is a referee for many international and national scientific journals. She is referee and evaluator for the International Health Economics Association (IHEA) scientific meetings, the European Health Economics Association (EuHEA), ISPOR (International and European Congress).

Alan Haycox BA MA PhD

Dr Alan Haycox is a Reader in Health Economics at the University of Liverpool Management School, UK. He completed his education with a BA in Economics, and later obtained a MA in Regional Economics and a PhD in Health Economics at the University of Lancaster, UK.

Within the Management School, Dr Haycox is the Head of Liverpool Health Economics (LHE). This group of Health Economic specialists aims to improve the quality and cost-effectiveness of resource utilization within the NHS and beyond by working in collaboration with the health services and their partners to inform and support healthcare decision-making. Under his leadership, LHE has gained an international reputation as a leader in the field of pharmacoeconomic research and practice.

Dr Haycox has extensive experience and expertise in health economic evaluations in a broad spectrum of disease groups and interventions. In addition to publishing extensively in peer reviewed journals such as the BMJ and Pharmacoeconomics, Dr Haycox has authored a number of Health Technology Assessment Monographs.

Dr Haycox is also an editorial board member/reviewer for a wide range of high impact journals, including:

- Alimentary Pharmacology & Therapeutics
- British Journal of Pharmacology
- British Medical Journal
- European Journal of Health Economics
- Evidence-based Healthcare
- Health Policy
- Journal of Epidemiology & Community Health
- Journal of Health Economics
- Pharmacoeconomics
- Social Science & Medicine

Dr Haycox is a member of the College of Experts who referee proposals submitted to a wide range of research funding Programmes in the UK. He is also an expert advisor to the National Prescribing Centre (NPC) in England, the Scottish Medicines Consortium (SMC) in Scotland and a wide range of national and international regulatory and funding authorities.

Dr Haycox is a founding director of the Liverpool Technology Assessment Reviews unit which works directly on evaluations to inform decision making by NICE. For the past four years he has been a member of the NICE Technology Appraisal Committee which decides on the introduction of new drugs into the British National Health Service.

Mette Kjer Kaltoft MPH RN PhD

Seeking to translate the WHO 1984 vision ’Health for All 2000’ into practice has led to innovative e-approaches to health literacy and care in meeting the challenges of working in deverse settings, e.g. as a health visitor in multi-ethnic communities. A MPH, Middle East studies, Modern Standard Arabic, Health Impact and Decision Analysis, and intercultural communication courses preceded the exploration of the potential of Multi-Criteria Decision Analysis (MCDA) to improve decision making at both the clinical and policy levels. Transforming (nursing) care required a mini-HTA (Health Technology Assessment) on the use of handhelds by nurses in acute care, and in this study MCDA was used as the policy-related framework to aid the transparent communication of the findings from a systematic literature review (handheldsfornurses). Testing MCDA-based interactive decision support in clinical cross-disciplinary settings in the field of Inflammatory Bowel Disease (IBD) was the empirical focus of my PhD, defended at University of Southern Denmark in 2015. The thesis included the development of a decision quality instrument, providing, among other things, a specific patient-provider measure of concordance. The findings from clinical IBD outpatient settings in London and Sydney are now being used as the background for developing home-based decision support in bone health as preparation for a subsequent consultation. The bone focus expands the primarily medicine and surgery options found in the IBD context. The major present challenge is implementing multi-disciplinary e-approaches, across the age-spans and Danish health care sectors, which tap into existing health platforms and involve novel ways to prepare from home; in brief, setting up a shared e-platform for better decisions, allowing informed and preference-based consent in real-life and real time. Our present bone health study, which runs until the end of 2017, is funded by the Danish national health authorities, who are repeatedly calling for a cultural change towards citizen-based and person-centered approaches, including the incorporation of the preferences of the person into decision-making.

Lorenzo Lorusso MD

Lorenzo Lorusso is a Consultant Neurologist with experience in Neuro-immunology at the Neurology Unit in Chiari-Brescia in Northern Italy. He is involved in Orphan disorders receiving for ten year (1999-2009) a European grant for para-neoplastic syndromes and a National grant by Minister of Health. He is carrying out research on Multiple Sclerosis, Neuro-Oncology and other autoimmune disorders. He was scientific director of the Italian Association of the Multiple Sclerosis charity in Brescia organizing public meetings for spreading information regarding this disorder. For 20 years, he has interest in ME/CFS with national and international collaborations and with an involvement in the Cost Action called EUROMENE. He is member of the scientific committee for the Italian Association for CFS patients in Pavia managing conferences, studies with the University of Pavia and other national and international public and private institutions. He has also interest in History of Neuroscience as past President of the International Society of the History of Neuroscience (ISHN). He was professor of the History of Medicine at the University in Milan. Currently, he is chairman of the history committee for the Federation of European Neuroscience Societies (FENS) with a promotion of the European scientific medical historic institutions (museum, libraries and archives).

James Marcum PhD

James A. Marcum is Professor of philosophy and the Medical Humanities Program at Baylor University in Waco, Texas, USA. He earned doctorates in philosophy from Boston College and in physiology from the University of Cincinnati Medical College. He also holds a Masters degree in theology from Gordon-Conwell Theological Seminary. He was a postdoctoral fellow at Harvard Medical School, a research associate at Massachusetts Institute of Technology, and a faculty member at Harvard Medical School for almost two decades before coming to Baylor University. He received grants from several funding agencies, including the National Institutes of Health, National Science Foundation, and American Heart Association, as well as having the distinction of being awarded the first Frederik B. Bang Fellowship at the Marine Biological Laboratory in Woods Hole, Massachusetts. He is recipient of Senior Vice-Presidential Medal of the European Society for Person Centered Healthcare. He delivers invited lectures at both national and international conferences. His current research interests include the philosophy and history of science and medicine.

Examples of his recent publications appear in *Annals of Science*; *International Studies in the Philosophy of Science*; *Synthese*; *Perspectives on Science*; *History and Philosophy of the Life Sciences*; *Journal of the History of Medicine and Allied Sciences*; *Medicine, Health Care and Philosophy*; *Perspectives in Biology and Medicine*; and *Theoretical Medicine and Bioethics*. His books in philosophy of medicine include *An Introductory Philosophy of Medicine: Humanizing Modern Medicine*. Philosophy and Medicine series, volume 99, New York: Springer, 2010, and *The Virtuous Physician: The Role of Virtue in Medicine*. Philosophy and Medicine Series, volume 114, New York: Springer, 2012. Finally, he is editor of *The Bloomsbury Companion to Contemporary Philosophy of Medicine*. Bloomsbury Companions series, London: Bloomsbury, 2017.

Matthew Mercuri PhD

Mathew Mercuri completed a PhD in Health Research Methods at McMaster University, and a postdoctoral fellowship in the Department of Medicine at Columbia University. His research interests include variations in medical practice, organization of health care services, and radiation exposure from medical imaging. Mathew is currently an assistant professor in the Department of Medicine (Division of Emergency Medicine) at McMaster University, and a research associate at the African Centre for Epistemology and Philosophy of Science at the University of Johannesburg. He is also pursuing a second PhD at the Institute for History and Philosophy of Science and Technology at the University of Toronto, where his interests are focused on the concept of evidence in clinical medicine.

Brendan McCormack RGN BSc (Hons) DPhil

Head of the Division of Nursing; Head of the Graduate School; Associate Director, Centre for Person-centred Practice Research, Queen Margaret University, Edinburgh. Honorary Nurse Consultant (Gerontology), NHS Fife. Professor II, University College of South East Norway, Drammen, Norway; Extraordinary Professor, Department of Nursing, University of Pretoria, South Africa; Professor of Nursing, Maribor University, Slovenia & Visiting Professor, Ulster University.

Brendan's internationally recognised work in person-centred practice development and research has resulted in successful long-term collaborations in Ireland, the UK, Norway, The Netherlands, Canada, Australia and South Africa. His writing and research work focuses on person-centred practice, gerontological nursing, and practice development and he serves on a number of editorial boards, policy committees, funding panels and development groups in these areas. He has a particular focus on the use of arts and creativity in healthcare research and development. Brendan has more than 600 published outputs, including 180 peer-reviewed publications and 10 books. He is the 'Editor Emeritus' of the "International Journal of Older People Nursing". Brendan is a Fellow of The European Academy of Nursing Science. In 2014 he was made a Fellow of the Royal College of Nursing, awarded the 'International Nurse Researcher Hall of Fame' by Sigma Theta Tau International and listed in the Thomson Reuters 3000 most influential researchers globally. He is currently in the top 100 'most cited' nurse researchers globally. In 2015 he was recognized as an 'Inspirational Nursing Leader' by *Nursing Times* (UK nursing magazine).

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

Professor Andrew Miles is Senior Vice President and Secretary General of the European Society for Person Centered Healthcare (ESPCH). He is Editor-in-Chief of the *European Journal for Person Centered Healthcare*, Editor-in-Chief of the *Journal of Evaluation in Clinical Practice* and holds a Professorship at the Centre for Public Engagement, Joint Faculty of Health, Social Care and Education, St. George's University Hospital Campus, London. Gaining his first Chair at the age of 30, he was formerly Professor of Clinical Epidemiology and Social Medicine & Deputy Vice Chancellor (Deputy Rector) of the University of Buckingham UK, holding previous professorial appointments in the departments of primary care and public health medicine 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 has been a Visiting Professor to the medical schools at the University of Milan, Italy and at Francisco de Vitoria University, Madrid, Spain and is a former Fellow at the WHO Collaborating Centre for Public Health Education and Training, Faculty of Medicine, Imperial College London UK. He is a Visiting Professor to the Medical University of Plovdiv and to the National University of Bulgaria and is a Distinguished Academician of the National Academy of Sciences and Arts of Bulgaria. He trained at the University of Wales and its Medical School in Cardiff UK and holds four higher degrees: two Master's degrees (prostate pathology, clinical audit/evaluation) and two Doctorates (pineal gland neuroendocrinology, person-centered medicine), one of the two latter being awarded *honoris causa* for his contribution to the advancement of person-centered healthcare internationally. He has published extensively in the peer reviewed medical and biomedical press, has co-edited 47 medical textbooks in association with an extensive number of medical Royal Colleges 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 that spans back to 1994. He lectures widely in person-centered healthcare across Europe. Professor Miles is accredited with having changed the direction of the global EBM debate away from scientistic reductionism based on population-derived aggregate biostatistical data and rigid foundationalism, towards the embrace of the complex and the personal within international medicine and health policymaking. He has a profound interest in the modern management of 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 Miles co-founded the ESPCH with Professor Sir Jonathan Asbridge in 2013.

Derek Mitchell BS (Hons) MA PhD

Derek Mitchell first studied philosophy at Oxford and subsequently at the University of Kent and Kings College, London. After a long career in the National Health Service which included ground breaking work in primary care clinical effectiveness and clinical governance Derek retired from the Health Service in 2004 due to a serious illness. Derek now teaches philosophy independently to small groups of adults and works as a patient spokesman for people with a stoma in East Kent. His first book *Heidegger's Philosophy and Theories of the Self* was published in 2001 and his second, *Everyday Phenomenology*, in 2012. Derek has just completed
a two-year studentship on the philosophy of person centered healthcare supported by the European Society for Person Centered Healthcare.

Derek Pheby BSc MBBS LLM MPhil FFPH

Derek Pheby is Visiting Professor of Epidemiology at Buckinghamshire New University, High Wycombe. A former single-handed rural GP, he has higher degrees in social policy and law. When researching social policy at the University of York, he worked closely with the health economists there. He became an epidemiologist more than thirty years ago, initially specialising in cancer. He was Director of the cancer registry for the South-West of England, and was the founder and first chairman of the UK Association of Cancer Registries. He was the UK representative on the Permanent Steering Committee of the European Network of Cancer Registries, and chairman of its Data Definitions group. He coordinated the development of clinical information systems in the south-west of England, and chaired the Project Assurance Team at the NHS Centre for Coding and Classification, which developed the READ codes. Following family illness, he developed an interest in ME/CFS, and ten years ago became the Project Coordinator and Principal Investigator for the National ME Observatory, a three-year collaborative project involving three universities, having been awarded what remains the largest medical research grant ever given by the National Lottery. At the same time, having been asked the question as to why ME/CFS appeared to be more common in north-western Europe than in southern or eastern Europe, he initiated the EUROMENE collaborative research network, and acted as its scientific coordinator for some years. In the UK, he was successively a member of the National Task Force on ME/CFS, the Chief Medical Officer's Working Group on ME/CFS, and the MRC Expert Group on ME/CFS. Currently, he is chairman of the Socio-Economics Working Group within the European Union COST Action which is supporting the work of EUROMENE, and in that role was responsible for recruiting and supporting the work of a Europe-wide group of health economists with an interest in this field who have kindly volunteered their help.

Amy Price PhD

Amy Price PhD is a 2017 Medicine X ePatient Scholar in the Everyone Included Emerging Leaders track. She is a BMJ Research Fellow and a member of the BMJ Patient Panel. Amy leads the PLOT-IT (Public Led Online Trials-Infrastructure and Tools) project. Her institutional affiliation is the University of Oxford. Her goal is build clear channels to propel evidence into practice by supplying the public, and those in low resource areas, with tools to make evidence based health care choices. Responsible shared decision making requires access to standardized and accurate shared knowledge.

She and her team plan to engage, train, and empower the public to plan, prioritize, and take part in all aspects of research including the formation of online randomized controlled trials prioritized by the public and supported through expert methodological input. Her background in international relief work, clinical neurocognitive rehabilitation, service on the boards of multiple patient organizations, and as a trauma survivor has equipped her with the flexible mindset to relate to all stakeholders and cultures. Amy's experience has shown her that shared knowledge, interdisciplinary collaboration, and evidence based research will shape and develop the future.

Marilyn Ray RN BSN MSN MA PhD

Marilyn Anne Ray, RN, BSN, MSN, MA, PhD, CTN-A, FSfAA, FAAN, FESPCH (hon) is Professor Emeritus at Florida Atlantic University, Christine E. Lynn College of Nursing, Boca Raton, Florida, USA. She holds 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 Transcultural Nursing from the University of Utah, Salt Lake City, Utah. Ray has held faculty positions at the University of San Francisco, University of California San Francisco, McMaster University, the University of Colorado, and the Eminent Scholar position at Florida Atlantic University. Her focus is caring science publishing and presenting nationally and internationally and advancing her Theories of Bureaucratic Caring and Transcultural Caring Dynamics in Nursing and Healthcare. She is a retired Colonel in the United States Air Force Nurse Corps and served in aerospace nursing research and practice, and administration for 32 years. Ray has received numerous awards and most recently Lifetime Achievement status from Who's Who Biographers, and the University of Colorado College of Nursing. Her Archives of Caring are housed in the Museum at Florida Atlantic University.

Elizabeth Rider MSW MD

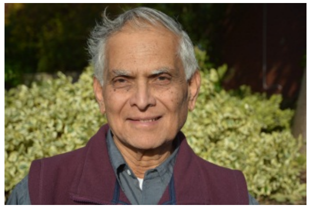
Elizabeth A. Rider, MSW, MD, FAAP, a pediatrician and medical educator, is the Director of Academic Programs at the Institute for Professionalism and Ethical Practice, Boston Children's Hospital, Harvard Medical School. She founded and directs Boston Children's Hospital / Harvard Medical School's Faculty Education Fellowship in Medical Humanism and Professionalism, and the first Faculty Fellowship for Leaders in Collaborative and Humanistic Interprofessional Education. On the faculty at Harvard Medical School, Dr. Rider teaches and consults internationally. She received her MD degree from Harvard Medical School, and MSW from Smith College, and brings her dual background as a physician and child/family therapist to her leadership, teaching and clinical roles.

In 2009, she was named Community Pediatrician of the Year by Boston Children's Hospital. In 2012 Dr. Rider received the National Academies of Practice's Nicholas Cummings Award for "extraordinary contributions to interprofessional healthcare education and practice." In 2016, she was awarded the Platinum Medal for Excellence in Person-Centered Healthcare by the European Society for Person-Centered Healthcare (ESPCH).

Dr. Rider is Vice President of Partnerships and Networking, immediate past Chair of the Medicine Academy, and Carlton Horbelt Senior Fellow of the National Academies of Practice. She is a member of the Global Compassion Council of Charter for Compassion International, and chair of the advisory board and a founding member of the Institute for Communication in Healthcare (formerly the International Research Centre for Communication in Healthcare), now at Australian National University. She leads the *International Charter for Human Values in Healthcare* initiative, a collaborative global effort of people, organizations and institutions working to restore core human values to healthcare.

Dr. Rider's academic interests include relationship-centered care, values, communication skills, professionalism, reflective practice, enhancement of relational competency in learners at all levels, narrative, and medical and interprofessional education and curriculum development. She is an Associate Editor for the journal *Patient Education and Counseling*, and lead author of the book *A Practical Guide to Teaching and Assessing the ACGME Core Competencies* (2007 & 2010).

Shashi Seshia MD FRCP



Dr. Seshia MD (Bombay) & FRCP (Canada and Edinburgh) is Clinical Professor of Pediatrics (Division of Pediatric Neurology), University of Saskatchewan, Saskatoon, Canada. He has spent his professional career primarily as a front-line clinician and teacher in Child Neurology. He has published just over 100 peer reviewed papers and chapters, and been an invited speaker at national and international conferences; areas of interest have included coma, epilepsy, electroencephalography, headache, inter-observer variability, evidence-based medicine, critical appraisal, cognitive biases, decision making and patient-safety. He and his co-authors proposed the term 'cognitive biases plus cascade' to describe the spectrum and cascade of cognition-mediated factors that can subvert decisions.

Diana Slade BA MA PhD

Diana Slade, PhD (USyd), MA (U London) Grad DipEd (UniSA), BA (UAdel), RSA Certificate (TESOL, IH London), is Professor of Applied Linguistics, Australian National University and Director of the Institute for Communication in Health Care, ANU. She is academic researcher and educator in health communication, linguistics, description of spoken English, organisational communication and translational research design.

She has over 30 years of experience in researching, teaching and publishing in applied linguistics, linguistics and organizational communication. Her main research areas are the description and analysis of spoken English, and on communication in organisational and workplace settings. Over the last 9 years she has focused on the critical role of communication in the provision of safe and effective healthcare.

She has led 24 research projects including 11 competitive research projects on healthcare communication since 2011 across Hong Kong and Australia including two consecutive, large national Linkage grants, the first on Communication in Hospital Emergency Departments; the second on *Effective Communication in Clinical Handover*. Diana's current project is a national Australian Research Council Project project on communication at discharge from hospital to the community. Diana and Suzanne Eggins have also recently had philanthropic funding to undertake translational research at St Vincent's hospital on communication in nursing handovers and also with the Hong Kong team two grants - one with a large private hospital - Hong Kong Sanatorium Hospital - and another with Queen Elizabeth hospital (SPEAK up strategies). Committed to inter-disciplinary research and mentoring of younger colleagues, Diana has led research teams of medical, nursing and allied health academics and clinicians, linguists and communication specialists.

Her books include *Effective Communication in Clinical Handover: from research to practice* (with Eggins and Geddes, eds. 2016, de Gruyter Mouton, PASA, Patient Safety 16), *Communicating in Hospital Emergency Departments* (with Manidis et al 2015: Springer); *Conversation: from Description to Pedagogy* (with Scott Thornbury, 2006, CUP) *Analysing Casual Conversation* (with Suzanne Eggins, 1997/2004, Equinox). In addition she has published over 40 refereed journal articles and book chapters. Diana has been a leading contributor to the development of theoretical frameworks for describing and conceptualising the relationship between communication and patient safety and to the translation of empirical research to tangible outcomes that impact on practice.

Sandra Tanenbaum PhD

Sandra J. Tanenbaum is Professor of Health Service Management and Policy in The Ohio State University College of Public Health. After receiving her PhD from the Massachusetts Institute of Technology, she served as a policy analyst for the Ohio Medicaid Program before joining the faculty at OSU. Her research interests include US health policy broadly and especially government insurance programs such as Medicare and Medicaid, mental health and disability policy, and the role of evidence-based medicine in health care payment and quality regimes. She has published widely in such journals as the *Journal of Health Politics, Policy and Law*, where she served as book review editor and on the editorial board, *Health Care Analysis*, *Journal of Evaluation in Clinical Practice*, and *Health Affairs*. She is currently Co-Investigator on a project funded by the Patient-Centered Outcomes Research Institute (PCORI).

Jane Teasdale

Jane Teasdale, Joint Owner and Director Business Development and Community Relations, Mosaic Home Care Services & Community Resource Centres, Toronto, Ontario, Canada.

Jane is dedicated towards developing awareness of home and health care issues in the community and to developing relations between healthcare professionals, home care providers, not-for-profit agencies and other important services providers that are needed to provide the wider levels of support often required by those in need in the community.

She believes that the homecare services model of the future must put individuals, their families and their communities at its centre, and to develop service structures that help meet these very important life and lifestyle needs. In her presentations around the community she focuses on the importance of a more complete model of care that looks to maintain the journey of discovery that is life, and to allow an individual's character, vitality and life contributions to continue to shine through the care giving relationship.

Mosaic Home Care & Community Resource Centres offers a business model that is unique to the homecare industry. It operates community resources centres across the Greater Toronto Area: these centres not only provide information on both for profit and not for profit services and supports to families and individuals in need of assistance but regular educational and social events.

Mosaic has developed a great many partnerships in the community. One worth mentioning is its partnership with the Alzheimer Society of York Region with which Mosaic set up the first Alzheimer's Memory Café in York Region, Ontario and has recently set up a new Cafe and partnership with the Alzheimer Society of Toronto. Mosaic is well respected in the GTA as a best practice leader in homecare services, and especially so in the way it addresses human values and social and community interaction.

Jane Teasdale is also co chair of the North York Elder Abuse Network, a diverse group of North York community service partners committed to promoting awareness of elder abuse and providing educational and training opportunities supported by The Ontario Network For PreventionAgainst Elder Abuse. She was also actively involved with the "Toronto Seniors Strategy: Towards an Age-Friendly City" sitting on the committee with 33 other senior organizations in the Toronto area.

Mark Tonelli BA MA MD

Mark Tonelli is Professor of Medicine and Adjunct Professor of Bioethics and Humanities at the University of Washington, Seattle, USA. He is currently a Visiting Fellow at Clare Hall, Cambridge where he is working in the areas of medical epistemology and case-based reasoning.

Didier Vinot MS PhD

Professor Vinot teaches Health Management at the University of Lyon 3 since 2000. Formerly the Vice-President for Human Resources, he now serves as Vice-President for Economic and Social Affairs and Heritage. He is the author or co-author of 20+ publications on quality of care and hospital management (in French and English). He is the co-director of the chair 'Values of patient-centered care' in Lyons, France.

Bee Wee MA PhD FRCP FRCGP FAcadMEd

Professor Bee Wee is on secondment to NHS England as National Clinical Director for End of Life Care for 2 days per week. In this role, she provides strategic leadership for improving end of life care across England. In 2015, she co-led the development and publication of the *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.* This framework was endorsed in the Government's response to the Review of Choice in End of Life Care in 2016. She continues to co-chair the national Ambitions Partnership which now consists of over 30 partner organisations.

The rest of the time, she is a clinical academic in palliative medicine in Oxford. Originally from Malaysia, she trained in medicine, then general practice, in Ireland and worked in Hong Kong, then became Consultant/Senior Lecturer in Palliative Medicine, and later, Deputy Director of the Medical School, Southampton University. She moved to Oxford in 2003 as Consultant in Palliative Medicine at Sir Michael Sobell House, Official Fellow of Harris Manchester College and Associate Director of Clinical Studies at Oxford University and Head of the Oxford WHO Collaborating Centre for Palliative Care. She is also Associate Professor at Oxford University, Visiting Professor at Oxford Brookes University and University of Worcester, and Honorary Professor at Sichuan University, China. She chairs the Quality Standards Advisory Committee for the National Institute of Health and Care Excellence (NICE) as a regular commitment. In her spare time, she enjoys cooking, eating and allotment gardening with her husband, Richard.

Peter Wyer MD

Dr. Peter Wyer is Associate Professor of Medicine at Columbia University Medical Center in NYC in the specialty of emergency medicine. He has an extensive background as a teacher, advocate and critic of evidence based medicine. He is widely recognized for having introduced the disciplines to the specialty of emergency medicine in North America. He taught in the annual evidence-based clinical practice workshop at McMaster University for 15 years and contributed to the Users' Guides to the Medical Literature series published by *JAMA*. Dr. Wyer founded and chairs the Section on Evidence Based Health Care at the New York Academy of Medicine in New York. In that capacity he has developed innovative approaches to linking training experiences related to evidence-based practice to quality improvement initiatives in real world settings. He is a founding member of the Guidelines International Network North America steering committee. Dr. Wyer has published and lectured extensively on the limitations of evidence-based medicine and on the need to subsume research literacy within the social processes that define the delivery of care to individual patients. He is an editor of *Annals of Emergency Medicine*, *Journal of Evaluation in Clinical Practice* and *BMC Medical Education*. His work as an educator has been funded by the US Agency for Healthcare Quality and Research and the Patient Centered Outcomes Research Institute.

THE 2017 ANNUAL AWARDS CEREMONY AND CONFERENCE RECEPTION

Dear Reader

The Society's awards are intended to recognise various degrees of achievement and excellence in person-centered healthcare advocacy, scholarship, research, teaching, and in the design, evaluation and measurement of PCH-driven clinical services.

The 2017 international consultation exercise was conducted, as in 2014, 2015 and 2016, using a simple nomination form requesting recommendations supported by an accompanying justification. The 2017 consultation generated a grand total of 297 suggestions from which the Awards Selection Panel made its choices.

The President of the Society will confer the Society's medals and prizes at the formal Awards Ceremony on the evening of Thursday 26 October 2017, immediately prior to the Conference Reception.

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18.15 Introduction to the Awards Ceremony

Professor Andrew Miles

18.25 Presidential Address to Award Winners and Guests

Professor Sir Jonathan Asbridge

18.35 Award of the Presidential Medal

Winner: Bee Wee MA PhD FRCP FRCGP FAcadMEd

The **Presidential Medal** of the Society for Excellence in Person Centered Healthcare is awarded to **Professor Bee Wee**. Professor Wee is National Clinical Director for End of Life Care for NHS England and Consultant in Palliative Medicine at Sir Michael Sobell House, Oxford University Hospitals NHS Foundation Trust, UK. She is Head of the World Health Organisation Collaborating Centre for Palliative Care in Oxford, UK. As National Clinical Director she led the Leadership Alliance for the Care of Dying People and is co-Chair of the National Partnership for Palliative and End of Life Care which was responsible for publishing the 'Ambitions for Palliative and End of Life Care: a national framework for local action' in 2015. Professor Wee's relentless focus on the person of the patient, not the 'system', has resulted in substantial developments in the person-centeredness of palliative and end-of-life care not only in the UK but, leading by personal example, elsewhere globally in addition.

18.40 Award of the Senior Vice-Presidential Medal

Winner: Benjamin Djulbegovic MD PhD

The **Senior Vice-Presidential Medal** of the Society for Excellence in Person Centered Healthcare is awarded to **Dr. Benjamin Djulbegovic**. Dr. Djulbegovic is Professor of Oncology and Director of Research, Department of Supportive Medicine and Department of Hematology, City of Hope, Duarte, California, United States of America. Dr. Djulbegovic's major academic research interests lie in the areas of evidence-based medicine (EBM), decision-analysis, clinical reasoning, systematic reviews/meta-analysis and comparative effectiveness research, ethics and design of clinical trials, practice guidelines, outcomes research, the impact of clinical trials and the role of uncertainty in medicine. Dr. Djulbegovic has published extensively on EBM within the international medical literature and, in latter years, has focussed additionally on the philosophies and methods through which to 'bridge the gap' between the EBM and PCH theses, work that continues to advance current understandings of the epistemologies of

EBM and PCH which are of direct significance to the field of person-centered healthcare moving forward.

18.45 Award of the Platinum Medal

Winner: Diana Slade BA MA PhD

The **Platinum Medal** of the is awarded to **Professor Diana Margaret Slade**. Professor Slade is Professor of Applied Linguistics and Director of the Institute for Communication in Health Care at the Australian National University, Canberra, Australia. She has over 20 years' experience in researching, teaching and publishing in applied linguistics, linguistics and organisational communication. She was primary Chief Investigator on an ARC Linkage (2007-2010) entitled Emergency Communication: Addressing the challenges in health care discourses and practices and is currently the Chief Investigator of a three year ARC project entitled 'Effective clinical handover communication: improving patient safety, experiences and outcomes'. Professor Slade's intensive research in clinical communication and her recent foundation of the new Institute for Communication in Health Care at the Australian National University is resulting in substantial advances in the person-centeredness of clinical communication and care.

18.50 Award of the Gold Medal

Winner: Jane Teasdale

The **Gold Medal** of the Society is awarded to **Ms. Jane Teasdale**. Ms. Teasdale is Director of Business Development at Mosaic Health Care Services, Toronto and Markham, Canada. She is dedicated to the development of a greater awareness of home and healthcare issues in the community and to the development of enhanced relationships between healthcare professionals, home care providers, not-for-profit agencies and other important services providers that are needed to provide the wider levels of support often required by those in need in the community. Ms. Teasdale's work has been characterised by her belief that the homecare services model of the future must put individuals, their families and their communities at its centre, and to develop service structures that meet these very important life and lifestyle needs. Mosaic's enthusiastically person-centered business model has translated into very significant advances in the person-centeredness of community-based comprehensive care.

18.55 Award of the Silver Medal

Winners:

Elenka Brenna PhD

Lara Gitto PhD

Lorenzo Lorusso MD

Derek Pheby BSc MBBS LLM MPhil FFPH

The **Silver Medal** of the Society is awarded jointly to **Dr. Elenka Brenna, Dr. Lara Gitto, Dr. Lorenzo Lorusso and Dr. Derek Pheby** in recognition of their individual and joint endeavours as part of the EUROMENE Project on ME/CFS. ME/CFS is one of the so-called 'medically unexplained illnesses' which were examined in a major symposium of the Society held in September 2016 at St. George's University Hospital in London, with the aim of identifying more person-centered approaches to their management. The total costs of ME/CFS to individuals, health systems and Society as a whole, form part of the work of the EUROMENE Project and cannot be considered in isolation from the effectiveness of differing models for the investigation and management of ME/CFS - specifically in terms of the effects on clinical and social outcomes of models which are fully person-centered and those which are less so. Such concerns were considered in a recent paper accepted for publication in the *European Journal for Person Centered Healthcare* by Gitto and Brenna and entitled 'The economic burden of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME): an initial summary of the existing evidence and recommendations for further research'. Taken as a whole, this joint endeavour was judged as having contributed significantly to the advancement of the person-centered healthcare of ME/CFS.

19.00 Award of the Bronze Medal

Winner: Bernadette Brady

The **Bronze Medal** of the Society is awarded to **Ms. Bernadette Brady** in recognition of her work on building empathy among the people of an Emergency Department, specifically the two-way interaction of staff and patients. Ms. Brady was Director for Patient and Family Centered Care for ACT Health, Canberra, Australia from 2005 – 2012 and currently now works on a range of initiatives aimed at developing partnerships with patients in Australia. Her work in the context of emergency departments has captured the essence of what person-centeredness in that context actually means, enabling the sharing of the lived experiences of staff and patients, thereby encouraging empathetic feelings bilaterally between the patient and clinician and enabling each to ‘walk in each other’s shoes’. Her work, in enhancing such processes, has contributed significantly to the advancement of person-centered care in the emergency care setting.

19.05 Award of the Book Prize

Winner: Brendan McCormack RGN BSc (Hons) DPhil

The **Book Prize** is awarded to **Professor Brendan McCormack** in his role as First Editor of the recently published textbook ‘Person-Centred Healthcare Research’ (Eds. McCormack, B., van Dulmen, S., Eide, H., Skovdahl, K & Eide, T). Wiley & Sons, Ltd, September 2017). The volume was judged as representing a novel and innovative approach to exploring the range of research methodologies of value in investigating person-centered healthcare practices within and across healthcare disciplines, successfully bringing together 37 established experts in the field writing over 18 detailed chapters. The research methods identified, and the applications described, are of major significance to progressing the methodology of person-centered healthcare research and evaluation.

19.10 Award of the Essay Prize

Winner: Matthew Mercuri PhD

The **Essay Prize** is awarded to **Dr. Mathew Mercuri** in his capacity as First Author of the paper ‘Examining the role of the physician as a source of variation: Are physician-related variations necessarily unwarranted’. (Mercuri, M., & Gafni, A. *Journal of Evaluation in Clinical Practice* 2017 doi: 10.1111/jep.12770. [Epub ahead of print]). The narrative review was judged as having successfully examined whether or not physician-related variation is problematic for patient care, illustrating that observed physician-related variation is not necessarily unwarranted, irrespective of its magnitude, and recommending an improved measurement of the sources of variation, especially with respect to patient preferences and context, fundamental aspects of an authentically person-centered healthcare.

19.15 Award of the Young Researcher Prize

Winner: Ms. Karishma Jivraj

The **Young Researcher Prize** is awarded to **Ms. Karishma Jivraj.** Ms. Jivraj is a final year PhD candidate at the Joint Faculty of Health, Social Care and Education at Kingston University and St. George’s University of London, UK. Her research employs mixed methods aimed at exploring therapeutic relationships, shared decision-making and attitudes towards medication among service users and clinicians in the UK NHS, topics which have been widely explored in somatic disease, but which have received little attention in mental health. Ms. Jivraj’s findings to date were judged as having provided considerable insight into NHS prescribing practices, decision-making activities and therapeutic relationships between clinicians and service users, with immediate implications for assisting practitioners and services to reach a clearer understanding of the various reasons service users with mental illness have in taking or not taking their medications as recommended. Ms. Jivraj’s research is already proving of great value in improving the therapeutic relationships between NHS clinicians and service users and is informing future treatment planning of direct relevance in moving mental healthcare away from reductive approaches towards more person-centered models of mental healthcare and treatment planning.

19.20 Award of an ESPCH Honorary Distinguished Fellowship

An **Honorary Distinguished Fellowship** of the Society is conferred upon **Professor Jörg Schelling**, Chief Physician Specialist for General Medicine and Founding Director of the Institute of General Medicine of Ludwig-Maximilian University of Munich, Bavaria, Germany.

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