



ESPCH e-BULLETIN

THE INAUGURAL ISSUE

The Second Annual Conference of the ESPCH

The Inaugural Meeting of The Council and the 10 Year Strategic Plan of the ESPCH

Announcement of Latest Appointments to SIGs
Chairmanships and Recently Elected Members

Winners of the 2015 ESPCH Awards

Announcement of Winners of the ESPCH Postgraduate
Master's Degree Studentships

The ESPCH-UFV Collaboration

*...and more with recently
published PCH reports,
resources, literature,
and global educational
initiatives...*

TABLE OF CONTENTS

- 2-3 Letter from the Editor**
- 4-5 ESPCH Collaboration with Francisco de Vitoria University in Madrid, Spain**
- 6-59 Report on the Second Annual Conference and Awards Ceremony of the ESPCH, Madrid, 2015:**
 8-23 Day 1
 24-41 Day 2
 42-51 Winners of the ESPCH Awards 2015
 52-53 Winners of the EPSCH-Inaugral Postgraduate Master's Degree Studentships
 57-59 Inaugural Meeting of the Council of the ESPCH and the declaration of the 10 year Strategy for the Society on Moving Forward
- 60-73 ESPCH Appointments:**
 60 Officers of the Society
 61-65 Elected Chairmanships to the Special Interest Group Network
 66-73 Recent membership elections
- 74-76 ESPCH Academic and Clinical Publications**
- 77-81 ESPCH News and Planned Events**
- 82-89 Society Interviews:**
 Margot's Q&A with Professor Andrew Miles, ESPCH Senior Vice President & Secretary General
- 90-95 Book Reviews:**
 What did Dr. Margot Lindsay say about this book?
- 96-117 GLOBAL PCH:**
 96-99 Report: Exploring the health consumer's perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management.
 100-101 Report: Person-centred Care Around the World
 102-103 PCH Resources
 104-109 Published literature on PCH
 110-113 Editor's Pick: Recently published articles on PCH
 114-117 Global PCH educational initiatives
- 118-120 Membership Form for the ESPCH**
- 121-127 2016 ESPCH Awards Nomination Form**

LETTER FROM THE EDITOR

Welcome to the inaugural e-Bulletin of the European Society for Person Centered Healthcare, the quarterly Newsletter of the ESPCH

The purpose of the Society's new e-Bulletin is to communicate news and developments from the ESPCH on an ongoing basis to the rapidly growing membership of the Society and to a wide range of external colleagues and organizations, with an interest in the advancement of person-centered healthcare (PCH).

The e-Bulletin is international in its scope and will be published alongside the *European Journal for Person Centered Healthcare* (EJPCH), the official academic journal of the Society. With the EJPCH published at the end of each operational quarter and the e-Bulletin published during the middle of each operational quarter, ESPCH members and others will thus benefit from access to two differing but entirely complimentary publications of the Society, each with immediate relevance to all those working in the field. The e-Bulletin is free of cost to Society members.

This Inaugural e-Bulletin begins with a description of the Society's collaboration with Francisco de Vitoria University, Madrid, the first of many pan-European collaborations currently being established by the Society. It continues by presenting a detailed overview of the proceedings of the Society's Second Annual Conference and Awards Ceremony, held in Madrid on 18 & 19 June 2015. As the conference report, authored by Dr. Vivian Mounir of the Society's full time staff makes clear, that signal event proved a resounding success and brought together a wide variety of internationally distinguished speakers working in PCH from across the United States of America, Canada, Australia, New Zealand, South America, Turkey and from the length and breadth of Europe including Germany, Spain, Italy, France, United Kingdom, Norway, Sweden and Denmark. Dr. Mounir documents the content of the speakers' presentations and provides readers, in addition, with an account of the Awards Ceremony and its medal and prize winners. She introduces the first three postgraduate Master's degree students of the Society, describes the Society Conference Dinner and reviews the first Meeting of Council of the Society.

A regular feature of the quarterly e-Bulletin of the Society will be the publication of lengthy interviews with notable figures working within the global PCH movement, including individual clinicians and academics, transformational/servant leaders, patient advocates, policymakers, politicians, presidents/heads of European medical and other healthcare societies/associations and industry executives. The very particular perspectives that the e-Bulletin will harvest from such colleagues will prove, it is anticipated, useful to readers, providing valuable insights into the current status of thinking across the PCH field. An additional regular feature of the Society's quarterly e-Bulletin will be its sections on recommended reading. These 'Editor's picks' will point readers to the most important 'hot off the press' publications of relevance to PCH: peer reviewed papers within the global medical and scientific literature, the most recently published volumes and monographs of relevance to PCH and the most recently published reports of relevance to PCH from governments, non-governmental organizations, charities and Industry.

A further – and important – feature of the quarterly e-Bulletin will be the publication of the names, institutions and interests of the latest colleagues who have joined the Society as ordinary members, associates,

fellows, distinguished fellows or students. News from existing members will also be presented, detailing, for example, grants received, research and other protocols being designed, details of papers in press/recently published and any promotions and honours obtained by Society members. The e-Bulletin will therefore provide, in addition to so many other things, an excellent means of on-line networking between colleagues working within different health systems and geographical regions of the globe. In this context, readers are encouraged to write a Letter to the Editor of the e-Bulletin, if considered useful, describing their research/intended research and inviting potential national, regional or international collaborators to their work. The e-Bulletin will be pleased to publish such communications in a direct effort to move our field forward.

No e-Bulletin would be complete without a listing of forthcoming conferences, courses and study days/sessions of relevance to PCH and the Society will endeavour to be circumspect in identifying and recommending to readers only those events and initiatives that it considers to be of the greatest relevance to the advancement of PCH as the Society understands it. The Society will engage in negotiating an ESPCH discount for members of the Society should they wish to attend such activities.

Finally, this first e-Bulletin of the Society closes with a Membership Application Form, encouraging readers who are not currently members of the ESPCH to join the Society in order to take part in its work, and a Nominations Form for the Society's 2016 Awards. We urge all colleagues in receipt of the website link to this e-Bulletin to consider forwarding it to all those of their own colleagues who hold an interest in this rapidly developing and all-embracing component of modern clinical practice and healthcare systems, with an encouragement to support the Society's work.

The Society, as always, looks forward to being of the fullest service to its members and welcomes reader feedback and opinion. Comments on this e-Bulletin (or on the Society's work in general), with any suggestions for improvement, may be sent to me, as Editor of this e-Bulletin (and SVP/Secretary General of the Society), at: andrew.miles@pchealthcare.org.uk

Yours collegially



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



Universidad
Francisco de Vitoria
UFV Madrid

ESPCH COLLABORATION WITH FRANCISCO DE VITORIA UNIVERSITY IN MADRID, SPAIN

A collaboration was established between the European Society For Person Centered Healthcare and the Faculty of Medicine at the Francisco de Vitoria University in Madrid, in October 2014, representing the first of many institutional partnerships within Europe. Both institutions share a mutual vision for the re-integration of medicine's humanism into clinical practice alongside continuing biomedical and technological advance. In a formal ceremony, the agreement was signed by Professor Andrew Miles, on behalf of the ESPCH and Dr. Daniel Sada Castaño, Rector of UFV.



Formal Signing Ceremony with the signatories: Professor Andrew Miles (left) and Dr. Daniel Sada Castaño (right)

The scope of the agreement covers the areas of training, research and the development of programs between both institutions for undergraduate and postgraduate medical education, targeting all health professionals, UFV teachers and students. Currently, the ESPCH HQ is split between UFV Madrid and London. The Society held its first two annual conferences at UFV Madrid.

In 2010, University Francisco de Vitoria initiated its new 6-year medical degree with a program designed to cover not only the intensive transmission of theoretical knowledge, but also offering students opportunities to develop an integral professional competence, including an emphasis on communication skills, clinical reasoning, the natural integration of social and ethical aspects of the medical profession as well as the recovery of a properly humanistic vision of medicine. The UFV Curriculum focuses on five main areas to support the development of ethics and professionalism in medical students: student selection, curriculum design, role modeling, new teaching and learning methods as well as assessment method.



Left to right: Professor Andrew Miles, Dr. Daniel Sada Castaño, Dr. Juan Pérez-Miranda (Vice Rector, International Relations, UFV) and Dr. Fernando Caballero Martínez (Dean of Medicine, UFV)

Universidad Francisco de Vitoria (UFV) is a non-profit private Catholic University located in metropolitan Madrid, Spain. It was founded in 1993 as an affiliate of "Universidad Complutense" and achieved full accreditation in 2001. Since then, it has become a fast-growing, international institution of higher education with 3.500 undergraduate and 1.500 postgraduate students. Today, the Campus houses six major Faculties and one school of culinary arts, collectively covering the full spectrum of research and education.



Edited by Dr Vivian Mounir MBChB, Senior Project Manager. European Society for Person Centered Healthcare

Reviewed by Professor Andrew Miles MSc MPhil PhD DSc (hc), Senior Vice President/Secretary General

The Second Annual Conference and Awards Ceremony of the European Society for Person Centered Healthcare was held in Madrid on 18 & 19 June 2015 (MADRID 2015). The Conference, which proved an outstanding success, built valuably on the First Annual Conference and Awards Ceremony of the Society organized one year earlier in the same city on 3 & 4 July 2014, bringing together an extensive and indeed stellar line up of distinguished speakers from the United States of America, Canada, Australia, New Zealand, South America, the Middle East, Turkey, the United Kingdom, France, Spain, Italy, Germany, Norway, Denmark and Sweden.

The Society was privileged to secure the enthusiastic participation of so many global scholars in the 2015 Conference, all of whom are working in their institutions and indeed worldwide to advance the development and implementation of person-centered healthcare approaches within modern medicine and multidisciplinary healthcare more generally. In the present Conference Report we provide a detailed record of the proceedings of the Conference, interspersing the text with key photographs which capture the spirit and vivacity of the 2015 event. As we write this Report, a Steering Group has been constituted to establish the content and direction of the Third Annual Conference and Awards Ceremony of the Society, scheduled for September 2016 in central London. The Society's Fourth Annual Conference will be held at the Medical University of Plovdiv, Bulgaria in 2017.



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE

THE SECOND ANNUAL CONFERENCE AND AWARDS CEREMONY

CONFERENCE REPORT

18-19 JUNE 2015

Francisco de Vitoria University, Madrid, Spain



THE CONTEXT

MADRID 2015 was organized with direct reference to the ongoing global epidemic of long term co- and multi-morbid, socially complex illness. These illnesses, which now account for over 70% of global morbidity and mortality, are imposing intolerable burdens on individual patients and their families and are threatening, in the words of the World Health Organization, to bankrupt health systems worldwide. Here, the classic formula of 'diagnose, treat, cure, discharge' is inapplicable and the effective management of these complex conditions requires an altogether different approach. The use of accumulated and accumulating science and technology remains, of course, pivotal – that is axiomatic, a *sine qua non*. But a purely biomedical approach to dealing with these conditions is increasingly recognized to be of limited value. Indeed, patients present to clinicians not as a simple collection of organ systems, one or more of which may be dysfunctional, requiring given pharmacological or technological interventions. Rather, they present as integral human beings with narratives, values, preferences, psychology, emotionality, existential and spiritual concerns, worries, hopes, goals, fears and anxieties, a cultural and societal context – thus living in relationship with spouses, families, employers and with Society in general. Yet health systems have not only largely failed to address the comprehensive needs of these patients and their families, but have also struggled to grapple with a wider problem within modern healthcare systems – the ongoing crisis of *knowledge* (uncertainty over what counts as 'evidence' for decision-making and what does not), *care* (a deficit in sympathy, empathy, compassion, dignity, autonomy), *patient safety* (neglect, iatrogenic injury, malpractice, excess deaths), *economic costs* (which threaten to bankrupt health systems worldwide) and *clinical and institutional governance* (a failure of basic and advanced management, inspirational and transformational leadership).

Given these realities, and they are realities, it is no surprise that patients, clinicians, academics, policymakers and politicians have all called for a new way of 'thinking and doing' in the care of the sick. They are calling for a better way, the right way, of responding to these patients' needs. A way, which by its nature, is far better placed to accompany chronically ill patients therapeutically during the whole length of their illness trajectory. A way of containing or decreasing healthcare costs, while maximizing health outcomes, adding value to health services provision and increasing patient and clinician satisfaction with care. This new approach has been termed 'person-centered healthcare', recently explicated in its most modern form by Professor Andrew Miles and his colleagues, and it was with the specific aim of developing this new approach that the European Society for Person Centered Healthcare was created and which the 3 & 4 July 2014 and the 18 & 19 June 2015 conferences of the Society were designed to explore. We turn now to the proceedings of the June 2015 Conference (MADRID 2015).

DAY 1: 18 JUNE 2015

CONFERENCE OPENING ADDRESS

On behalf of the Rector of the University, the conference was opened by **Dr Juan Pérez-Miranda, Vice Rector for International Relations, Francisco de Vitoria University, Madrid, Spain.**



Dr. Juan Pérez-Miranda

Dr. Pérez-Miranda welcomed the President and Chairman of Council of the Society, Professor Sir Jonathan Asbridge DSc (hc), along with speakers, chairmen and delegates. After delivering the Rector's salutations, Dr. Miranda proceeded to outline the mission and history of the University for the information of those present.

Francisco de Vitoria University (UFV), Dr. Pérez-Miranda explained, was founded by the Legionaries of Christ, a worldwide Catholic Order, in 1993, initially as an affiliate institution of the historic Universidad La Complutense in Madrid. Later to become a fully independent and widely recognized Catholic seat of learning, UFV is in a state of rapid expansion, defying, as it were, the expected effects of the European economic crisis. Dr. Pérez-Miranda explained how the University is committed in its beliefs and ethos to the centrality of the human person in all aspects of social life and organization. The Medical School at UFV illustrates these beliefs, he told the Conference, by having created an undergraduate medical school founded on the principles of person-centered healthcare, with humanistic values inculcated into student teaching alongside the highest level of scientific education. These values, Dr. Pérez-Miranda explained, while fully operational in the Medical School, were being actively extended to all other faculties of the University by Order of the Rector.

In concluding his **Welcoming Address**, Dr. Pérez-Miranda, as Chairman of the Early Morning Session of Day One of the Conference, called upon **Professor Sir Jonathan Asbridge DSc (hc), President and Chairman of Council of the European Society for Person Centered Healthcare, to deliver the Presidential Address.**



Professor Sir Jonathan Asbridge

Sir Jonathan commenced his **Presidential Address** by extending his own welcome to speakers, chairmen, panel discussants and delegates at the Second Annual Conference and Awards Ceremony of the Society, noting with great appreciation that speakers and delegates had travelled to Madrid not from just two or three continents of the world, but from no less than five.

Sir Jonathan reflected on the success of the first Society conference one year ago in Madrid (3 & 4 July 2014) and confirmed how delighted he was with the extraordinary extent of progress that the Society had been able to make over the intervening year. He noted as progress here, not simply the fact of the Second Society Conference itself and the global derivation of its speakers and delegates, but also the work underway in the organization of the forthcoming 2016 Society conferences and publications on the person-centered care of the frail elderly, the person-centered care of people living with HIV/AIDS, the work on medically unexplained symptoms such as chronic fatigue syndrome and fibromyalgia and the work programme being put in place for 2017, which will feature projects focusing on diabetes, breast and prostate cancer and on many of the neurodegenerative diseases, together with other challenging conditions.

Sir Jonathan noted, with satisfaction, the great strides being made by the *European Journal for Person Centered Healthcare* (EJPCH), the Official Journal of the Society, with Volume 3 (2) having been published a month ahead of schedule and with 3 (3) and 3 (4) – the remaining issues of 2015 – already edited and complete, awaiting their respective months of publication of September and December 2015. It was deeply gratifying, Sir Jonathan said, and very heartening, to see such large volumes of high quality papers being submitted to the EJPCH on a weekly basis from all around the globe, making necessary an expansion in the annual page budget of the journal in 2016, with formal indexing of the EJPCH by PubMed fully expected in 2016.

To be remembered also, Sir Jonathan added, was the steady progress being made in assembling the Society's seminal 55-chapter academic textbook 'Person-centered Healthcare: How to Practise and Teach PCH'. Further major projects, Sir Jonathan told the Conference, were represented by the forthcoming 50,000 word treatise 'Person-Centered Healthcare: Theory and Practice' and by the 150,000 word 'Preliminary Lexicon and Dictionary of Terms for Person Centered Healthcare'. The Special Interest Groups of the Society were also beginning to work well and energetically on their tasks in hand, with a range of clinical handbooks on person-centered healthcare to be published in 2016/2017, with other individual SIG activities and events to follow.

As the Society continued to move forward in this way, it would be vitally important, Sir Jonathan emphasized, for a range of developments in the governance of the Society to be put in place. He referred here to the draft Constitution and Terms of Reference of the Society and also to the 10 Year Strategic Plan of the Society. These, and other matters, he said, would be discussed at the Society's Inaugural Meeting of Council, which he looked forward to chairing following the conclusion of Day Two of the Conference on 19 June 2015. Sir Jonathan concluded his Presidential Address by wishing all those present a stimulating and productive Conference.



Top: Conference Opening Address (Left to right): Dr. Juan Pérez-Miranda, Professor Andrew Miles, Sir Jonathan Asbridge.
Lower: Professor Sir Jonathan Asbridge delivering the Presidential Address

SESSION ONE: ONGOING DEBATES IN THE PHILOSOPHY OF MEDICINE AND HEALTHCARE

Following the conclusion of the **Presidential Address, Dr. Pérez-Miranda invited Dr. James Marcum, Professor of Philosophy & Director, Medical Humanities Program, Baylor University, Texas, United States of America (Winner of the 2015 ESPCH Vice Presidential Medal for Excellence in Person Centered Healthcare)**, to address the Conference under the title **'Healthcare personalism and the nature of the Person. How can personalist thought advance the conceptual basis of person-centered healthcare?'**

Healthcare personalism, Dr. Marcum argued, represents a multifaceted approach to modern healthcare and its delivery, that champions the centrality of the person. *Ontologically*, the person is an embodied agent, embedded holistically within biological and social contexts. For healthcare personalism, the value that underlies this ontological dimension of the person is health, that is, the proper functioning of the embodied agent within a given context—whether biological or social. Illness, on the other hand, represents an improper functioning or a dysfunction of the person within a given context. *Epistemologically*, Dr. Marcum asserted, the person is a cognitive or rational/logical agent, who can discern fact from fiction. For healthcare personalism, the virtues animating the epistemic agent are *phronesis* or practical wisdom and *sophia* or theoretical wisdom, especially on the part of the healthcare provider. For the patient, additional virtues include patience and perseverance to ensure that the healthcare provider hears and understands the patient's illness story. *Ethically*, Dr. Marcum emphasized, the person is a relational agent with respect to other persons and to their given context. For healthcare personalism, the chief virtue of the ethical agent, especially healthcare providers, is care, along with two associated virtues compassion and competence. Through caring for the patient *qua* person the provider is able to take care of the patient's healthcare needs. The chief virtue of the patient is gratitude for the healthcare providers who strive to reduce the suffering associated with illness. Dr. Marcum concluded his presentation by stressing that the value animating healthcare personalism, overall, is the dignity of each person involved in the healthcare encounter. For healthcare personalism, then, the notion of person in terms of its ontological, epistemological, and ethical dimensions is crucial for providing a philosophical framework to explicate quality healthcare and its delivery.

Following Dr. Marcum's presentation, Dr. Pérez-Miranda invited **Professor Michael Loughlin, Professor of Applied Philosophy, Manchester Metropolitan University, England, United Kingdom & Chairman, ESPCH SIG on Health Philosophy (Winner of the 2014 Senior Vice Presidential Medal for Excellence in Person Centered Healthcare)**, to address the Conference, under the title **'Person-centered healthcare and the ontology of value'**.

Professor Loughlin made clear that the debates about how we conceptualise health, disease and illness are still beset by the suspicion that 'value judgements' are in some special sense 'subjective', so that a motivation for defending biomedical definitions of health and disease that are 'value-neutral' is to defend the objectivity of diagnosis. There are background assumptions at work here, Professor Loughlin argued, about the relationship between knowledge, truth, objectivity, science, value and reality that require urgent analysis. The movement towards 'person-centred' healthcare, he asserted, is frequently associated with the idea that medical diagnosis is inevitably value-laden. Until these background assumptions are brought to the fore and examined, this idea will raise concerns that the movement is driving an approach to health that is anti-science and associated with relativist accounts of health and illness.

The clearest illustration of the assumptions at work here, Professor Loughlin argued, can be found in the history of the debate about the reality of mental illness, where there has historically been a divide between those who accept that diagnosis is 'value-laden' (and therefore accept a relativist/subjectivist account of mental illness) and those who feel the need to deny the value-laden nature of diagnosis

to defend the reality of mental illness. More nuanced analyses note, Professor Loughlin asserted, that (a) all medical diagnosis is arguably value-laden & (b) this does not imply that medical conditions are unreal. All judgement (about value or fact), he emphasized, requires a subject, but it does not follow that it is 'subjective' in any sense implying ontological relativity. The implications are substantial: either all medical judgement is relative (a thesis many – quite correctly – regard as counter-intuitive and deeply problematic) or realism about value is true. To justify our claims in diagnosis, Professor Loughlin argued, we need to discuss and defend our value-judgements. We must reject 'scientism' for an openly value-laden account of human functioning. Medical epistemology requires value-realism.

Following the conclusion of Professor Loughlin's presentation, Dr. Pérez-Miranda invited **Dr. Rani Lill Anjum, Research Fellow & Director of CauseHealth, School of Economics and Business, Norwegian University of Life Science, Oslo, Norway** to address the Conference under the title **'CauseHealth: creating a new ontological foundation for person-centered healthcare'**.

There is a move within the medical paradigm, Dr. Anjum noted, from evidence-based medicine and practice, towards a more person-centered healthcare. But the criticisms of the current medical paradigm is to a large degree divided into many separate debates: on methods (RCTs, statistical methods, qualitative studies, patient stories), models (biomedical model, biopsychosocial model), ontology (reductionism, dualism, holism), causation (mono-causal, multi-factorial, mechanisms) and practice (EBP, person-centered, empowerment). It is a sign of a crisis in a paradigm, Dr. Anjum contended, when its members start participating in philosophical and metaphysical discussions, which many of these debates seem to involve. In her conference presentation, Dr. Anjum argued for the need to consider these criticisms in unison, pointing in the same direction. Instead of adding person-centered healthcare on top of the existing paradigm of evidence-based medicine, we should, she argued, make a more radical change that includes practice, methods, concepts and ontology.

By introducing a new philosophical framework, including an ontology of dispositions and a new theory of causation, it is possible to offer, Dr. Anjum emphasized, a new ontological foundation for person-centered healthcare. This foundation would have clear implications for a change in methodology and practice, promoting (1) holism over fractionism, (2) genuine complexity and interaction of causal factors over mereological compositions of parts, (3) context-sensitivity and heterogeneity over robust correlations, (4) medical uniqueness over homogeneity, (5) singular propensities over statistical frequencies, (6) level-specific intervention over reductionism and medicalization and, finally, (7) person-centered healthcare over evidence-based practice.

Following Dr. Anjum's presentation, the Chairman, Dr. Pérez-Miranda, asked all three early morning speakers to join him on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**, inviting, in addition, **Dr. Mark Tonelli, Professor of Intensive Care Medicine and Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, United States of America & Chairman of the ESPCH SIG on Case-based Decision Making**, as a Panel Discussant. Vigorous debate ensued, with lively audience participation. The vital necessity for an ongoing conceptual clarification of the PCH thesis was unanimously recommended, with the role of intensive epistemological, ontological and ethical enquiries being strongly affirmed.



Top Left: Dr. Rani Lill Anjum
Lower Left: Dr. Mark Tonelli



Top Right: Dr. James Marcum
Lower Right: Professor Michael Loughlin

SESSION TWO: PERSON-CENTERED HEALTHCARE AND THE CONTEXTUALIZATION OF EVIDENCE-BASED MEDICINE – I

Following the mid morning break, the Conference resumed and **Professor Andrew Miles, Senior Vice President & Secretary General of the European Society for Person Centered Healthcare, Madrid Spain, and London, UK**, assumed the Chairmanship of the Late Morning Session. After delivering a brief overview of the purpose of the session, Professor Miles invited **Dr. Peter Wyer (Associate Clinical Professor of Medicine at Columbia University College of Physicians and Surgeons, Emergency Medicine Department, Columbia University Medical Center; Chair of the Section on Evidence Based Health Care at the New York Academy of Medicine, New York, United States of America & Co-Chairman, ESPCH SIG on PCH and EBM)** to address the Conference under the title **'What's In A Name? The Myth of 'Evidence-Based Medicine'**.



Left: Dr. Peter Wyer
Right: Professor Andrew Miles

Dr. Wyer commenced his presentation by pointing out that discourse focused on epistemological and philosophical informants of healthcare relevant to evidence-based medicine (EBM) has, in recent years, elicited a growing number of responses from the EBM community. Some of these responses, Dr. Wyer argued, suggest that resolution may fruitfully be sought *via* dialogues and skirmishes between divided scholastic communities identified with constructs such as nominalism, realism, constructivism, evidentialism and reliabilism. However, the integration of potentially conflicting healthcare domains calls, he argued, for a deeper consideration of the foundations of medical knowledge and the relationships between evidence, knowledge, decisions and policies.

The term 'evidence-based medicine' has become an obstacle, Dr. Wyer contended, to addressing those issues, partly because it is frequently used in an overly broad fashion and partly because of the way it was branded in 1992. In the latter, information from clinical research was to be dominant over other domains in the care of individual patients and in the training of clinicians. Negative responses led, Dr. Wyer demonstrated, to formulations that acknowledged the importance of patient perspectives and circumstances, but in a fashion that suggested that EBM subsumes them. One such formulation included patient-centered considerations and information from research and practice context within a single two-dimensional plane within which the clinician presides as the interpreter and arbiter of decisions, that is, as a kind of 'fact finder' in charge of compiling data from intersecting spheres.

Dr. Wyer continued by stressing that if the prefix 'evidence-based' did not already connote a non-viable construct when it was conjoined to the term 'medicine', it certainly has come to do so since at the hands of its defenders. If, on the other hand, he argued, we recognize that knowledge, properly defined, serves a purpose within the mission of healthcare, we find ourselves in a more liberating framework, particularly if our understanding of knowledge is aligned with that of the renowned Brazilian educator Paulo Freire. Freire's 'constructivism', (not to be confused with 'anti-realism'), resonates with the conceptual framework

developed by the Chilean school of Maturana and Varela and appears to offer a viable platform for complex integration, as opposed to linear reductionism.

Recognition of this conceptual framework may in turn, Dr. Wyer suggested, be used as a metric against which claims regarding the potential viability of approaches to integration of humanist and scientific dimensions of healthcare may be evaluated. In order to exemplify his argument, Dr. Wyer referred to the concept of relationship-centered care (RCC), posited in 1994, which embraces this epistemological current. The proponents of RCC posit relational process as the primary unit of action in healthcare and as the key to viable incorporation of the fruits of EBM into practice. Epistemological clarity allows us, he emphasized, to recognize the premonitory alignment of the Balints' concept of 'patient-centered care (PCC)' with the tenets of RCC, and also that their original understanding of PCC importantly differed from that of many who attempted to follow their lead. On the other hand, the proposed metric allows an easy identification of non-person, non-relationship centered approaches to, for example, shared decision-making (SDM). Such can be found in the literature on the GRADE system for evidence synthesis in the context of guideline development. The latter, Dr. Wyer concluded, espouses that evocation of SDM in clinical practice be dictated by epidemiologically driven assessments of risk and benefit of interventions as applied to populations.

Following the conclusion of Dr Wyer's presentation, Professor Miles invited **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 UK & Chairman, ESPCH SIG on Health Impact Analysis & Winner, 2015 ESPCH Gold Medal**, to address the Conference under the title **'Person-centred healthcare requires a re-conception, not a renaissance of evidence-based practice'**.



Professor Jack Dowie

The call for a renaissance in Evidence-Based Medicine (EBM) will not, Professor Dowie argued, result in the delivery of person-centered healthcare (PCH). In PCH, the relative importance of the considerations that matter to the person is elicited and combined, at the point of decision, with the best estimates available on the performance of the available options on those criteria. Prior option evaluations based on average preferences that constitute the conventional 'evidence-base', he argued, cannot be part of this process, even if some of the underlying data may be of use. The ethics of transparent PCH require the evidence-base to be re-conceptualized as the unsynthesized matrix of option performance rates on person-important criteria. Abdicating in the face of the challenges resulting from this re-conception is a case of the methodological tail wagging the ethical dog.

Professor Dowie explained that in his conception and that of his colleagues working closely in this area, best practice and ethical PCH accepts (i) that the individual person has multiple outcomes and other considerations that matter to them and (ii) that the clinical decision-



Panel Discussion of Session One, Ongoing Debates In The Philosophy Of Medicine And Healthcare, with the attending delegates.
Top: At panel (left to right); Dr. James Marcum, Dr. Mark Tonelli, Professor Michael Loughlin, Dr. Rani Anjum, Dr. Juan Pérez-Miranda

making process is committed to explicitly eliciting the person's values and preferences in regard to these multiple criteria and integrating them into the decision in a transparent way. But person-centered decision-making, Professor Dowie emphasized, is not solely about the incorporation of the person's values and preferences. These need to be integrated with 'evidence' at the Point of Decision (POD), so that the concepts of 'evidence-base' and 'evidence-based' are central to any discussion of PCH and a differentiation between them essential to moving PCH forward.

Professor Dowie argued that the task of storing all the individual pieces of evidence and integrating them with the person's values and preferences at the POD is cognitively beyond the human being or human team, absent time and resource constraints, let alone with them. That person-centered healthcare requires highly effective and efficient decision support is therefore, he asserted, a no-brainer. Indeed, the actual implementation of PCH at the individual level will often be limited by the legal standards in operation in the jurisdiction as well as economic and equity issues, so that only PCH as he and his co-workers have defined it, he contended, can provide 'perfected' - and documented - informed consent.

In concluding, Professor Dowie argued that the call for a renaissance in EBM will not result in the delivery of PCH, stressing that the difference between patient-centered medical care in the clinic and PCH in the community. Rather than seeing the future as patient-centered medical care delivered within the 'medical home' - the medical facility expanded to embrace the person's home - Professor Dowie saw progress in PCH as that which 'flips the clinic', expanding the person's home to embrace the medical facility.

Following the conclusion of Professor Dowie's presentation, Professor Miles invited **Dr. Mark Tonelli (Professor of Medicine, Division of Pulmonary and Critical Care Medicine & Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, United States of America & Chairman, ESPCH SIG on Case-based Decision Making)** to address the Conference under the title '**Negotiating Clinical Knowledge without Hierarchies**'.

Dr. Tonelli argued that multiple hierarchies of evidence have been promulgated by proponents of evidence-based medicine, but none has proven useful for clinical decision-making. Clinicians, he asserted, must utilize medical knowledge from a variety of sources, including clinical research, clinical experience and pathophysiologic understanding - these differ in kind not degree. This understanding renders hierarchies of medical knowledge either incomplete or epistemically untenable. Warrants supporting a clinical decision or recommendation, Dr. Tonelli contended, derive from and find backing in these sources of medical knowledge. Beyond medical knowledge, the experiences, values and goals of individual patients also provide compelling warrants for clinical choices. Dr. Tonelli was clear that patient-derived warrants do not belong on a hierarchy of evidence or medical knowledge and that incorporating these warrants into clinical decisions requires inquiry and empathy on the part of clinicians, as the presence of and backing for such warrants may not always be clear. Clinical reasoning, Dr. Tonelli asserted, necessitates the evaluation and weighting of multiple and potentially conflicting warrants from a variety of sources, scientific and otherwise. Hierarchies of evidence or knowledge therefore hold no sway, as warrants derived from any source may be more compelling in a particular case. Medical reasoning then, according to Dr. Tonelli, is a casuistic endeavor, requiring practical wisdom and resulting in only probable conclusions. Here, clinicians are responsible for elucidating all relevant warrants for all appropriate sources and should be able to make their reasoning explicit, rendering conclusions subject to rebuttal from a variety of sources. Concluding, Dr. Tonelli asserted that the product of clinical reasoning may be a decision, a recommendation, or a list of options, depending upon the strength of the argument and the skill of the clinician in incorporating patient-derived warrants.

Following the conclusion of Dr. Tonelli's presentation, Professor Miles invited **Dr. Michael Makhinson, (Associate Clinical Professor, Department of Psychiatry and Biobehavioral Science, David**

Geffen School of Medicine, University of California, Los Angeles & Co-Director of Inpatient Psychiatry and Attending Psychiatrist, Department of Psychiatry, Harbor-UCLA Medical Center, Torrance, California, United States of America) to address the Conference under the title: '**Beware of cognitive biases 'plus!' How the brain undermines our decision-making and its relevance to EBM**'.



Dr. Michael Makhinson

Cognitive biases 'plus' are, as Dr. Makhinson outlined, a set of universal, systematic imperfections in human decision-making processes, reasoning and behavior which are rooted in a complex confluence of evolutionary, social and psychological influences. They cause irrational judgments and behaviors that may undermine decisional paradigms in evidence-based medicine (EBM) and in healthcare organizations. Cognitive biases 'plus' are comprised, Makhinson explained, of different categories of cognitive-based processes. These included, as he explained: i) Cognitive biases, which represent faulty systematic information processing errors that cause deviations from rational decision-making. ii) Fallacies which represent logical errors in reasoning and iii) Conflicts of interest (Cols) which, according to the Institute of Medicine USA are "sets of circumstances that create a risk that professional judgment or actions regarding a primary interest will be unduly influenced by a secondary interest."

Cols, Makhinson asserted, are closely associated with self-serving bias and create a risk of swaying behavior toward iv) ethical violations, which range from subtle cheating to outright fraud. Cols, self-serving bias, and self-deception are strong catalysts for unethical behavior; this cascade of cognition and behavior erodes the quality of the healthcare evidence landscape. Reviewing these areas of bias, Makhinson also highlighted the additional cognitive biases 'plus' that are of particular importance in healthcare evidence. These include, as he detailed, authority bias, automation bias, in-group conformity, groupthink and herd behavior. These processes, he explained, have a neuro-anatomic and evolutionary basis, which renders them intrinsic to both individuals and groups and difficult to recognize and correct. In concluding, Dr. Makhinson suggested that an understanding of cognitive biases 'plus' can help us not only to understand their potential detrimental impact on healthcare evidence and the integrity of the EBM paradigm, but also to formulate preventive and remedial measures.

Following Dr. Makhinson's presentation, the Chairman, Professor Andrew Miles, asked all four early morning speakers to join him on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**. Vigorous debate ensued, with lively audience participation. The vital necessity for an ongoing clarification of the inter-relationship of PCH and EBM was unanimously recommended and strongly affirmed.



Top: Professor Jack Dowie presenting "Person-centred healthcare requires a re-conception, not a renaissance of evidence-based practice"
Middle: Dr. Michael Makhinson presenting "Beware of cognitive biases 'plus!' How the brain undermines our decision-making and its relevance to EBM"
Lower: Panel Discussion of Session Two, Person-Centered Healthcare And The Contextualization Of Evidence-Based Medicine - I, with the attending delegates. At panel (left to right); Professor Jack Dowie, Dr. Mark Tonelli, Dr. Michael Makhinson, Dr. Peter Wyer, Professor Andrew Miles.

SESSION THREE: PERSON-CENTERED HEALTHCARE AND THE CONTEXTUALIZATION OF EVIDENCE-BASED MEDICINE – II

Following the re-assembling of the Conference after the break for Luncheon, **Professor Andrew Miles, Senior Vice President & Secretary General of the European Society for Person Centered Healthcare, Madrid, Spain and London, UK** assumed the Chairmanship of the Early Afternoon Session and invited **Dr. Shashi S. Seshia, Clinical Professor, Department of Pediatrics, Division of Pediatric Neurology, University of Saskatchewan, Canada**, to address the Conference under the title **'Evidence-informed person-centered healthcare, 'cognitive biases plus,' the EBM paradigm and healthcare organizations: exploration of a hypothesis'**.



Dr. Shashi S. Seshia

There is, Dr. Seshia observed, increasing concern about the reliability and applicability of evidence and the EBM paradigm, particularly in relation to PCH. Cognitive biases 'plus' jeopardize the quality of decisions and even experts are vulnerable to them. Dr. Seshia proposed that cognitive biases 'plus' in those individuals involved in creating and promoting the EBM paradigm are responsible for (i) its long standing shortcomings and also (ii) affect opinions and policies of organizations that influence healthcare. Consequently, he argued, both healthcare delivery and the evidence that informs PCH are often compromised.

EBM, Dr. Seshia pointed out, is founded on "assumptions" (*sic*) and the tenets of EBM: (i) the hierarchy, (ii) biostatistical methods & (iii) primacy of systematic reviews and pre-appraised evidence, are also opinion-based. Each tenet has limitations that impact evidence. Intellectual bias (a non-financial conflict of interest-Col), planning and sunk cost fallacies at individual and EBM expert group levels, together with scientific inbreeding and groupthink are, Seshia asserted, major (but not exclusive) contributors to the failure of EBM experts to anticipate, prevent, recognize and correct EBM's limitations. Critiques of EBM were typically countered with fallacies, he noted, with the EBM tenets adopted by all organizations without reservation (herd effect), potentiating and entrenching EBM's shortcomings.

The organizations studied by Dr Seshia, with Dr. Michael Makhinson, the previous speaker, were industry, political bodies, regulators, non-industry funders, researchers, universities, hospital/health administration authorities, professionals and societies, the publication industry and advocacy groups. Elements of cognitive biases 'plus' co-occur, he said, and are inherent in all the organizations and the individuals belonging to them, though some appear more organization-relevant than others. Potentially, both financial and non-financial Cols are common to all; Cols are catalysts for self-serving bias. Healthcare industries, Dr. Seshia argued, are the epicentres of financial Cols that often involve all the other organizations, to varying degrees. Biases of health regulatory agencies result in treatments being approved without robust evidence of effectiveness and harm. Scientific inbreeding among researchers and publication biases can result in the validation of erroneous information, he noted, with the Cols and biases of physicians and their societies having the potential to result in inappropriate guidelines and treatment.

Ethical misconduct, Dr. Seshia asserted, including subtle manipulation of statistics and selective publication by industry and researchers, with potentially very serious consequences. Cognitive

biases 'plus' in high impact publications can result in the ratification and dissemination of "misleading..." evidence, through authority bias. Thus, cognitive biases 'plus' underlying EBM and within organizations are at the core of a complex cascade, sequentially 'flawing' evidence to the point of care.

In concluding, Dr. Seshia recommended that the involvement of ethicists and behavioral researchers may help: (i) Minimize cognitive biases 'plus,' especially Cols, in relevant organizations and promote critical and logical thinking and (ii) Rectify shortcomings of EBM; biases of scientific inbreeding and groupthink among its experts must be neutralized for effective reform. Most importantly, integrity, he insisted, must be restored and valued universally in all organizations.

Following the conclusion of Dr. Seshia's presentation, Professor Miles invited **Ms. Mette Kjer Kaltoft MPH, Research Unit of General Practice, Institute of Public Health, University of Southern Denmark & Odense University Hospital Svendborg Sygehus, Denmark** to address the Conference under the title **'Assessing decision quality in person-centered care requires a preference-sensitive measure'**.



Ms. Mette Kjer Kaltoft

The investment in decision aids to facilitate person-centred healthcare has, Ms. Kaltoft discussed, revealed the need for a patient-reported outcome measure of decision quality. Current instruments using the term 'decision quality' have adopted a decision and thus condition-specific approach. Ms. Kaltoft argued that PCH requires decision quality to be regarded as both preference-sensitive across multiple relevant criteria and generic across all conditions and decisions. The increase in the range of options available for health and disease management, coupled with the shift towards greater patient involvement in recent years, has led, she observed, to a profusion of decision aids and related support systems aimed at the patient, clinician and the medical team. Ms. Kaltoft contended that there was a need for evaluation measures that address the overall quality of decisions, as distinct from measures that address particular aspects of decision-making. The PCH philosophy, she pointed out, necessitates that decision quality be regarded as preference-sensitive and that the relevant preferences are those of the patient facing the decision, as opposed to the average preferences of a group of patients with the same condition or those of the health professional(s) involved in the decision.

Ms. Kaltoft presented MyDecisionQuality (MDQ), a web-based generic and preference-sensitive instrument which can constitute a Patient-Reported Outcome Measure (PROM), documenting the patient-centredness of healthcare services as well as providing a clinical practice measure (<http://healthbook.health.usyd.edu.au/>). MDQ, she explained, is grounded in Multi-Criteria Decision Analysis (MCDA) and employs a simple expected value algorithm to calculate a score for the quality of a decision that combines, in the clinical case, the patient's individual preferences for eight quality criteria (expressed as importance weights)

and their ratings of the decision just taken on each of these criteria (expressed as performance rates). It is thus, as she illustrated, dually personalised.

The development of MDQ, as Ms. Kaltoft described, followed an assessment of the available instruments for evaluating decision-aids which established that none of these instruments generated a generic and preference-based index of overall decision quality; as opposed to ones that were: (i) condition-setting or decision-specific; or (ii) measured one or more possible aspects of decision-making such as preferred involvement in decision, satisfaction with the decision or decision conflict experienced, rather than overall decision quality; or (iii) did not weight their components to produce an index measure (i.e. were profile instruments) or, if they did enable weighting, did not elicit weights from the specific patient on the specific decision occasion. She continued by enumerating the 8 criteria making up the two-part MDQ.

MDQ, Ms. Kaltoft emphasized, also provides patients with help in prioritizing the quality criteria for future decision-making by calculating, for each criterion, the Incremental Value of Perfect Rating, *i.e.* the increase in their decision quality score that would result if their performance rating on the criterion had been 100%, importance weightings unchanged. So, if the consultant is willing to enter their perception of the patient's weights and their own ratings into a parallel version of the MDQ instrument, there is the basis, she explained, for a decomposable measure of concordance indicating how future decision quality could be improved; that is, a measure which can be broken down element by element for clinician and patient separately. Concluding, Ms. Kaltoft summarized the challenge of validating a generic, patient-specific, preference-based instrument such as MDQ, which does not appear to have been addressed in the literature thus far. Thus, she and her co-workers, continued to seek assistance in this respect and, given the personalized character of MDQ, she confirmed that her group are particularly interested in exploring the use of N of 1 study designs.

Following the conclusion of Ms. Kaltoft's presentation, Professor Miles invited **Dr. Suzana Alves de Silva, Senior Researcher & Clinical Cardiologist, National Institute of Cardiology and Amil Assistencia Medica Internacional, Rio de Janeiro and Hospital do Coração (HCor), São Paulo, Brazil, South America & Co-chairman, ESPCH SIG on PCH and EBM**, to address the Conference under the title **'SIMPLE Integration of Social Process and Evidence in Healthcare: A Brazilian Anecdote'**.



Dr. Suzana Alves de Silva

There is widespread agreement, Dr. Silva observed, that person-centered healthcare needs to reflect successful integration of the requirement that healthcare serve and respect the needs of patients as persons with the ability to maximize the value of research in so doing. "Scientifically Informed Medical Practice and Learning (SIMPLE)" is, she contended, one published representation of what an integrated model needs to look like. SIMPLE does not attempt to propose a formula for deriving healthcare decisions from values, circumstances, research findings and other categories of information and knowledge. Nor is it a 'reconstitution of evidence-based medicine (EBM)'. It attempts, rather, Dr.

Silva outlined, to put the elements where they belong, in a fashion that illustrates why they all are critically necessary. The SIMPLE construction might be compared, she said, to the relationship between a person's brain and their circulatory system. The brain ultimately dominates the personhood of the individual. However, without the circulation, the brain and the person, must wither and die.

Dr. Silva presented an example from the Brazilian healthcare system which illustrated the consequences of cutting off what is represented as the "relational field" in the SIMPLE model from nourishment by information from clinical research. The Brazilian healthcare system is largely unregulated by agencies such as NICE in the UK or comparable agencies in North America. As a result, political and other relational processes, Dr. Silva pointed out, largely dictate health practice and policy with minimal attention to relevant research. Obstetric practice, she contended, is one useful example. There is ample research indicating that natural childbirth, in general, is associated with better maternal and fetal outcomes. However, over 90% of births in the Brazilian private system and up to 50% in the public system are cesarean. A combination of limited standing resources and patient reluctance to be served by an unknown delivery team, particularly among private patients, largely precludes preference for spontaneous delivery. Hence, deliveries are largely planned in advance *via* caesarian section.

Within the entire context, Dr. Silva explained, inputs from relevant published outcomes research and also from practice-based outcomes tracking in Brazil are minimal. Although the public sector of the Brazilian healthcare system maintains a central Health Technology Assessment agency staffed by not more than 20 analysts and 50 regional divisions, this resource is largely occupied, she outlined, by applications for approval of new drug therapies and high cost procedures and has little involvement with other types of medical intervention. The Brazilian judicial system arbitrates coverage and access to all types of clinical care, including tests, hospital admissions, procedures and other treatments, in response to patient initiated complaints. All such appeals are approved based only upon the submission of a physician's prescription. These actions come before all judges in the system and the decisions usually do not require consideration of the scientific merit of the interventions.

Concluding, Dr. Silva emphasized that, within Brazil, there is minimal regulation of the quality of care within either public or private sectors. Furthermore, private patients are routinely forced to go to specific hospitals for the care of their conditions, including pregnancy, based only upon contractual arrangements on the part of their insurers, rather than on the existence or absence of qualified specialty services in those facilities. Obstetric care in Brazil offers, she asserted, an example of a system that operates almost exclusively within the relational field and is largely oblivious to relevant information from outcomes research either within or without the country. The resulting context does not offer a formula for bringing different categories of knowledge and information to bear on healthcare decisions. It is therefore, Dr. Silva concluded, a poignant example of the consequences of constructing decisions and actions exclusively within the relational field in the absence of nourishment by the best available scientific information.

Following Dr. Silva's presentation, the Chairman, Professor Andrew Miles, asked all four early morning speakers to join him on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**, inviting in addition **Dr. Peter Wyer (Associate Clinical Professor of Medicine at Columbia University College of Physicians and Surgeons, Emergency Medicine Department, Columbia University Medical Center; Chair of the Section on Evidence Based Health Care at the New York Academy of Medicine, New York, United States of America & Co-Chairman, ESPCH SIG on PCH and EBM** as a Panel Discussant. Vigorous debate ensued, with lively audience participation. The vital necessity for an ongoing clarification of the inter-relationship of PCH and EBM was, as in the former Panel Discussion, unanimously recommended and strongly affirmed.

My Decision Quality - Person (Weightings)

How important to YOU is each of these criteria in making a decision?

0 = of NO importance ... 5 = of MODERATE importance ... 10 = of EXTREME importance

	0	1	2	3	4	5	6	7	8	9	10
OPTIONS Importance of being clear about the possible OPTIONS for me and what they involve	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
EFFECTS Importance of being clear about the possible EFFECTS and outcomes of each of the options for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
IMPORTANCE Importance of being clear about the relative IMPORTANCE of the different possible effects and outcomes for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CHANCES Importance of being clear about the CHANCES of the different effects and outcomes happening to me, including the uncertainties surrounding the best estimates of them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
TRUST Importance of being able to TRUST the information I was given was the best possible	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
SUPPORT Importance of feeling I received the level of SUPPORT and consideration I wanted throughout the decision process, especially in regard to communicating at my level	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
CONTROL Importance of feeling I was in CONTROL of my decision to the extent I wished	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
COMMITMENT Importance of feeling COMMITTED to acting on the decision taken	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Top: MyDecisionQuality (MDQ) Tool for Patient-Reported Outcome Measure (PROM), presented by Ms. Mette Kjer Kaltoft during her presentation of "Assessing decision quality in person-centered care requires a preference-sensitive measure" by courtesy of University of Sydney.

Lower Left: Dr. Suzana Alves de Silva presenting "SIMPLE Integration of Social Process and Evidence in Healthcare: A Brazilian Anecdote"

Lower Right: Dr. Shashi S. Sheshia presenting "Evidence-informed person-centered healthcare, 'cognitive biases plus,' the EBM paradigm and healthcare organizations: exploration of a hypothesis"

Opposite Top: Panel Discussion of Session Three, Person-Centered Healthcare And The Contextualization Of Evidence-Based Medicine – II, with the attending delegates. At panel (left to right); Dr. Suzana Alves de Silva, Ms. Mette Kjer Kaltoft, Professor Andrew Miles, Dr. Peter Wyer and Dr. Shashi S. Sheshia

Opposite Lower: Delegate discussions at luncheon

SESSION FOUR: PERSON-CENTERED HEALTHCARE – WHAT ARE THE WAYS FORWARD: I

Following the re-assembly of the Conference after the Mid Afternoon Break, **Dr. Mark Tonelli, Professor of Intensive Care Medicine and Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, United States of America & Chairman of the ESPCH SIG on Case-based Decision-Making**, assumed the Chairmanship of the Early Afternoon Session, inviting **Mr. Ed Harding, Director, The Health Policy Partnership, London, United Kingdom**, to address the Conference under the title **'Who is doing what worldwide in person-centered healthcare? The concept and results of The Health Foundation International Environment Scan'**.



Mr. Ed Harding

Mr. Harding presented an overarching 'state of play' narrative in the research, implementation of measurement of person-centred care, illustrated through key examples of recent and ongoing work and materials. This synthesis had been drawn together from a pragmatic search of recent literature, including the perspectives of a selected key commentators in the field. The resulting report, Mr. Harding announced, was scheduled for publication in July 2015, and he proceeded to describe some interim findings in advance of the formal publication of the Document.

Mr Harding noted that the PCH Community was constituted by an international array of key personae. Beyond some core principles, he had been able to observe that person-centred care is understood in many different ways by many different people. Nevertheless, a substantial international body of work currently exists across a heterogeneous and evolving community, with complex synergy between 'person-centred care' and other associated groupings (e.g. 'patient-centred care', 'patient engagement', etc.). Person-centred care", Mr. Harding observed, is a term rooted in culture and context, with an observable diversity appearing to reflect the different needs of different populations and healthcare settings.

Mr. Harding told the Conference that the commentators with whom he had been in contact gave different *emphasis and priority* to different qualities of person-centred care. Certainly, a range of strategic research issues had been identified by the Scan, including a lack of common definitions, the presence of research 'hotspots' in different settings and diseases, but which were siloed activities and, behind some promising evidence of impact, there were still questions about differentiating processes, outcomes and indicators and what is to be counted as 'success'. Patient involvement in helping to share research priorities was, Mr. Harding had observed, rare.

Mr Harding told the Conference that the Scan had identified some strategic issues associated with PCH implementation. Here, he observed, was the significant presence of 'person-centred care' in healthcare policy in English speaking and Northern European countries. However, implementation lagged a considerable way behind. The implementation challenge, he asserted, would require a 'whole system response', for example, organisational change models, formal education and training for healthcare professionals, but also efforts to tackle resistance and misunderstanding and to connect and explore with deeper,

ethical and personal values at the individual level. Notwithstanding these observations, was the issue of measurement, a factor widely considered to be vitally important in embedding person-centred care in the mainstream, yet there appeared to exist a paucity of evaluation and measurement methods, representing a challenge for the mainstream use of PCH-type interventions and tools. Setting and monitoring more personalised outcomes is regarded as important by key contributors, but models are largely experimental. Linking measurement to financial incentives and performance assessment, Mr. Harding observed, seems rare and fears of measurement 'overload' and capacity issues in management and care professionals highlighted the need for practical models of PCH in the everyday setting.

Following the conclusion of Mr. Harding's presentation, the Chairman invited **Dr. Stephen Buetow, Associate Professor, Department of General Practice and Primary Health Care, University of Auckland, New Zealand & Chairman, ESPCH SIG on Research in PCH**, to address the Conference under the title **'Person-centered care: what it is and what it isn't – building upon the 2014 Reflection'**.



Dr. Stephen Buetow

Medicine, Dr. Buetow asserted, faces a crisis of depersonalization, scientism and unsustainable costs, which cannot be solved by subprime national initiatives to produce, from evidence, medicine centered on patients. One of the most prominent initiatives is taking place in the US, Dr. Buetow noted, where comprehensive health reforms are integrating patient-centered concepts into standards of clinical care through innovations in service delivery such as patient-centered medical homes. Yet, patient-centered medicine is, he contended, part of the overall problem. Raising concerns about a patient-centered medical ethics of principle-governed action for patient welfare and population health, Dr. Buetow suggested a need instead for *person-centered* medicine.

Despite having received the imprimatur of international organizations including the World Health Organization, person-centered medicine (or people-centered medicine) has yet to define itself clearly. Dr. Buetow engaged the Conference by suggesting eight defining values of person-centered medicine which distinguish this medical practice model conceptually from values of patient-centered medicine. Moreover, he suggested that the values of *person-centered* medicine link to virtues that dispose patients and physicians, as *moral equals*, to balance their welfare, by doing the right things for the right reasons and thus to flourish.

Following the conclusion of Dr. Buetow's presentation, the Chairman invited **Dr. Carmel Mary Martin, Associate Professor of Family Medicine, Northern Ontario School of Medicine, Ontario, Canada & Visiting Academic, Department of Public Health and Primary Care, Trinity College Dublin, Republic of Ireland & Co-Chairman, ESPCH SIG on Complexity and Health (Co-Winner of**

the ESPCH 2014 Book Prize) to address the Conference under the title **'A Brave New World. Big Data and Person-Centered Healthcare: Opportunities and Threats'**.

There are unquestionably enormous amounts of data on health systems and individuals being collected, Dr. Martin observed, that will increase exponentially in the digital age. Looming close on the horizon is the vast patient genomic data and their promise for personalized medicine. In short, there is, she pointed out, a potential tsunami of data coming straight at an already overburdened healthcare industry. The 'internet of things' and the 'quantified self' together with health system data collections present a Brave New World of information.

There are, however, Dr. Martin asserted, opportunities that a combination of data-driven, evidence-based medicine and modern tools to prod patients to lead healthier lives will go a long way to reducing waste in health spending. The judicious application of smartphones and software could save patients, insurers and governments, enormous amounts of money. Data that are routinely collected can be analyzed, she contended, to improve care delivery without the addition of expensive major research studies and to address some of the challenges of randomized controlled trials. Data-centric methods and increasing analytic power to both diagnose, treat and monitor will become increasingly more sophisticated, Dr. Martin predicted. Patients themselves may be empowered and learn to monitor personal health data themselves. Big Data are manageable, but it is individualized data that are both more likely to have the most effect on our personal health and much more difficult to deliver. It is claimed that IT vendors can deliver processor, networking and database infrastructures that are capable of handling the data volumes and variety of information fast enough for real-time decision-making. Arguably, she said, the healthcare industry will enter into a new era of efficiency that still offers far better outcomes for patients.

Certainly, increasing accessibility of evaluation, informatics and big data from health organization systems and individuals has the potential to create, Dr. Martin predicted, major challenges to privacy ethics and person-centeredness. Health services draw on predominantly technical and 'objective' rather than subjective approaches and it is very difficult, she noted, for such systems to *integrate* interpretivist (subjective) and positivist (objectivist) information and knowledge. The increasing reduction of personal experiences to metrics in the positivist paradigm may underplay their meaning and importance. Nevertheless, in the future, she added, the intention is to shift from collective and system perspectives to the perspective of the individual, integrating personalized 'omics' and information at the point of delivery. This flux of knowledge between and within paradigmatic or pragmatic approaches has the potential to expose or obscure the uncertainty and the 'unorder and disorder' in what is known and from whose perspective and what it means. Transdisciplinary, complex adaptive systems theory with multi-ontology sense making are discussed as an overarching framework for the exposition and pragmatic resolution of tensions and contradictions in person-centered care and big data analytics.

Concluding her articulation of a transdisciplinary approach within a complexity framework, Dr. Martin recommended that a person-centric framework for big data should focus on to the individualizing of care and enhancing experiences of persons in health settings.

Following the conclusion of Dr. Martin's presentation, the Chairman invited **Dr. Thomas Fröhlich, Physician, Heidelberg, Germany & ESPCH Vice President (Western Europe)**, to address the Conference under the title **'Does an update of the Biopsychosocial Model improve its applicability for person-centered healthcare?'**

To initiate a debate about an advanced biopsychosocial (BPS) model, Dr. Fröhlich suggested a formal approach to achieving a better communication of its up to now diverging and mutually isolated constituents. The principal problem that researchers have identified with the current BPS model, Dr. Fröhlich argued, is its complete lack of internal formal homogeneity. While the aims of the BPS model are respected and widely accepted, he asserted, its eclecticism and the loose (if any) formal

connection of its divergent approaches hinder its theoretical basis and clinical application. An advanced BPS model should be easier and more intuitive, Dr. Fröhlich suggested, enabling a wider application than has proved possible with the previous model. Working with renowned co-authors, Dr. Fröhlich had applied various tools in a modification of the model which he believed had resulted in a wider applicability of the model, with an enactment of some basic initial choices that have enabled entities that are fundamentally different on a structural level, to be effectively addressed.

Dr. Fröhlich described the approach he and his co-workers had taken as involving the application of the well-established concept of sets formed in a *dynamic*. Members of sets have something in common that makes them belong to something common and, if they are more than one, he said, then they have also something that makes them individual and distinct. A simple distinction, then, is the one of lasting *versus* changing aspects. The latter can be understood as realized states, whereas the entity hypostasized as being their lasting source is in fact always a hypothesis concerning this supposed basis and sequence of events. Beginning with these assumptions, Dr. Fröhlich continued by articulating 10 Statements which collectively constituted an initial working model for further discussion.

The model issues in precise form, Dr. Fröhlich argued, the pivotal point of any qualified approaches to science and humanities. Thus, in considering the formal differences between stochastic and ordered processing, a more detailed discussion will reveal that it allows the coherent interactions on a physical and, if given biological level, as well as the different levels of human activity, to be addressed, including selective reactivity and experience and including experience of oneself as an individual and unique subject. Concluding, Dr. Fröhlich asserted that attributions of meaning, also in an emotional and existential sense, are easily described, as well as realizations in the form of verbal utterances and their mutual understanding. Hence, the model, he argued, has an improved applicability in a human medicine correctly understood as person-centered.

Following the conclusion of Dr. Fröhlich's presentation, the Chairman, Dr. Mark Tonelli, asked all four late afternoon speakers to join him on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**, inviting in addition **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 UK & Chairman, ESPCH SIG on Health Impact Analysis & Winner ESPCH 2015 Gold Medal)** as a Panel Discussant. Vigorous debate ensued, with lively audience participation. Following the close of the Panel Discussion, Dr. Tonelli called upon **Professor Andrew Miles, Senior Vice President & Secretary General, European Society for Person Centered Healthcare, Madrid, Spain & London, UK**, to give the **Closing Remarks** for Day One of the Conference.



Dr. Thomas Fröhlich



Dr. Carmel Martin



Top: Thomas Fröhlich presenting 'Does an update of the Biopsychosocial Model improve its applicability for person-centered healthcare?'
 Middle: Dr. Carmel Martin presenting 'A Brave New World. Big Data and Person-Centered Healthcare: Opportunities and Threats'
 Lower: Dr. Stephen Buetow presenting 'Person-centered care: what it is and what it isn't – building upon the 2014 Reflection'
 Opposite: Panel Discussion of Session Four, Person-Centered Healthcare – What Are The Ways Forward - I, with the attending delegates. At panel (left to right); Professor Jack Dowie, Mr. Ed Harding, Dr. Carmel Martin, Dr. Thomas Fröhlich, Dr. Stephen Buetow, and standing, Dr. Mark Tonelli

DAY 2: 19 JUNE 2015

SESSION FIVE: PERSON-CENTERED HEALTHCARE – WHAT ARE THE WAYS FORWARD: II

Day Two of the Conference was opened by **Professor Andrew Miles, Senior Vice President & Secretary General, European Society for Person Centered Healthcare, Madrid, Spain & London, UK.**

Following the Opening Welcome and Remarks, **Dr. Sandra Tanenbaum, Professor, Health Services Management and Policy, College of Public Health, Ohio State University, Ohio, United States of America & Chairman ESPCH SIG on PCH and Health Policy**, assumed the Chairmanship of the Early Morning Session and invited **Professor Brian Broom, Consultant Physician (Clinical Immunology), Department of Immunology, Auckland City Hospital and Adjunct Professor, Department of Psychotherapy, Auckland University of Technology, New Zealand** to address the Conference under the title **'The power of 'story', symbolic illness, relationship-based healing and person-centered healthcare'**.



Professor Brian Broom



Dr. Joachim Sturmberg

Diagnosing depression and anxiety is not enough, Professor Broom contended. Indeed, in respect of illness, he said, the patient's story may be predisposing, precipitating and perpetuating. Concluding, Professor Broom insisted that we are not talking merely about post-illness narrative-making and addressing meaning adds a powerful dimension to therapy.

Following the conclusion of Professor Broom's presentation, the Chairman invited **Dr. Joachim Sturmberg, Associate Professor of General Practice, Monash University, Melbourne, Australia and Co-joint Associate Professor of General Practice, University of Newcastle, Newcastle, Australia & Co-Chairman, ESPCH SIG on Complexity and Health (Co-Winner, ESPCH Book Prize 2014)** to address the Conference under the title **'A person-centered approach to the understanding and management of multi-morbid, socially complex illness'**.

Multi-morbidity, Dr. Sturmberg reminded the Conference, remains a poorly defined concept. For some it is a numerical concept, the total number of diseases in the one person (multiple morbidities), for others it is the number of other diseases occurring concurrently in relation to an index disease (co-morbidities) and yet others see it as a persistence of diseases over time (chronic disease). Each of these concepts, Dr. Sturmberg asserted, has significant limitations: they neglect the patient's subjective experience of their illness, they neglect the severity of the disease and its impact on daily functioning and they fail to provide an integrated understanding of the underlying mechanisms resulting in the patient's disease presentations.

Multi-morbidity is the end product of an emergent process resulting from the constant perturbations of our various physiological networks, Dr. Sturmberg said. The main regulators of these interconnected networks are the mediators of the hypothalamic-pituitary-axis and sympathetic nervous system. Their feedback loops control gene, mitochondrial and cell function, which can both stabilize or exacerbate disease processes. However, external environmental inputs can, he contended, modulate the hypothalamic-pituitary-axis and sympathetic nervous system and thus influence disease progression.

These understandings of multi-morbidity, Dr. Sturmberg told the Conference, offer new insights into the management of people at risk or already established disease. At an individual level allopathic interventions need to consider potential unintended network perturbation that might result in the exacerbation of other disease processes. Greater emphasis is needed on managing stress as stress increases the pro-inflammatory load contributing to disease progression.

At the population level greater emphasis is needed, Dr. Sturmberg said, to reduce the effects of our ever increasing environmental stressors: pollution, poor housing, job insecurity, family relationships, poor social infrastructure, degrading physical infrastructure, access to healthy fresh food. etc. Concluding, Dr. Sturmberg insisted that person-centered management of multi-morbidity does embrace the complexities of the physiological networks operating at the subcellular and cellular levels in the context of the complexities of the person's social and societal environments. Such understandings were seen as vital to the development of PCH going forward.

Following the conclusion of Dr. Sturmberg's presentation, the Chairman invited **Professor Roger Ellis OBE, Director, Social and Health Evaluation Unit & Emeritus Professor of Psychology, Universities of Chester, United Kingdom and University of Ulster, Northern Ireland & Chairman, ESPCH SIG for Learning Difficulties**

to address the Conference under the title **'Better Lives through Personalization – the example of PCH for those with challenging learning difficulties'**.

Professor Ellis described to the Conference a Personalisation Programme provided by the organization Choice Support (UK) for adults with learning difficulties. The programme was provided for seventy adults with learning difficulties, many with severe such difficulties. The programme, Professor Ellis reported, achieved significant improvements in quality of life for most people and with substantial savings.

Personalization, synonymous with PCH, means thinking about care and support services in an entirely different way. It means starting, Professor Ellis explained, with the person as an individual with strengths, preferences and aspirations and putting him or her at the centre of the process of identifying their needs and making choices about how and when they are supported to live their lives. It requires a significant transformation of adult social and healthcare, so that all systems, processes, staff and services are 'geared up' to put people first.

Professor Ellis proceeded to describe the Choice Support Personalization Programme. This, he explained, had three principal features: (1) Person Centered Planning; (2) Individual Service Funds and (3) Better Nights, a new form of night support which encourages greater independence. Here, Person Centered Planning means exploring in detail what each individual wants and needs and planning support accordingly. Exploring needs and preferences with a group of people, many of whom had severe learning difficulties and little or no spoken language, required special skills from support staff. An Individual Service Fund represents, Professor Ellis explained, a notional allocation of money to each individual for support based on individual need and preference as opposed to a block grant and a standard support for all. Better Nights was a shift, he explained, from Waking Nights with support staff available and monitoring individuals throughout the night to Sleep In where the care staff followed normal waking and sleeping patterns together with the individuals thus encouraging a more normal life style with greater independence.

The Social and Health Evaluation Unit, of which Professor Ellis is Director, has completed two programme evaluations - one of Better Nights and one of Personalization more broadly. In each case the Unit's Trident method was used focusing evaluation questions on outcomes; process; and stakeholder perspectives. Data from the evaluation were assessed together with the substantial savings achieved.

Specially devised audit tools, Professor Ellis explained, were devised to assess quality of life and risk management. Overall, the results of these audits showed a maintenance or improvement in quality of life for the service users and effective management of risks. These quantitative data were complemented with individual case studies. The process of implementation was described in sufficient detail to allow replication, learning and continuous improvement. Stakeholder perspectives were surveyed from care staff, parents and relatives and social services staff. The process of implementation, Professor Ellis explained, required sustained innovative responses at strategic, organizational and clinical levels and these are described and their implications for person-centered healthcare discussed.

Concluding his presentation, Professor Ellis told the Conference that, overall, the programme had achieved its stated outcomes in PCH, with substantial savings. For the minority of service users whose quality of life did not appear to improve, further detailed analysis and planning was being undertaken.

Following the conclusion of Professor Ellis' presentation, the Chairman invited **Dr. Mark Tonelli, Professor of Medicine, Division of Pulmonary and Critical Care Medicine & Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, United States of America & ESPCH Chairman, Case-based Decision Making** to address the Conference under the title **'Setting Limits: Can PCH assist clinicians in the allocation of increasingly limited resources?'**

The role of the clinician in person-centered healthcare has not, Dr. Tonelli asserted, been fully elucidated. Clearly, the clinician's role is more active than that espoused in some versions of the patient-centered movement, where the clinician may be viewed only as a purveyor of information. For healthcare to be person-centered, Dr. Tonelli argued, the clinician must recognize the patient as a person and join him in the process of healing. The positive aspects of this active role have been emphasized in the early literature of the person-centered movement.

But the clinician is also a person, embodying personal, professional and societal values. To advocate that she should completely subjugate her values to the will of the patient would seem, Dr. Tonelli asserted, to be asking too much. In the United States of America, there is an ongoing debate regarding whether a clinician's personal religious values allow him to withhold interventions desired by the patient, for instance pregnancy termination or prescriptions for contraception. Dr. Tonelli did not address this issue directly. Instead, he proposed that a clinician's professional and societal values do allow, and in some cases require her, to set limits with regard to medical treatments available to the patient. This would include saying no to requests for some interventions requested explicitly by a patient who believes he will benefit from that intervention. The grounds for such refusal, Dr. Tonelli contended, can be considered bedside rationing and may stem from agreed upon professional values regarding the proper role of the clinician and/or from recognition of the clinician's role as a steward of limited resources. Defining inappropriate treatment, interventions that should not be offered or provided even when requested, requires professional consensus and societal acknowledgment, but in a person-centered medicine will usually be made at the level of a particular patient, rather than a system-wide denial. Concluding his presentation, Dr. Tonelli asserted that limit setting should be made explicit and subject to challenge, but the locus of decision-making in such cases lies solidly with the clinician.

Following the conclusion of Dr. Tonelli's presentation, the Chairman, Dr. Sandra Tanenbaum, asked all four late afternoon speakers to join her on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**. Vigorous debate ensued, with lively audience participation.



Top: Dr. Mark Tonelli
Lower: Professor Roger Ellis OBE





Top Left: Professor Roger Ellis OBE presenting 'Better Lives through Personalization – the example of PCH for those with challenging learning difficulties'.

Top Right: Dr. Joachim Sturmberg presenting "A person-centered approach to the understanding and management of multi-morbid, socially complex illness"

Lower: Panel Discussion of Session Five, Person-Centered Healthcare – What Are The Ways Forward - II, with the attending delegates. At panel (left to right); Dr. Mark Tonelli, Dr. Joachim Sturmberg, Professor Brian Broom, Professor Roger Ellis OBE, Dr. Sandra Tanenbaum

SESSION SIX: PERSPECTIVES ON IMPLEMENTATION – I. EVOLVING HEALTH POLICY, RESOURCE ALLOCATION AND DIGITAL AND mHEALTH

Following the re-assembly of the Conference after the mid morning break, **Dr. Peter Wyer**, (Associate Clinical Professor of Medicine at Columbia University College of Physicians and Surgeons, Emergency Medicine Department, Columbia University Medical Center; Chair of the Section on Evidence Based Health Care at the New York Academy of Medicine, New York, United States of America & Co-Chairman, ESPCH SIG on PCH and EBM) assumed the Chairmanship of the Late Morning Session. Dr. Wyer called upon **Dr. Sandra Tanenbaum**, Professor, Health Services Management and Policy, College of Public Health, Ohio State University, Ohio, United States of America & Chairman ESPCH SIG on PCH and Health Policy to address the Conference under the title 'Person-Centered Health Policy: The Case of the Patient-Centered Outcomes Research Institute (PCORI) of the United States of America'.



Dr. Sandra Tanenbaum

One of the many provisions of the Affordable Care Act of 2010, sometimes referred to as 'Obamacare', was the establishment of the Patient-Centered Outcomes Research Institute (PCORI). PCORI, Dr. Tanenbaum explained, is a public-private agency concerned primarily with funding and guiding comparative effectiveness research. Health policy experts had long recommended that comparative effectiveness research be undertaken along with the more common effectiveness studies of a single healthcare intervention. Comparative effectiveness research would determine, Dr. Tanenbaum elaborated, which of multiple interventions is most effective for a specific condition. PCORI was created to accomplish this task, and the politics of healthcare reform yielded a uniquely American institution. PCORI, she explained, is not a purely public agency, but has ties to the federal government; its findings may not be used as the sole basis for coverage under government health programs and the comparative research undertaken must be "patient-centered." In a concession to disability activists and political conservatives, PCORI is mandated to answer the question of comparative effectiveness in the context of "patients like me." Dr. Tanenbaum illustrated how patient-centeredness takes a number of forms in both the solicitation of research proposals and the requirements that funded investigators must meet. She reviewed these characteristics and principles in general, employing a specific PCORI-funded study on which she functions as a co-investigator, detailing the ways in which PCORI's patient-centeredness is and is not person-centered.

Following the conclusion of Dr. Tanenbaum's presentation, the Chairman invited **Dr. Carmel Mary Martin**, Associate Professor of Family Medicine, Northern Ontario School of Medicine, Ontario, Canada & Visiting Academic, Department of Public Health Primary Care, Trinity College Dublin, Republic of Ireland & Co-Chairman, ESPCH SIG on Complexity and Health (Co-Winner, ESPCH 2014 Book Prize), to address the Conference under the title 'Implementing Person-Centered journeys through hospital stays and home and community care in 3 European Countries: Conceptual and practical challenges'.



Dr. Carmel Martin

Person Centered Health Care (PCHC) models, Dr. Martin asserted, aim to transform systems to achieve 'better clinical outcomes, increase patient and clinician satisfaction and decrease or contain healthcare costs' in the current 'epidemic' of chronic and multi-morbid illnesses. PCHC must thus address the needs of the frailer, multi-morbid population with potentially low levels of vision, hearing and computer literacy, vulnerability to social isolation and also care for their caregivers who are often elderly themselves. Patients and caregivers, she contended, need to drive their own care, education and information generation and use, respecting the older patient's desires and capacity for sharing decision-making and with enablement as a key goal. Developing a PCHC patient journey system through hospital stays, primary care and home care in 3 different European health and social care settings – Cork, Bangor and Lübeck provides many opportunities and challenges.

Complex Adaptive Systems Theory (CAS), Dr. Martin described, provides a framework for personal health journeys. Transforming historically dependent, non-linear dynamic, self-organizing health systems through the framework of PCHC need, accounts for *Historical influences* (including trajectories of ageing and health and capacity for self-organization within different systems at individual, service and societal levels), *Current influences* (including family and community relationships, health systems and social services dynamics, culture and *Future opportunities* (understanding and acting on radical innovation products and processes, as well as incremental improvements, while recognizing emergence, self-organizing systems and adaptation).

She continued by explaining how the introduction of office-based carers (advocates) supports vulnerable older people and their caregivers using experts systems which aim to ensure that the patient voice is central to and appropriately driving healthcare decisions. This addresses, she pointed out, the 'impersonal' nature of big data analytics that are increasingly driving healthcare to work to business models and efficiencies.

A focus on individual journeys within unique health services and systems with different languages and cultures is required, Dr. Martin contended, for PCHC development in different geographical and cultural settings. The challenge, she told the Conference, is to develop 'generic' linkages among care silos from in-hospital, GP outpatients and home settings - taking a personal journey approach that connects individuals with their health service event information, rather than trying to link massive record systems with different 'languages' of provider groups that use Big Data analytics. This radical shift prioritizes, Dr. Martin emphasized, rather than overshadows, the patient 'voice' and experience in health systems. Individual experiences and care events can be language and culture agnostic if modelled mathematically using natural language processing. Individual data can provide real time risks and predictive data that are appropriate to feed into all clinical contexts including hospital, GP and homecare. Providers access current, historical and predictive individual information at the point of care across silos with rolling communication and feedback via a dynamic patient journey data service. Care advocates enhance and monitor personal journey care. Care coordination among disciplines and services is not achieved by mere juxtaposition, if it is not supported by human engagement and advocacy when patients are frail and vulnerable.

Following the conclusion of Dr. Martin's presentation, the Chairman invited **Dr. Dwight McNeill, Instructor of Health Policy and Population Health, Suffolk University, Boston, Massachusetts, United States of America (Winner of the ESPCH 2015 Book Prize)** to address the Conference under the title 'Is Digital Health a Viable Pathway to Advance Person-Centered Healthcare'?

Dr. McNeill commenced his presentation by telling the Conference that the American way of producing health is failing. It continues, he said, to rank very low among developed countries on our basic human need: to live a long and healthy life. Abundant research shows that our own behaviors as humans can be far more consequential in determining our healthy longevity than the actions taken by others on our behalf. Indeed, five behaviors of everyday life, including eating poorly, smoking tobacco, drinking alcohol, exercising too little and not taking medications account for the majority of years of healthy life lost, largely due to chronic illnesses. Yet changing and sustaining these behaviors, Dr. McNeill asserted, has been seemingly intractable for a sizeable at-risk population. Doctors, governments and a burgeoning self-help industry exhort people to change, but their efforts have not been sufficient. With reference to this, the central question Dr. McNeill posed in his presentation was whether digital health tools can help enable, equip and engage people to be active co-producers of their own health.

Societal trends, Dr. McNeill contended, indicate that people may be poised to act. People are breaking free of medical paternalism that breeds dependence. More information has been liberated for their use and technologies make it more accessible and sharable. With the large increase in out-of-pocket financial exposure due to the new generation of health insurance plans with astonishingly high deductibles, people are more vigilant about the value of healthcare. Additionally, he said, people want convenience, eschew encumbrances and believe in themselves to do many of the tasks previously owned by professionals in many aspects of their lives. And innovative technologies offer a variety of promising, cost-effective tools including self-administered diagnostic tests, self-monitoring devices and coaching software to control glucose and blood pressure, smartphone apps and "adds" to maintain healthy behaviors - and much more.

There are significant barriers, Dr. McNeill contended, to the widespread development and adoption of these digital health tools including physician practice norms, reimbursement policies and cost, proof of cost-effectiveness and substantial privacy concerns. But, perhaps the most important challenge at this stage, he thought, was to accomplish a basic business function - to please the customer.

Technology innovators produce the apps and adds, the connected devices, social network platforms and computing capacity to power digital health. But, so far it has not produced the 'killer app' or even captured much consumer attention. The business model, so successful for other purposes and mostly for fun, has to change when it comes to behavior change. It needs, Dr. McNeill contended, to change from making us 'click' for the purpose of generating advertising revenues, to understanding what makes us 'tick' in order to make behavior change stick. Technology, he reminded the Conference, is very capable of producing wise, insightful information to know the individual better than he or she knows themselves. It can develop "digital hugs" to engage the individual emotionally because that social connection is so important for change and it can provide dynamic, smart coaching to help people overcome barriers and sustain new behaviors.

Concluding, Dr. McNeill asserted that the 'bottom line' is that people need to be their own Chief Life Officer and invest the time to reap the full benefit of our substantial birth asset. The surest way to do this, he felt, was to stay healthy and manage the five behaviors of everyday life. Increasingly, people are grabbing the baton, he said, others are welcoming them as true partners in health and powerful digital tools are emerging to equip them to be successful.

Following the conclusion of Dr. McNeill's presentation, the Chairman invited **Mr. Kevin Dolgin MBA, President, Observia,**

Associate Professor at IAE de Paris, Université Paris I (Panthéon-Sorbonne), Paris, France & Chairman, ESPCH SIG in Patient Behavioural Studies, to address the Conference under the title 'Promoting PCH-mediated patient adherence via mHealth'.

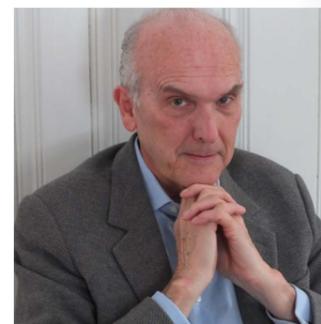
Mr. Dolgin commenced his presentation by telling the Conference that, over recent years, there has been increasing focus on the issue of adherence to treatment in the world of healthcare, whether on the part of patients, payers, prescribers or the pharmaceutical industry. With average adherence rates across chronic illnesses at roughly 50%, all players involved, he said, have begun to recognize the need to address this problem and a plethora of programs and aids have been initiated across the world.

Many different types of programs exist, Mr. Dolgin pointed out, and each of them employs some means of communicating with patients. Outside of pure financial/coupon programs (which are primarily American), adherence programs generally aim to motivate patients via both education and behavioral techniques; this requires communication and communication requires channels. These, he said, can be broadly categorized into automated and human channels: the first provide either a set message content or personalize content via an automated set of algorithms whereas the latter feature live communication with other people.

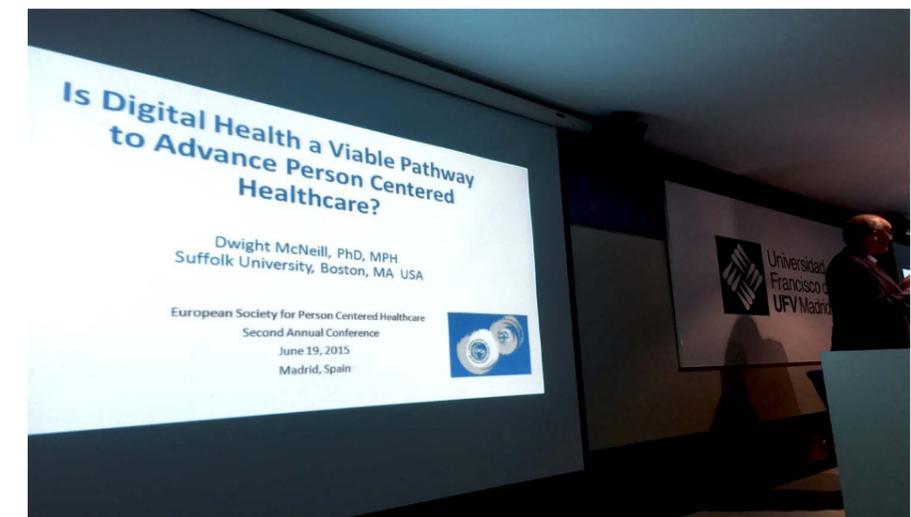
For those who would create adherence programs, this raises, Mr. Dolgin told the Conference, the question of which channels are most effective. The short answer is, he said, that a unique mix of channels will undoubtedly have the greatest impact. However, economic reality dictates that the more ambitious and costly a program is the less likely it is to see the light of day. Efficiency must be considered and the different channels considered on the basis of their cost-effectiveness. When this is done, he asserted, mobile communications, primarily through text messaging, often rises to the top as a particularly cost-effective means of building adherence programs.

There are numerous examples of text messaging programs across regions, patient types and pathologies that highlight the effectiveness of this channel, even for populations that may seem on the surface to be counter-intuitive and Mr. Dolgin described some of these. However, text-based programs should not be confused with reminders, he insisted. Some are indeed limited to simple treatment reminders, but the most effective make use of sophisticated profiling algorithms to provide individualized coaching, based on behavioral theories such as the theory of planned behavior or the transtheoretical model of change. Concluding, Mr. Dolgin told the Conference that by employing such approaches, the cost effectiveness of mHealth programs focusing on text messaging has been demonstrated to be significantly greater than other remote channels, even those allowing direct contact with healthcare professionals. The reasons behind this are best investigated, he contended, via frameworks that come not from the world of medicine, but from behavioral science, including consumer behavior.

Following the conclusion of Mr. Dolgin's presentation, the Chairman, Dr. Peter Wyer, asked all four late morning speakers to join him on the Conference Platform to constitute the **Panel Discussion with Delegate Participation.** Vigorous debate ensued, with lively audience participation.



Left: Mr. Kevin Dolgin
Right: Dr. Dwight McNeill



Top: Dr. Dwight McNeill, presenting "Is Digital Health a Viable Pathway to Advance Person-Centered Healthcare?"
Middle Left: Dr. Carmel Martin presenting "Implementing Person-Centered journeys through hospital stays and home and community care in 3 European Countries: Conceptual and practical challenges"
Middle Right: Mr. Kevin Dolgin Presenting "Promoting PCH-mediated patient adherence via mHealth"
Lower: Panel Discussion of Session Six, Perspectives On Implementation - I: Evolving Health Policy, Resource Allocation and Digital and mHealth, with the attending delegates. At panel (left to right); Dr. Sandra Tanenbaum, Dr. Carmel Martin, Dr. Dwight McNeill, Dr. Kevin Dolgin, Dr. Peter Wyer

SESSION SEVEN: PERSPECTIVES ON EDUCATION AND TRAINING

Following the re-commencement of the Conference after Luncheon, **Dr. Mark Tonelli, Professor of Medicine, Division of Pulmonary and Critical Care Medicine & Adjunct Professor of Bioethics and Humanities, University of Washington, Seattle, United States of America & ESPCH Chairman, Case-based Decision Making**, assumed the Chairmanship of the Early Afternoon Session. The Chairman invited **Professor Roger Ruiz Moral, Professor of Medicine and Clinical Communication, Faculty of Medicine, Francisco de Vitoria University, Madrid, Spain** to address the Conference (on behalf of **Dr. Fernando Caballero Martínez, Dean of Faculty of Medicine of Francisco de Vitoria University, Madrid, Spain & Chairman, ESPCH SIG on Undergraduate Medical Education, Winner ESPCH 2014 Gold Medal**) under the title **'Building a person-centered medical school. Why? How? What remains to be done?'**



Dr. Fernando Caballero Martínez



Professor Roger Ruiz Moral

Francisco de Vitoria University (UFV) opened a School of Medicine in 2010, following the implementation of the Bologna Process in Europe. The new policy environment, Professor Ruiz Moral told the Conference, created a unique opportunity to consider which innovations in undergraduate medical education would have the potential to provide a superior model of medical education that would, by its nature, satisfy the University's ambitions for the training and formation of future doctors. In considering this potential, the University decided to adopt a person-centered medicine approach that could enhance the person-centeredness of health systems, by inculcating notions of values and other components of the humanistic approach from the very first years of undergraduate training.

All of the individuals involved in the construction of the Medical School (students, university teachers and doctors in practice) were able, Professor Ruiz Moral explained, to agree on the deficiencies inherent within traditional university medical programs and which acted to preclude an ability of the doctor to deal with the range of patient needs that extend beyond the purely biological and physical. With this considered, UFV decided, he said, to immerse its medical students in a framework of explicit professional values, inspired by the ethical thinking of Dr Edmund Pellegrino. Thus, UFV understands and teaches, that the relationship between a patient and a doctor is a meeting of two people in a spirit of service, where the doctor gives all he/she has to offer and where he/she places the patient's welfare before his/her own. For such a relationship to be productive, Professor Ruiz Moral told the Conference, complete trust between the doctor and patient is a complete prerequisite. Within this relationship, the doctor will attend to the patient's physical needs, to organ dysfunction, organic disease, etc., and will use some or many principles of evidence-based medicine (EBM) in order to do so.

Professor Ruiz Moral outlined how UFV teaches that the patient

is more than a subject or object or complex biological machine and that the wise physician needs to consider how to deal with a range of other patient needs, many of them 'subjective' in their character. Indeed, the 'good' doctor will have successfully learned the appropriate relational and professional abilities to guarantee complete respect for the patient's rights, values and autonomy. These skills include the ability to enter into shared decision-making with the patient and to ensure that objective facts do not enter unnecessary conflict with subjective values.

UFV, Professor Ruiz Moral explained, believes that person-centered healthcare is one means of doing this, through its conceptual and practical ability to negotiate between facts and values and because it allows clinical practitioners to draw heavily on medicine's science, but also heavily on all of the other sources of knowledge in medicine that are of additional relevance to the making of good clinical decisions and thus to responding well to the unique clinical circumstances of the individual clinical case. It is for this very reason, Professor Ruiz Moral emphasized, that the University strongly encourages person-centered care teaching, in order for its students to learn how to integrate scientific advance with kindness, care, compassion and a deep respect and attention to the patient's personal narratives, values, preferences, his/her cultural, relational and social situation, psychology, emotions and spirituality, their human dignity - in short their biography as a person. This 'holistic approach' is, Professor Ruiz Moral confirmed, what UFV believes to be directly representative of an authentic account of clinical medicine and the best way forward in our modern times and a highly effective means for dealing well with the patient's suffering.

To illustrate the practical means through which the University's philosophy of person-centered medicine is taught, Professor Ruiz Moral detailed some specific approaches of the School of Medicine to implementing its vision. He described the UFV system for selecting candidates who wish to join the Medical School. This evaluates academic performance and intellectual level, but also and critically, seeks to identify specific personality traits that predict the behaviour that the School expects from doctors, in accordance with the School's values as discussed above. The School also has, he explained, a teaching programme on clinical communication and relational abilities (supported by a standard patient programme employing patient actors). Additionally, it provides a teaching programme for the intensive clinical training of the students, based on a phase of advanced clinical simulation (robot) before clerkships and an on-line, real time supervision of each student's performance during hospital experience, by means of an electronic portfolio (supported via a Tablet with its own evaluation software). Moreover, the School has, as Professor Ruiz Moral detailed, a teaching programme in the medical humanities, which is taught throughout the whole degree, with a progressive training in the history of thinking, anthropology, general ethics and applied bioethics. Social and human science, taught in cross-section, is part of this and aims to provide for students an attractive learning experience, given that it involves practical placements, for example, in palliative care environments and in psychiatric environments. With bioethics in mind, the University has also, Professor Ruiz Moral told the Conference, organized student visits to locations which commemorate Medicine and the Holocaust. Such innovations highlight the human and social dimensions of medicine and are introduced in the first year of the medical degree. Finally, the University has a teaching programme on clinical research, orientated to person-centeredness and delivered via small groups working cooperatively, which analyze various aspects of patients' experience as they enter and experience health systems.

Concluding, Professor Ruiz Moral affirmed that all of the curricular innovations described above are fully compatible with the essential scientific 'soundness' characteristic of any Faculty of Medicine within Europe and elsewhere. The difference at Francisco de Vitoria University, Madrid, Spain, is that at UFV the medical students are taught how to contextualise medicine's accumulated and accumulating science

– the context being that of the whole person who, ill and suffering, approaches his/her doctor and clinicians for assistance.

Following the conclusion of Professor Ruiz Moral's presentation, the Chairman invited **Dr. Nathan Schou Bertelsen, Visiting Assistant Professor, Koç University School of Medicine, Istanbul, Turkey & Director of Primary Care, Program for Survivors of Torture and Assistant Professor of Medicine and Population Health, New York University School of Medicine, United States of America and Winner, ESPCH 2015 Silver Medal**, to address the Conference under the title **'Empathy in graduate medical education milestones'**.



Dr. Nathan Schou Bertelsen

Competencies in both empathy and cross-cultural health care, Dr. Bertelsen pointed out, considered essential skills for physicians. As part of his work, a bedside learning activity was developed and piloted to define and teach empathy for residents, in order to improve clinical skills in cross-cultural patient care. This activity was done on an inpatient medicine teaching service at Bellevue Hospital Center and New York University School of Medicine in New York City, USA. Dr. Bertelsen described this study. Twenty-nine residents in internal medicine and thirteen faculties participated in one bedside session each. The objective of this exercise was, he outlined, to help the learner utilize empathy to: 1) gauge a patient's identity and culture; 2) assess health literacy and 3) change clinical management.

Patients with communication barriers were interviewed with the BATHE technique. All participants received anonymous surveys. Seventy six per cent of participating residents agreed that this activity improved their ability to provide cross-cultural care, 87% agreed that it assessed their patient's health literacy and 87% agreed that it changed their clinical management. Empathy, Dr. Bertelsen emphasized, offers a promising bedside exercise in which to gauge health literacy and to demonstrate effective cross-cultural patient care. Based on this experience, an instructor's guide was written for faculty, for use in training residents in empathy and cross-cultural patient care.

Following the conclusion of Dr. Bertelsen's presentation, the Chairman invited **Professor Brian Broom, Consultant Physician (Clinical Immunology), Department of Immunology, Auckland City Hospital and Adjunct Professor, Department of Psychotherapy, Auckland University of Technology, New Zealand** to address the Conference under the title **'The challenges of training clinicians towards person-centered care in hospitals, private practice, general practice, allied health disciplines and psychotherapy'**.

A whole person approach to physical illness, Professor Broom contended, faces many challenges in Western healthcare contexts that are underwritten by positivism, mind and body dualism, physico-material reductionism, anti-subjectivity, diagnosis-centeredness, specialist-based fragmentation of care, the privileging of technological information over other human realities and the consequent economic structuring of healthcare.

Professor Broom continued by describing his personal experience of the challenges that arise from these observations,

deriving from his training both as a specialist clinical immunologist and as a psychotherapist; instigating a multidisciplinary private health center aspiring to whole person care; private practice as a consultant immunologist and psychotherapist; instigating a national network of clinicians interested in whole person approaches; instigating and leading a University Master's training program in whole person approaches with clinicians from a wide variety of disciplines; many years supervising psychotherapists and other clinicians working in a person-centered way with persons with physical illnesses and, over the last eight years, working as a senior physician in a conventional tertiary hospital immunology department, promoting whole person approaches. The training philosophy has been to enable clinicians *to bring change to their clinical practices in their ordinary disciplinary workplace*. Professor Broom posed the 'question: 'What have we learned about the transformation of practice to person-centeredness?' Responding, he presented six possible answers.

Professor Broom argued firstly for the need for *intellectual and conceptual clarity*. Most clinicians, he argued, find it is impossible to change to a whole person approach unless they have a solid paradigmatic framework that makes sense and can be rigorously defended. A clinician cannot do consistent non-dualist work if strongly residually dualistic. Secondly, he argued for the need for a supportive change environment. Clinicians may listen and get excited but feel confused and powerless when back in the 'real' clinical environment. Change typically occurs in people who enter sustained change programs. Social pressures, the need to belong, feeling incompetent and vested interests are powerful inhibitors, whatever the evidence that change is needed. Thirdly, Professor Broom argued, we need a person-centered care demands listening and intimacy skills. Some clinicians are 'naturals' and mainly need permission and support. Others need a journey of personal change and some cannot face this. Fourthly, he argued, procedural skills in the consultation are needed. It takes time, he emphasized, to learn how to welcome and host both physical and non-physical aspects of persons in the same clinical time/space. Fifthly, while many of the challenges are generic, each health discipline and work context has its own typical and very specific challenges. Sixthly, Professor Broom argued, was an understanding of the factor of resistance to change, which appears far more a clinician and health system problem, than a patient or 'client' problem. Concluding, Professor Broom appeared clear that patients, especially those with chronic conditions, greatly appreciate a whole person approach. While much good comes from focusing on the *supply* side (the clinicians) of whole person care, it does mean confronting, he asserted, a very dominant paradigm, powerful vested interests and enormous structural inertia. Stimulating the *demand* side (the patients) is a real option.

Following the conclusion of Professor Broom's presentation, the Chairman, Dr. Mark Tonelli, asked all three mid afternoon speakers to join him on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**. Vigorous debate ensued, with lively audience participation.



Professor Brian Broom

SESSION EIGHT: FAMILY-CENTERED CARE AND PATIENT COMMUNICATION

Following the conclusion of the Early Afternoon Session, **Professor Bernie Carter, Professor of Children's Nursing at the University of Central Lancashire UK, Director of the Children's Nursing Unit (CNRU) at Alder Hay Children's NHS Foundation Trust, Clinical Professor, University of Tasmania, Visiting Professor, Edge Hill University & Editor-in-Chief, Journal of Child Health Care and the Winner of the 2015 Presidential Medal of the European Society for Excellence in Person Centered Healthcare**, assumed the Chairmanship of the Mid Afternoon Session. **Professor Carter invited Professor Linda Shields, Professor of Nursing, Tropical Health Research Unit, James Cook University and Townsville Hospital and Health Service, College of Healthcare Sciences, James Cook University, Townsville, & Honorary Professor, School of Medicine, The University of Queensland, Australia & ESPCH SIG Chairman on Child and Family Centered Care and Winner, ESPCH 2014 Silver Medal**, to address the Conference under the title 'Family-centered care: history, application and subversion'.

Following the conclusion of Professor Shield's presentation, the Chairman called upon **Professor Wendy Chaboyer, Director, NHMRC Centre of Research Excellence in Nursing Interventions for Hospitalised Patients (NCREN) & Centre for Health Practice Innovation (HPI), Menzies Health Institute Queensland, Griffith University, Queensland, Australia & Professor, Institute of Health and Care Sciences, Gothenburg University, Sweden**, to address the Conference under the title 'Engaging Patients in Communication about their Care Transitions'.



Top Left: Panel Discussion of Session Seven, Perspectives On Education And Training, with the attending delegates. At panel (left to right); Dr. Nathan Schou Bertelsen, Professor Brian Broom, Professor Roger Ruiz Moral, Dr. Joachim Sturmberg

Top Right: Professor Brian Broom presenting "The challenges of training clinicians towards person-centered care in hospitals, private practice, general practice, allied health disciplines and psychotherapy"

Lower Left: Dr. Nathan Schou Bertelsen presenting "Empathy in graduate medical education milestones"

Lower Right: Professor Roger Ruiz Moral presenting "Building a person-centered medical school. Why? How? What remains to be done"



Professor Bernie Carter



Professor Linda Shields

Family-centered care, Professor Shields outlined, is currently the philosophical cornerstone of paediatric practice. It is to be found in policy documents and guidelines in children's healthcare across the world and is becoming widely discussed for care across the lifespan. While it sounds good, it is not supported by rigorous evidence and is under scrutiny as other models emerge and healthcare changes.

Professor Shields commenced her presentation by discussing the historical development of family-centered care and why it is now being questioned. She then turned to an exposition of how family-centered care can be subverted to meet evil ends. For example, when the Fascist Party came to power in Germany in 1933, policies were implemented that had been designed to support the family, to encourage families to develop good habits and good health and to have many children. There was even a particular *programme*, *Lebensborn*, designed to selectively breed "good" Aryan children.

What we would call family-centered care today had a real place in the Nazi world, provided the family was racially "pure", fitted the definitions of a "good racial mix" and that its members were not "life unworthy of life". Family-centered care, Nazi style, led, Professor Shields described, to the so-called "euthanasia" programmes which saw disabled and ill children and adults killed if they were deemed to be "useless feeders" and a drain on the healthy family and the healthy state.

Concluding, Professor Shields summarized this subversion of family-centered care to meet a truly malevolent philosophy, calling for the world never to forget what things can be advanced possible under descriptions such as 'child and family-centered care'.



Professor Wendy Chaboyer

Engaging patients in clinical communication is founded, Professor Chaboyer outlined, on the belief that patients have a legitimate right to be included in their own care and decision-making. Yet, this is not a simple thing to enact, with organisations struggling to involve patients in authentic ways. Existing strategies for actively involving patients in clinical communication about their care transitions are poorly understood.

Professor Chaboyer presented her study on the exploration of how healthcare professionals engage patients in communication associated with care transitions. An instrumental case study approach was used. A purposive sample of key stakeholders representing (a) patients and their families; (b) hospital discharge planning team members and (c) healthcare professionals was recruited in five Australian health services. Individual and group semi-structured interviews were conducted to elicit detailed explanations of patient engagement in transition planning. Interviews lasted between 30 to 60 minutes and were digitally recorded and transcribed *verbatim*. Data collection and analysis were conducted simultaneously and continued until saturation was achieved. First strategies and tools used by participants were extracted and described. Then, thematic analysis was undertaken.

In terms of sample size, Professor Chaboyer described a total sample of 62 people as having been interviewed, 27 (44%) individually and 35 (56%) in groups in a total of 11 groups. Thirty six nurses (58%), 9 allied health professionals (15%), 7 patients (11%), 7 physicians (11%), 2 volunteers or health advocates (3%) and 1 family member (2%) were interviewed. Participants described a number of different strategies used to engage patients and their families in communication about their care transitions, reflecting a multifaceted approach to engaging patients. Examples of these strategies included bedside handover, multidisciplinary rounds, and hourly rounding. When participants described these strategies, Professor Chaboyer described, they seemed to indicate that they improved communication in general and, as a result, communication about care transitions was also improved. An important characteristic of these strategies, she said, was that they were tailored to meet the needs of individual patients. Examples of tools described by participants include patient care boards, protocols and checklists and patient passports. The five themes that emerged were: 1) Organisational commitment to patient engagement; 2) The influence of hierarchical culture and

professional norms on patient engagement; 3) Condoning individual healthcare professionals' orientations and actions; 4) Understanding and negotiating patient preferences and 5) Enacting information sharing and communication strategies. Most themes illustrated how patient engagement was enabled. Barriers, however, also existed.

Concluding, Professor Chaboyer indicated that her findings demonstrated that strong commitment to patient-centred care throughout the organisation was a consistent feature of health services that actively engaged patients in clinical communication. Understanding patients' needs and preferences and having both formal and informal strategies to engage patients in clinical communication promoted, she said, this involvement.

Following the re-commencement of the Conference after the mid afternoon break, Professor Carter re-assumed the Chairmanship for the continuation of the Mid Afternoon Session and invited **Ms. Georgia Tobiano, Centre for Health Practice Innovation, Menzies Health Institute, Griffith University, Queensland, Australia**, to address the Conference under the title **'Patients' and Nurses' Preferences for Patient Participation in Nursing Care'**.

Patient participation, Ms. Tobiano told the Conference, is increasingly recognized as a vital strategy to improve patient safety and is a core concept of person-centred care. Unfortunately, patient participation, she asserted, is not easily achieved, with many barriers influencing its success. Nurses may play a key role in facilitating patient participation, yet their behaviors, the Conference learned, do not always reflect this.

In her presentation, Ms. Tobiano described how her research had explored patients' and nurses' preferences for patient participation in nursing care. Her ethnographic study was conducted in four medical wards, located in one public and one private hospital, in two States. Forty interviews were conducted, she explained, and fourteen nurses and two of their patients were observed. Patient and nurse interview transcripts were analyzed separately using inductive content analysis. Field notes of observations were organized into 'encounters'. An encounter began when the nurse entered the patient's room and ceased once the nurse left. Encounters were analysed using deductive content analysis, using Eldh and associates' framework which includes four types of participation; meaningful dialogue, shared knowledge, partaking in planning and managing self-care. Inductive analysis was undertaken on data that did not fit the framework or criteria for an encounter.

Four categories, Ms. Tobiano outlined, were uncovered in the patient data. The first category, valuing participation, showed patients' willingness for participation. Exchanging intelligence, the second category, was a way of participating where patients' knowledge was built and shared. The next category, being on the lookout, was a type of participation where patients monitored their care, showing an attentive approach towards their own safety. The final category, balancing power, was characterized, she described, by patients feeling their opportunities for participation were restricted, due to a sense of unbalanced power.

Five categories emerged from the nurses' views. Ms. Tobiano described how, first, acknowledging patients as partners showed nurses respected patients as legitimate participants. Second, she illustrated how managing risk emphasised nurses need to monitor participation to ensure rules and patient safety was maintained. Third, enabling participation demonstrated, she showed, how nurses' strategies enhanced patients' participation. Fourth, hindering participation encapsulated nurses' difficulty in engaging patients who had certain characteristics. Finally, Ms. Tobiano explained, nurses realised participation as patients being involved in physical activities or clinical communication.

Deductive analysis of the observational data generated by Ms. Tobiano's study showed that knowledge sharing (60/116 (52%) encounters) and meaningful dialogue (59/116 (50.8%) encounters) were more commonly practiced. Involving patients in planning (32/116 (28%) encounters) and managing their self-care (18/116 (16%) encounters) was less frequently witnessed. One inductive category, labelled "controlling the

environment" emerged, which showed some nurses' behaviours hindered patient participation.

Patients, Ms. Tobiano concluded, were motivated to and valued participation. Cultivating this motivation may, she contended, be essential for patient empowerment and patients' practices of safety-monitoring. The nurse's role in enacting participation is complex, having to accommodate each patients' risks and characteristics, highlighting the need for good assessment skills to maintain safety. Patients and nurses recognized, she told the Conference, the crucial role nurses have in facilitating patient participation, while displaying controlling behaviours may reduce patient participation.

Following the conclusion of Ms. Tobias' presentation, Professor Carter, the Chairman, invited **Ms. Macarena Quesada Rojas, Clinical Trials Department, Health Research Foundation (FFIS), Virgen de la Arrixaca Hospital & Department of Social Health Sciences, Faculty of Medicine, University of Murcia, Spain**, to address the Conference under the title **'Caring for carers: Spanish perspectives in palliative care'**.

As the human lifespan increases, Ms. Quesada told the Conference, the provision of care to the elderly becomes increasingly important. Developed countries, she said, have experienced a dramatic rise in life expectancy in the last twenty years, a situation set to become of even greater relevance given the United Nations population projections for 2050, suggesting that up to 30% of the European population will be over 65 by that time. The population of Spain, Ms. Quesada pointed out, will become the third oldest in the world, with 34.1% being aged over 65, behind only Japan and Italy (35.9 and 35.5 respectively). At the same time, because of the aging population, more people die after long illness from heart disease, cerebrovascular disease including stroke, chronic respiratory disease, respiratory infections and cancer. In Spain, the main cause of death among people age 40 to 79 is, Ms. Quesada detailed, cancer (314.8 per 100,000). Advanced cancer victims represent a large percentage of palliative care patients.

The World Health Organization defines Quality of Life (QoL) as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Palliative care, Ms. Quesada affirmed, offers a support system to help patients live as actively as possible until their death. It prizes life and regards dying as a normal process, but intends neither to hasten the former nor prolong the latter. Chronic disease that causes patients and caregivers to lose control over their lives, Ms. Quesada contended, has an adverse effect on their social, work, family/marital life and causes their health and QoL to deteriorate. The decrease in the caregiver's QoL influences the quality of care and thus the QoL of the patient. Ms. Quesada described how the time dedicated to a caregiver's activity is comparable to a standard working day, but where the hours tend to increase as the impact of the disease worsens. In the worst-case scenario, taking care of the patient becomes a full-time occupation for the family caregiver. Informal caregivers are usually the hidden victim of the disease and so have been labeled the "hidden patients".

Carer support, Ms. Quesada described, is based on five specific areas: (1) information about the illness suffered by their family member, (2) training in patient care, (3) how they take care of themselves, (4) the carer's own needs and (5) the amount of help they receive in undertaking their work.

Ms. Quesada concluded by telling the Conference that the relationship formed with the carer should be based on empathy and active listening, allowing carers to express their feelings, doubts, frustrations, fears about the future and uncertainty in the face of difficult situations. Health systems, she recommended, should try to assess the attitude and aptitude of carers and how caring has affected their personal life and that of the patient and if they are showing any signs of excessive strain. We should, she told the Conference, try to anticipate that strain and, once we have assessed the carer's situation, we can then move on to

support strategies and begin to care for the carer. "Caring for carers", Ms. Quesada insisted, should become a priority in palliative care.

Following the conclusion of Ms. Quesada's presentation, the Chairman, Professor Carter, asked all four late afternoon speakers to join her on the Conference Platform to constitute the **Panel Discussion with Delegate Participation**. Vigorous debate ensued, with lively audience participation.



Ms. Georgia Tobiano



Ms. Macarena Quesada Rojas



Above: Panel Discussion of Session Eight, Family Centered Care And Patient Communication, with attending delegates. At panel (left to right); Ms. Macarena Quesada Rojas, Professor Wendy Chaboyer, Ms. Georgia Tobiano, Professor Linda Shields, Professor Sir Jonathan Asbridge, Professor Bernie Carter

**SESSION NINE:
CONTROVERSIES AND HORIZONS**



Top Left and middle: Professor Linda Shields presenting "Family-centered care: history, application and subversion"
 Top Right: Professor Wendy Chaboyer presenting "Engaging Patients in Communication about their Care Transitions"
 Lower Left: Ms. Georgia Tobiano presenting "Patients' and Nurses' Preferences for Patient Participation in Nursing Care"
 Lower Right: Ms. Macarena Quesada Rojas presenting "Caring for carers: Spanish perspectives in palliative care"

Following the conclusion of the Mid Afternoon Session, **Professor Sir Jonathan Asbridge DSc (hc), President and Chairman of Council of the European Society for Person Centered Healthcare**, assumed the Chairmanship of the Late Afternoon Session and invited **Mr. Harry van Bommel, Founding Member, Canadian Hospice Palliative Care Association and Hospice Palliative Care Association of Ontario, Canada & Executive Director, Resources Supporting Family and Community Legacies Inc., Founder of Canada 150 Project, Co-Founder NavCare Canada** to address the Conference under the title 'Assisted Dying or Assisted Living? Can physician assisted suicide form part of the person-centered healthcare framework'?



Mr. Harry van Bommel

Mr. van Bommel told the Conference that he would speak from a patient-family perspective and as the author of 50 books, half of which are in the field of family caregiving and healthcare. In Canada, he said, the debate to legalize assisted suicide is over. It had moved from theoretical debating points to practical implementation after a recent Supreme Court judgment of 9-0 declared that physician-assisted suicide must become legal by 2016. The Supreme Court decided, Mr van Bommel outlined, that "a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes suffering that is intolerable to the individual in the circumstance of his or her condition", has the legal right to physician-assisted suicide. This decision has the broadest parameters yet seen internationally which may allow almost anyone to ask for help to die.

Speaking from a review of historical trends, Mr. van Bommel identified for the Conference the specific reasons why he believed that assisted suicide and euthanasia have no place in person-centered healthcare, nor for that matter in any model of medical care, especially palliative care. He discussed the specific modern trends towards early deaths within healthcare systems of people considered vulnerable by age, ability, education, income level and other social determinants of healthcare, advancing some recommendations that assisted suicide and euthanasia be taken out of the medical realm altogether in order to provide what he believed to be a relatively more safe alternative for those who have been given the legal right to a state-sanctioned death. Mr. van Bommel's presentation did not include moral, religious or ethical reasons against assisted suicide and euthanasia, indeed, as he made clear, these have been well articulated as part of the international debate to date and are therefore well documented. Rather, he examined the historical consequences that legalization inevitably causes vulnerable people to die sooner and unnaturally as compared to valued people. In concluding, Mr. van Bommel strongly highlighted that no system of legalized state-sanctioned death has ever been proven to protect vulnerable people.

Following the conclusion of Mr. van Bommel's presentation, the

Chairman, Professor Sir Jonathan Asbridge DSc (hc) invited **Professor Andrew Miles (Senior Vice President & Secretary General, European Society for Person Centered Healthcare, Madrid, Spain and London UK)** to deliver a PowerPoint slide presentation 'Why Traditional, Complementary and Alternative Medicine (CAM) are intrinsic to the person-centered healthcare framework' on behalf of the author **Professor Paolo Roberti di Sarsina, Specialist in Psychiatry & President, Charity for Person Centred Medicine (Moral Entity), Bologna, Italy; Member, Observatory and Methods for Health & Coordinator Master's Course "Health Systems, Traditional and Non-Conventional Medicine", University of Milano-Bicocca, Milan, Italy & Chairman, ESPCH SIG on Traditional, Complementary and Alternative Medicine** who had been unable to deliver his presentation personally.



Professor Paolo Roberti di Sarsina

Professor Miles delivered, essentially *verbatim*, Professor Paolo Roberti Di Sarsina's narrative for the presentation. One of the facets of the modern debate on person-centered healthcare, Professor Roberti Di Sarsina had argued, was how PCH can be implemented in practice. Indeed, there is a real risk, without such implementation, that PCH will be marginalized as a lofty ideal without practical applicability. Although it may seem obvious to say that the focus of any medical intervention should be the patient, seen as a human being, he/she is still too often considered, Professor Roberti Di Sarsina contended, as nothing other than a set of organ systems, diseases and symptoms to be "put right" in a battle between the atavistic doctor and "clumsy" nature. Yet the holistic view of the person as a whole is nothing but the fundamental premise from which one must begin in medical science and not an understanding to be subsequently achieved. This was Professor Roberti Di Sarsina's core thesis.

From Professor Roberti Di Sarsina's point of view, Traditional, Complementary and Alternative Medicine (CAM) must form part of the person-centered healthcare framework. He says this because if, for biomedicine, the important roles of the external environment, social relationships, or the quality of food/nutrition are fairly recent discoveries, for CAM they have always been, he asserts, the foundation of diagnostic and therapeutic intervention. For CAM, the human being becomes a dimension in space, manifest through the integration of a multiplicity of different dimensions. This complexity, referred to as a reflection of Nature and the Cosmos more generally, necessitates, Professor Roberti Di Sarsina contends, by its nature, a fully person-centered healthcare.

For Professor Roberti Di Sarsina, from the ontological point of view, CAM is an anthropologically-based, humanly founded system which was already being exercised by doctors in the ancient world long before the biomedical paradigm emerged. The need for a person-centered medicine naturally emerges in any course of treatment and



Top: Mr. Harry van Bommel presenting "Assisted Dying or Assisted Living? Can physician assisted suicide form part of the person-centered healthcare framework?"
Lower: Professor Andrew Miles presenting "Person-centered Healthcare – Quo Vadis? Opportunities and Horizons"

is fundamental to therapeutic success. In biomedicine, only informed consent has been typically required. However, in CAM, Professor Roberti di Sarsina insists, the participation of the patient in CAM therapy is an inseparable component of the therapy itself. It is part of the CAM belief system, he says, that the expectations that the patient and the doctor hold regarding the therapy significantly influence the outcome. Indeed, if the treatment setting is producing a considerable influence on the emotional state of the patient then that indicates that this is precisely the point from which one needs to begin to understand how important and cost-effective the centrality of the person is, not only in the therapeutic context, but also in the experimental one.

Following Professor Miles' presentation of Professor Paolo Roberti di Sarsina's slides and narrative, Sir Jonathan's invited Professor **Andrew Miles, Senior Vice President & Secretary General, European Society for Person Centered Healthcare, Madrid, Spain and London, UK**, to deliver the final presentation of the Second Annual Conference, under the title 'Person-centered Healthcare – Quo Vadis? Opportunities and Horizons'.



Professor Andrew Miles

In commencing his presentation, Professor Miles indicated that it was not his intention to reflect on the progress that PCH has made to date, but on what developments he believed are now necessary to secure its *ongoing progress*. In this context, Professor Miles identified 10 core areas of necessary progress.

Firstly, Professor Miles talked of the need for an *ongoing conceptual and epistemological clarification of PCH*. It is clear from the literature, he argued, that PCH means different things to different people, whether clinicians, managers, politicians and policymakers and the general public. More work is therefore needed in order to clarify divergent understandings and agree common definitions.

Secondly, Professor Miles called for *more dynamic education in PCH principles and practice*. It is axiomatic, he told the Conference, that general education in PCH principles and practice is fundamental to efforts to re-humanize clinical services. Education in this context should have as its priority, he said, the education in PCH of: (a) undergraduate medical and non-medical clinical students, beginning with screened entry selection for clinical training & (b) health services managers, health policymakers and politicians & (c) patients and patient advocacy organizations themselves.

Thirdly, Professor Miles argued that while the undergraduate education of medical students, other clinicians and other health system workers was vital to the advancement of PCH, such a compartmentalization of teaching to the early years of study was insufficient. Thus, *postgraduate training in PCH was equally necessary as a logical continuation of undergraduate teaching*. Indeed, continuing professional education and development is a moral duty of all clinicians, he said, and it is a responsibility of health systems to ensure that such education is properly in place. While education in PCH theory and practice is likely to permeate undergraduate medical and clinical curricula over time, the majority of clinicians who are currently working in practice will not therefore have received the benefit of such teaching. Given this, it is important that appropriate training be provided to such colleagues. This will require the development and use of educational packages in different forms.

Fourthly, Professor Miles contended, was a need for *service re-configuration and re-design*. Clinical services, he pointed out, have traditionally been designed with the needs of the organization and its staff in mind and not with reference to the needs of patients, so that patients approaching the system are typically fitted into pre-existing organizational structures and processes. For an effective PCH, services must be built around the patient, not patients built around the health system. To enable the implementation of agreed approaches to PCH, various levels and extents of service re-configuration and design would be necessary.

Fifthly, Professor Miles asserted, was the need for *much more transformational and servant leadership within health systems*. He was clear that while a conceptual/epistemological clarification of PCH, a PCH-enriched undergraduate and postgraduate education and training and a recognition of the need to re-configure and re-design clinical services are all vital for the advancement of healthcare personalization, it remained highly unlikely that such developments would have any effect in terms of implementation without the exercise of transformational and servant leadership by those experienced in the exercise of such functions. The creation of transformational and servant leaders of PCH is therefore necessary, he insisted, and methods to form these leaders are thus a priority.

Sixthly, Professor Miles strongly advocated the need for *multidisciplinary team working within health systems*. The implementation of PCH is unlikely to occur, or to be sustainable, he argued, without a clear acknowledgement of the need for MDT working. Medical colleagues alone are not sufficiently equipped to effect a transition away from the current de-personalized models of care to a more person-centered approach, he said. An acknowledgement of the vital place of effective MDT working for PCH implementation and the development of policies and methods to enable was therefore urgently required.

Seventhly, Professor Miles emphasized the role of *patient education, advocacy and empowerment*. The place of patients (and their families and friends) themselves in determining PCH plans and implementation strategies remains central, he said. A recently published systematic review of the literature on the methods of patient empowerment had reported that significant uncertainty remains about the best way to define and measure it and that a consensus is needed from which to develop a core set of patient empowerment constructs and appropriately validated measurement indices and tools. Increasing the health literacy of patients in understanding, self-managing and working with clinicians to manager their condition(s) was therefore key here, Professor Miles asserted, as is the urgent need to increase the political power of the patient voice in all matters relating to patient care – both at local and national levels.

Eighthly, Professor Miles advocated the *imperative to raise awareness of PCH principles and practice and of the need for a general advocacy of PCH*. Much work, he told the Conference, remains to be done in ensuring a continuing - and amplified - advocacy of PCH. The raising of awareness of PCH's benefits must combat the erroneous idea, prevalent in some medical and management circles, that PCH is in essence a sentimental activity which looks back to medicine's past, rather than looking forward to healthcare's future. PCH is, on the contrary, a dynamic activity that brings with it not only increases in patient and clinician satisfaction, but superior clinical outcomes when compared to 'care as usual' and with measurable decreases in health system costs. These observations, Professor Miles argued, based on a rapidly growing empirical research base, cannot be over-emphasized or over-communicated. Going forward, more effective external and public relations strategies are required for PCH and better use of social media by PCH leaders should form one plank of such activities. He suggested that such approaches, in combination with others, will lead to an increased awareness of the importance of PCH approaches in the medical, managerial, policymaker, political and public minds, thus making more likely an acceleration of the operational implementation of PCH into routine health and social care systems.



Top: Panel Discussion of Session Nine, Controversies and Horizons, with the attending delegates. At panel (left to right); Mr. Harry van Bommel, Professor Andrew Miles, Professor Sir Jonathan Asbridge
Lower: Professor Sir Jonathan Asbridge presenting his Closing Remarks for the Conference

Ninthly, Professor Miles stressed the vital importance of ongoing research into PCH. He told the Conference that a rapidly growing empirical research base indicates that PCH approaches to patient care increase patient adherence to both simple and complex medication regimens, that they decrease the frequency of primary and secondary care clinical consultations, that they decrease the frequency of disease and illness exacerbations, that they decrease hospitalization rates, that they decrease length of stay when hospitalization occurs, that they result in increased patient satisfaction rates, that they result in increased clinician satisfaction and reduced clinician burn out rates and that they result in reduced malpractice claim suits. An imperative for PCH, in addition to those suggested above, he said, must therefore be to confirm the result of these initial studies, thus to consolidate the evidence for PCH, enabling powerful arguments to be made for its adoption and funding in practice. It is here that economic studies are necessary, Professor Miles emphasized, in order to cost PCH-mediated changes in service utilization and delivery. The result of such research would be vital, he insisted, in securing the attention and action of health policymakers and the governments that they serve.

Tenthly, Professor Miles spoke of the need for new thinking in terms of systems for PCH Implementation. The implementation of new systems of working and governance in health services are often described, he said, in a binary fashion as 'top down' (stick) or 'bottom up' (carrot) – the carrot-stick metaphor being well recognized and much used within management theory. Professor Miles argued that systems for the implementation of PCH approaches must be 'bottom up', thereby providing 'carrots', rather than wielding 'sticks'. The idea (articulated elsewhere) that PCH can be implemented by top down, WHO or State Government designed strategies is, Professor Miles asserted, simplistic and naïve. On the contrary, the implementation of PCH should, he insisted, be progressed via democratic means, involving detailed collegial discussions with the clinical professions and their professional organizations at individual State level in collaboration with well-respected PCH leaders and with implementation planned in a bottom-up, democratic fashion and being fully sensitive to local and national cultural considerations and resource constraints.

Professor Miles concluded by contending that each and every one of the ten approaches he had outlined were necessary if we are to move PCH from a simple rhetorical advocacy into operational practice. Such a process is complex, he said, and will take time, almost certainly several decades. If successfully achieved, PCH will return to the clinical professions a definitive ambition to treat patients as persons, moving competence or even high competence in the direction of and to the achievement of clinical excellence.

Following the conclusion of Professor Miles' final presentation, the Chairman invited the speakers for the Late Afternoon Session to join him on the Podium for the **Panel Discussion with Delegate Participation**. Vigorous debate ensued, with lively audience participation.

Following the end of the Panel Discussion, the President and Chairman of Council of the European Society for Person Centered Healthcare, **Professor Sir Jonathan Asbridge DSc (hc)**, delivered his **Closing Remarks**.

PRESIDENT'S CLOSING REMARKS



Professor Sir Jonathan Asbridge

In his closing remarks, Sir Jonathan reflected on how intensive the two days of the Second Annual Conference and Awards Ceremony had been. He told the Conference that he was sure that they, like him, were at once exhausted by the sheer pace and breadth of proceedings, but at the same time exhilarated by what had been discussed, agreed and achieved. He noted again how the Conference has been successful in bringing together a very wide range of speakers from five continents, with scholarly input from the United States of America, Canada, Australia, New Zealand, South America, the Middle East, Turkey, the United Kingdom, France, Spain, Italy, Germany, Norway, Denmark and Sweden. He thanked the respective speakers for their most valued contribution to the Second Annual Conference and Awards Ceremony of the Society and saluted also the other conference delegates that had travelled significant and great distances in order to be present.

Sir Jonathan then turned his attention to all those things which needed, now, to be concentrated upon and achieved. He referred to his opening Presidential Address which had listed the rapid progress of the Society over a very short period of time and he emphasized how important he felt it was for such early momentum to be sustained and solidly built upon. Sir Jonathan said how confident he was that this would prove the case and how determined he was, personally, to ensure the ongoing success of the Society, supporting it in all ways necessary and possible, to achieve its aims. He looked forward, he said, to the continuing success of the *European Journal for Person Centered Healthcare*, the official journal of the Society, and to its expansion, given its substantial submission rates. And he looked forward, he said, to opening the forthcoming conferences of the Society in 2016 and to all the others scheduled for 2017.

Concluding, Sir Jonathan told the Conference that he was very much looking forward, after concluding his Address, to chairing the Inaugural Meeting of Council of the Society at the University that evening, a most important meeting which he believed, as the first of many annually, would be vital to ensuring the effective governance and success of a rapidly developing academic and clinical body – the European Society for Person Centered Healthcare.

Sir Jonathan wished all speakers and delegates a safe journey home to their respective countries and, with those words, declared the Second Annual Conference and Awards Ceremony of the Society, formally closed.

ACKNOWLEDGEMENTS

We are grateful to the individual speakers of the Conference for the use of their conference abstracts, via our edits, in ensuring the accuracy of the narrative text of this Conference Report and for granting the Society their permissions to employ the photographs that we have employed.

ANNOUNCEMENT OF THE 2015 WINNERS OF THE ESPCH MEDALS AND PRIZES



The ESPCH Medals and Prizes. Left to right: (a) The Presidential Medal for Excellence in PCH, (b) The Senior Vice Presidential Medal for Excellence in PCH, (c) The Platinum Medal, (d) The Gold Medal, (e) The Silver Medal, (f) The Bronze Medal, (g) The Book Prize & (h) The Essay Prize

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, delivery, evaluation and measurement of PCH-driven clinical services.

This year's international consultation exercise was conducted (as were the 2014 inaugural awards consultations) via a simple nomination form requesting recommendations supported by an accompanying justification. The 2015 consultation produced an excellent result, generating a grand total of 382 suggestions. It is from these nominations that the President and Vice President were able to select winners – with difficulty - given the outstanding nature of the large number of recommendations received.

During the Second Annual Conference and Awards Ceremony, held at Francisco de Vitoria University, Madrid, the President, Professor Sir Jonathan Asbridge DSc (hc), and Senior Vice President & Secretary General, Professor Andrew Miles MSc MPhil PhD DSc (hc), conferred the Society's medals and prizes at the formal Awards Ceremony prior to the Conference Dinner on the evening of Thursday 18 June 2015. The Society's first Postgraduate Master's Degree studentships were also announced followed by confirmations of the chairmanships of the ESPCH Special Interest Groups (SIGs). The Cocktail Ceremony prior to the Awards Ceremony and Conference Dinner was attended by the conference delegates and Dr. Juan Pérez-Miranda, Vice Rector for International Relations, Francisco de Vitoria University.

On the suggestion of Professor Linn Getz, the Society's Vice President for Northern Europe, the Society's 2016 awards will be extended to include a range of recognitions for young clinicians and young scientists working in the research and teaching of person-centered healthcare.



Presidential Medal For Excellence In Person Centered Healthcare

Professor Bernie Carter BSc PhD RSCN SRN FRCN
 Professor of Children's Nursing at the University of Central Lancashire UK & Director of the Children's Nursing Research Unit (CNRU) at Alder Hey Children's NHS Foundation Trust UK & Clinical Professor, University of Tasmania & Visiting Professor, Edge Hill University & Editor-in-Chief, Journal of Child Health Care.

Professor Bernie Carter is Professor of Children's Nursing at the University of Central Lancashire and Director of the Children's Nursing Research Unit (CNRU), Alder Hey Children's NHS Foundation Trust. She is also Clinical Professor at the University of Tasmania. She is a Fellow of the Royal College of Nursing in recognition of her contribution to children's pain. She is the Editor-In-Chief of the Journal of Child Health Care (Sage Publications).

The Society was proud to award the Presidential Medal to Professor Bernie Carter. Professor Bernie Carter has always been a strong and successful advocate for family-centered care. She is firmly committed to working with marginalised children whose voices are rarely heard and to contributing to the debates around children's agency and the ways in which children can be protagonists for change. While it is known that the implementation of family-centered care can be problematic, Professor Carter has provided an alternative way to focus care on children and their families as is set out within her seminal 2014 textbook 'Child-centered Nursing: Promoting Critical Thinking'.

Professor Carter developed the Children's Nursing Research Unit at the University of Central Lancashire UK, a collaborative initiative between the University, Liverpool John Moore's University UK, Edge Hill University UK and Alder Hey Children's NHS Foundation Trust UK. This initiative has brought together nursing scholars, clinicians, children and their families and is strongly focussed on research into the provision of person-centered care for children. Professor Carter's research is narrative, dialogic, appreciative, collaborative, and arts/activity-based in its approach. She works collaboratively with children and their families to ensure that her research resonates with those things that truly matter within their experiences and lives. She finds that framing teaching and research in an appreciative manner can help reveal stories of success and achievement that provide individuals and organizations/settings the confidence to explore new avenues of learning, growth and development. Professor Carter's research has focussed on the lives of children and their families which have become disrupted by pain, illness, disability and disadvantage and in the development of person-centered approaches to their care. She continues to be preoccupied with the development of the knowledge base underpinning person-centered healthcare practice and service delivery, how to address their complex health care needs and the role that children's nurses play in the lives of children, young people and their families. Using narrative and arts-based approaches means that dissemination can become an active process with participants being

able to share their experiences with other people facing similar situations (see for example, the *My Child is in Pain* web resource which has been developed with parents <http://mychildisinpain.org.uk/>).

Professor Carter is Editor-in-Chief of the Journal of Child Health Care, the official journal of the Association of British Paediatric Nurses and she has steered this journal from its foundation into what it is today – a periodical of high international reputation. Professor Carter is also Chairman of the Royal College of Nursing Pain in Children and Young People Community. Professor Carter has been awarded a Fellowship of the Royal College of Nursing in recognition of her reputation as one of the world's most important scholars in the study of how person-centered healthcare can be delivered to children and families.





Senior Vice Presidential Medal For Excellence In Person Centered Healthcare

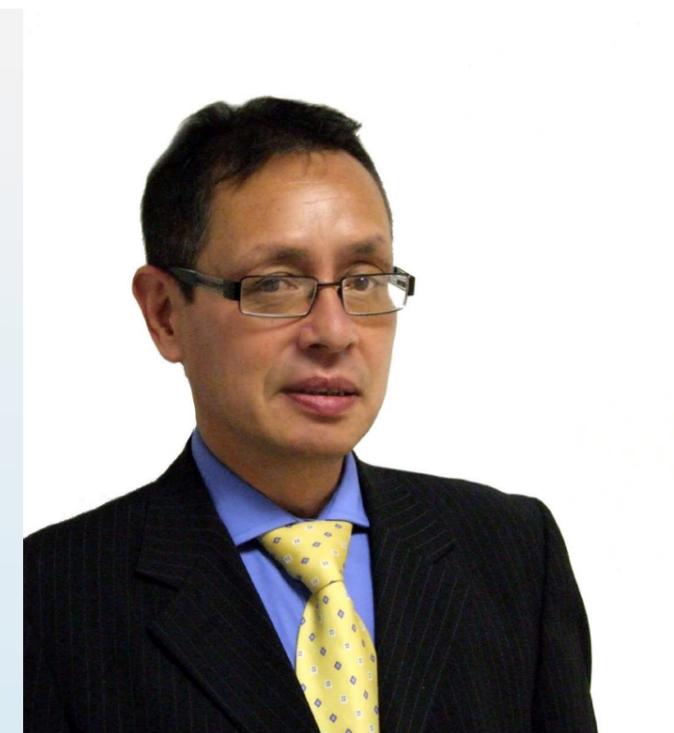
Dr. James A Marcum BSEd MS MATS PhD PhD

Professor, Department of Philosophy & Director, Medical Humanities Program, Baylor University, Texas, United States of America

Dr. James Marcum is an internationally distinguished authority in the philosophy of medicine, having studied the philosophy of science with Thomas Kuhn. Dr. Marcum contributed to the philosophy of science and medicine for over a decade at Harvard Medical School before moving to his current Chair at Baylor University. Dr. Marcum has published major works of signal relevance to person-centered healthcare in an extensive range of scholarly journals including *Synthese*, *Perspectives on Science, History and Philosophy of the Life Sciences*, *Journal of the History of Medicine and Allied Sciences*, *Perspectives in Biology and Medicine*, *Theoretical Medicine and Bioethics* and the *Journal of Evaluation in Clinical Practice*. His recent books 'An Introductory Philosophy of Medicine: Humanizing Modern Medicine' and 'The Virtuous Physician: The Role of Virtue in Medicine', Springer Publications 2008 and 2012 respectively, are major contributions to the global discourse on the philosophy of medicine with direct importance to the development of person-centered healthcare as is his ongoing work on personalist thought in the refinement of the person-centered healthcare thesis. The Senior Vice President of the Society was proud to award the Senior Vice Presidential Medal to Dr. James Marcum.

Dr. James A. Marcum is Professor of Philosophy and Director of 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 and Massachusetts Institute of Technology and a faculty member at Harvard Medical School for over a decade before moving to Baylor University. He received grants from several funding agencies, including the National Institutes of Health, the National Science Foundation, and the 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 delivers invited lectures frequently 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 research interest in the biomedical sciences was in the regulation of homeostasis. Examples of his science papers appear in *American Journal of Physiology, Journal of Biological Chemistry, Journal of Cell Biology, Journal of Clinical Investigations, Biochimica et Biophysica*

Acta, Biochemistry and Biophysical Research Communications, Experimental Cell Research, and Biochemistry. His most recent books are *The Conceptual Foundations of Systems Biology: An Introduction. Systems Biology—Theory, Techniques and Application Series*. x + 155 pp. Hauppauge, NY: Nova Science Publishers, 2009, and *The Virtuous Physician: The Role of Virtue in Medicine. Philosophy and Medicine Series*, volume 114. xiv + 241 pp. New York: Springer, 2012.



European Society For Person Centered Healthcare Platinum Medal

Mr. Steven Rose RN RMN MSc FRSA FCWR
Chief Executive, Choice Support, UK

Mr. Steven Rose has a proven outstanding and long term commitment to the person-centered care of people living with profound learning disabilities, continuously since 1974, and to the measurement of the resulting benefits. He has shown a lifetime of dedication to the person-centered care of people living with challenging learning disabilities and acted indefatigably as the Director of a Charity that has become the largest single supplier of staff to support disabled people in the UK. He has overseen a personalisation programme that has resulted in a significant improvement in the life of adults with learning difficulties via the charity Choice Support. Mr. Rose's personalization programme has replaced a standard level of support funded through a block grant with person-centered care and support organized through person-centered plans and individual service funds. Formal analysis of this scheme has not only demonstrated that it has resulted in an improvement in the lives of people (and their families) with profound learning disabilities, but that it has achieved significant savings in addition. Mr. Rose's efforts have resulted in a new model of care for people with learning disabilities in the UK, with lessons cross-applicable in Europe, based on his sustained vision and leadership.

Mr. Steven Rose has worked with people with learning disabilities for over forty years. He commenced his career in the NHS and was appointed a Director of Nursing at the age of 29. In 1991 after seventeen years in the NHS he was appointed to his current position, Chief Executive of the charity Choice Support. Mr. Rose is a Fellow of the Centre for Welfare Reform, Vice Chair of the Housing & Support Alliance and a Visiting Senior Research Fellow in Learning Disability Research and Policy Development at Buckingham New University. As Chief Executive of Choice Support he has overseen its growth and development from an organisation with 10 employees, and annual turnover of £1 million based in a single London borough to become one of the leading disability charities in the England; employing approximately 2000 staff, including over 400 disabled people, with an annual turnover approaching £40 million, providing support to 1450 people. In 1991 Mr. Rose managed the first large scale externalisation of NHS learning disability services to the voluntary sector from Camberwell and Lewisham Health Authorities and subsequently he led work on the closure of six learning disability hospitals. In 1994 he was appointed by the Chief Nursing Officer for England to co-lead a national project. Choice Support has a long history of innovation; current examples include its contract with the Care Quality Commission to provide 'Experts by Experience' (currently over 450) to support its registration and inspection processes; and being the first organisation in England to convert a £6.5 million block contract to 83

Individual Service Funds (ISFs). Independent research (Better Lives) established that the ISF personalisation project saved the local authority £1.8 million (29% of budget) and demonstrated significant qualitative improvements in people's lives. Steven is widely published in professional journals and book chapters.

Choice Support <http://www.choicesupport.org.uk/> is a pioneering social care charity supporting disabled and disadvantaged people. It was formed in London in 1984 as Southwark Consortium, to support people with learning disabilities to leave long-stay institutions. Now, as well as people with learning disabilities Choice Support provides services for homeless people, and people with autism, mental health needs, physical disabilities and complex health needs.

Choice Support is governed by a voluntary Board of Trustees who bring a wide range of skills and experience to the organisation. The Board includes two members with learning disabilities and a parent carer. Responsibility for the operational management of Choice Support lies with the Senior Management Team, led by Chief Executive Steven Rose MSc, RN(LD), RMN, FRSA, FCWR. When Rose took up his post in 1991 Choice Support employed 10 people, had an annual turnover of £1 million and was based in a single London borough. It is now one of the leading disability charities in the England, employing approximately 2000 staff, including over 400 disabled people. It has an annual turnover approaching £40 million, and provides support to 1450 people.

Writing recently about Choice Support's values, Rose said: "At Choice Support we believe in a fair society where people with disabilities receive the support that they want, to allow them to live as equal contributing citizens. In our experience this is usually achieved by putting people in control of their lives. This means having self-determination, a clear sense of direction, control of money, a home, the right support and being part of a local community. People must also be safe from abuse and exploitation. We achieve this through active partnerships with the people we support, their friends and families. We listen closely to what people say they want and respond accordingly, always upholding their rights. We also believe that it is important to be open to new ideas and to have the courage to put them into practice."

Choice Support has been characterised by innovation since its inception. It was the first consortium of its type, and oversaw the first large scale resettlement programme from a mental handicap institution.

In 1991 when Rose came into post Choice Support piloted individual budgets in Southwark, and is now working with local authorities across the country to hand over budgetary control to the people it supports. The same year it opened some of the first supported living services in the country, which gave people more income and security of tenure by separating support and housing provision. The following year it instigated one of the first service brokerage projects in the country.

Since then the values Rose writes about have continued to find expression in many aspects of Choice Support's work, while influencing the wider social care scene. A quality department, which continually monitors services, includes a team of quality checkers - people with support needs trained to check and assess services. This experience of harnessing the power of personal experience in service monitoring led to Choice Support being awarded a contract to employ, train and manage Experts by Experience for the Care Quality Commission (CQC). Experts by Experience are people with experience of receiving health and social care services, who work with CQC inspectors to monitor all health and social care services across England.

Choice Support continues to seek new ways of making its services more responsive, personalised and effective. It looks to a future when anyone needing care and support can, with the help of their families, friends, advocates and professionals, choose, plan, and purchase the services they want and need. The ESPCH is proud to recognise this scale of achievement through its award of the Platinum Medal of the Society to Mr. Steven Rose.




European Society For Person Centered Healthcare Gold Medal

Professor Jack Dowie MA PhD
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 UK & Chairman, ESPCH SIG on Health Impact Analysis

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. Professor Dowie was a founder member of the Health Economists Study Group and the Society for the Study of Gambling. He recently completed ten years' service as a member of the Appraisals Committee of the then National Institute for Clinical Excellence (NICE). He formally retired in 2003 but remains active in the School and University of Sydney School of Public Health, mainly in connection with his software implementation of Multi-Criteria Decision Analysis. 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. Professor Dowie is responsible for the online postgraduate course on Translational Health in Sydney.

Professor Dowie has made an outstanding contribution to the theory and practice of clinical decision-making and to the advancement of the field of person-centered healthcare. His current work on the development and evaluation of Annalisa, a user-friendly implementation of Multi-Criteria Decision Analysis which he designed in order to facilitate a more equal balancing of intuition and analysis in health decision-making, whether it the community setting of screening, the clinical setting of the doctor-patient consultation or the macropolitical setting of health and non-health sector policies, programmes and projects, has been groundbreaking and is of direct relevance to the advancement of person-centered healthcare. Of equal relevance to person-centered healthcare has been his work in clarifying the ways in which such decision tools should be evaluated and in establishing the principles appropriate for action evaluation (decision-making in medicine or public health), a process very different from those that are appropriate for knowledge evaluation ('science', whether it be biophysical, epidemiological or social). The ESPCH is proud to recognise this scale of achievement through its award of the Gold Medal of the Society.

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





European Society For Person Centered Healthcare Silver Medal

Dr. Nathan Schou Bertelsen BA MD
 Visiting Assistant Professor, Koç University School of Medicine, Istanbul, Turkey, and Assistant Professor of Medicine and Population Health, Bellevue Hospital, New York University School of Medicine, United States of America

Dr. Bertelsen has made a signal contribution to the cultivation and maintenance of empathy as part of medical training via his work 'Empathy in Graduate Medical Education Milestones' and to the person-centered care of people victimized by torture. The ESPCH is proud to recognise Dr. Bertelsen's achievements through its award of the Silver Medal of the Society.

Dr. Nathan Schou Bertelsen MD BA is a clinician educator in internal medicine. He is currently a Visiting Professor at Koç University School of Medicine (KUSOM) in Istanbul, Turkey and Assistant Professor of Medicine and Population Health at Bellevue Hospital / New York University School of Medicine (NYUSOM) in New York City, USA.

Dr. Bertelsen completed residency training in internal medicine at Cornell University/New York Presbyterian Hospital, received his M.D. from University of Minnesota Medical School, and has a B.A. in government/international relations at Georgetown University. At NYUSOM, he directs the Global Health Selective for medical students and Global Health Elective for residents in internal medicine and at KUSOM he organizes the curriculum in bedside teaching and cross-cultural communication. In 2011, he was awarded The Faculty of the Year recognition in the NYU Division of General Internal Medicine and in 2014 he completed the Merrin Master Clinician Bedside Teaching Fellowship Program from the NYU Program for Medical Education Innovations and Research, with his focus on teaching empathy in medical training.



European Society For Person Centered Healthcare Bronze Medal

Dr. Chiung-Jung (Jo) Wu BN MN DrHlthSc RN FACN
 Senior Research Fellow, School of Nursing, Midwifery and Paramedicine, Faculty of Health Sciences, Australian Catholic University, Visiting Fellow, School of Nursing, Queensland University of Technology, Brisbane, Australia, Honorary Research Fellow, Mater Research Institute-University of Queensland, Brisbane, Australia and Honorary Research Fellow, Royal Brisbane and Women's Hospital, Brisbane, Australia

Dr. Wu has made major contributions to the field of self-management for patients with coronary heart/cardiovascular disease and diabetes through technological interventions. She has influenced and led novel research (competitively funded as an individual and in participation with medical and nursing teams), nationally and internationally, to study these issues from inpatient status to home. She has pioneered the implementation of her research (telephone, text messaging, internet technology) in order to develop innovative methods to reduce hospital re-admission and to improve health outcomes. She has developed an efficient, effective, safe, patient-centered and equitable care programme dedicated to the improvement of health outcomes. Her work is cross-applicable to European health systems. The ESPCH is proud to recognise this achievement through its award of the Bronze Medal of the Society.

Dr. Chiung-Jung (Jo) Wu MSc RN DrHlthSc FACN is a Senior Research Fellow, Faculty of Health Sciences, Australian Catholic University (ACU), and has previously held a Research Fellow position, Nursing Academic at the School of Nursing, Queensland University of Technology (QUT). She is also a Fellow of The Australian College of Nursing (FACN), Visiting Fellow with QUT, an Honorary Research Fellow with the Royal Brisbane and Women's Hospital (RBWH), and Mater Research Institute-University of Queensland (MRI-UQ). Dr Wu has over 16 years' clinical working experience in intensive care units/coronary care units and as a diabetes educator in Australia and in Taiwan.

Her doctoral studies emanated from over 16 years' clinical experience in the Coronary Care Unit (CCU) where she observed differences in the progress of cardiac patients with diabetes. Her post-doctoral studies have continued to advance knowledge in the promotion of self-management for patients with coronary heart disease and diabetes. Dr. Wu is currently collaborating with clinicians, national and international researchers towards further studies on promoting self-management incorporating telehealth into the delivery of the program, evaluating different delivery modes and undertaking the intervention in different cultural contexts.

Dr. Wu has been awarded a number of competitive research grants with an approximate value of AUD\$2.1million, has published papers including systematic reviews (quantitative and qualitative) in refereed journals and has presented at several international and national conferences. Dr. Wu is Chair of The Expert Reference Group, Cardiovascular Node (Southern Hemisphere), a reviewer of nursing/behavioural journals, nursing textbook chapters and grant applications,

and an Editorial Board member of The International Nursing Review (Official Journal of the International Council of Nurses).

Dr. Wu has been an accredited supervisor since the completion of her doctoral qualification. She supervises 6 higher degree research students (2 PhDs, 1 Research Masters and 1 Honours student successfully to completion), as well as providing mentorship to less experienced colleagues and clinical staff in undertaking research.





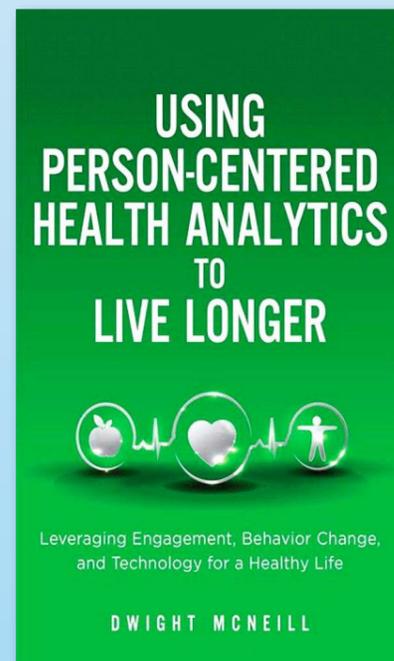
European Society For Person Centered Healthcare Book Prize

Dr. Dwight McNeill MPH PhD

Instructor of Health Policy and Population Health, Suffolk University, Boston, Massachusetts, United States of America

Assistant Commissioner for Health Data and Analytics for the Division of Health Care Finance and Health Policy of the Department of Health and Human Services, McNeill helped bring an analytic focus to healthcare reform in Massachusetts. At the Agency for Healthcare Research and Quality, McNeill helped translate research to action and promoted the importance of performance measurement and national priorities at the National Quality Forum.

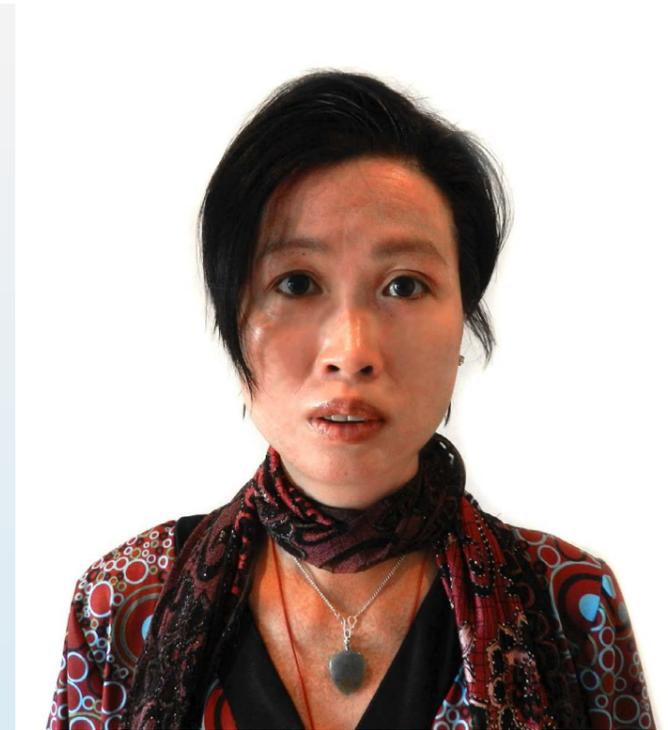
Dr. McNeill has published numerous articles in Health Affairs and other prestigious journals. He is the author of three books on health analytics. His latest is "Using Person-Centered Health Analytics to Live Longer: Leveraging Engagement, Behavior Change, and Technology for a Healthy Life", the subject of the essay prize. His other books on health and healthcare analytics include: "A Framework for Applying Analytics in Healthcare: What Can be Learned from the Best Practices in Retail, Banking, Politics and Sports" and "Analytics in Healthcare and the Life Sciences: Strategies, Implementation Methods, and Best Practices".



Dr. McNeill's book is extremely timely. While the United States continues to argue about whether and how to provide all of its citizens with health insurance and how to contain the high costs of healthcare, it has lost sight of the purpose of it all. The purpose of the vast \$USD 2.8 trillion health care industry, the most expensive by far of all countries in the world, is to produce better health for all Americans. Dr. McNeill's book shows that this is failing and is getting worse, with the Nation spending much more time worrying about saving dollars than about saving lives. Dollars, as McNeill's book points out, are far easier to measure, so that even the value of a life is measured in these terms. At its best, the health system is about getting more value for money spent, but the achievement of better quality and outcomes through known approaches is typically not attempted because either it costs too much, is not rewarded financially, or is hard to accomplish successfully. Dr. McNeill emphasizes that despite the well-intentioned actions of governments, life sciences and technology, the most important resource for achieving our full health potential is ourselves. Dr. McNeill's book is about how people themselves can achieve better health and how others can help them to do this. Dr. McNeill introduces person-centered health analytics (pcha) and shows how it can be used to master five everyday behaviours that cause and perpetuate most chronic diseases. Dr. McNeill's book provides a detailed insight into these issues and offers the reader a comprehensive framework and practical tools for living longer and healthier lives. His book provides a clear path forward for both individuals and stakeholders, including providers, payers, health promotion companies, technology innovators, government and analytics practitioners. The ESPCH is proud to recognize Dr. McNeill's work through the award of the Society's Essay Prize.

Dr. Dwight McNeill is a teacher, author, and consultant. He is a Lecturer in the Healthcare Administration Program at the Sawyer Business School, Suffolk University, Boston, USA, where he teaches courses in population health and health policy. McNeill, who has a PhD (Brandeis University) in Health and Social Policy, as well as a MPH (Yale University) in Epidemiology and Public Health, specializes in advanced analytics that support population health, person centered health, and healthcare transformation.

Over his 30-year career, he has worked in corporate settings and state levels; analytics companies and provider settings. McNeill has extensive experience working in such corporate settings, most recently as the global leader for business analytics and optimization for the healthcare industry for the IBM Corporation, and previously as Director of Healthcare Information at GTE Corporation (Verizon). As the former



European Society for Person Centered Healthcare Essay Prize

Dr. Sandro Tsang PhD

Senior Postdoctoral Visiting Fellow, University of Nottingham & Tutor at the Peoples Open Access Education Initiative, Manchester, UK

Tsang S. Arrow physicians: Are economics and medicine philosophically incompatible?. *Journal of Evaluation in Clinical Practice*. 2015 June; 21(3): 419-426 (<http://onlinelibrary.wiley.com/doi/10.1111/jep.2015.21.issue-3/issuetoc>)

Dr. Tsang's recent Essay directly challenges the claim that economics and medicine are philosophically incompatible disciplines, by drawing on the ideas of economist Kenneth Arrow who considered the relationship between trust, reciprocity and the efficient use of communal resources. Tsang uses the term 'Arrow Physicians' to characterize "a humanistic carer who has concern for the patient and acts on the best available evidence with health equity in mind". Dr. Tsang's Essay contributes valuably to person-centered healthcare in arguing for an interdisciplinary approach which strongly contends that the application of economics to medicine can actually help to humanize, rather than de-humanize, the medical encounter. Tsang's thinking, set out in this Essay, argues that Arrow Physicians are entirely communitarian in approach, but with a thorough and profound concern for the individual in front of the clinician. The ESPCH is proud to recognize the importance of Dr. Tsang's Essay through the award of the Society's Essay Prize.

Dr. Sandro Tsang PhD has been trained as an Economist. She was awarded a PhD in Empirical Economics (Management) by the University of Granada, Spain, in 2011. She was also awarded an MSc in Economics from the University of Surrey and a PgDip in Financial Economics and a BSc in Economics from the University of London. Her research focus has been on medical decision-making both in general or specific contexts such as eHealth and antibiotic prescription decisions. In 2011, she was introduced to epistemology research by Professor Michael Loughlin of Manchester Metropolitan University. Since then, she has been conducting research related to the ethics of medical practice. So far, she has published five sole-author papers, and co-authored two papers with Dr. John Lane, a former academic of London School of Economics. Her publications include mathematical modelling, statistical modelling and applied epistemology. The results have implications for deriving practicable policies. She is a postdoctoral research associate at the Chinese University of Hong Kong and involved in several government projects. She spends her spare time on volunteer tutoring for the People's Open Access Education Initiative (PU). She delivers health economics and academic writing skills to MAster's students, and is an examiner and advisor of dissertations for the Master's Degree of public health at PU. She is currently a senior postdoctoral visiting fellow at The University of Nottingham, and is working with a trans-disciplinary team to study

clinical decision-making for influenza-like illness. She has introduced epistemology elements into the research. She is also involved in analysing the qualitative data from individual clinician interviews by applying fuzzy clustering analysis to fully explore the potential of qualitative data. The results will have implications for deriving policies related to influenza pandemic preparedness and response as well as facilitating the understanding of antimicrobial prescribing behaviours.



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE INAUGURAL POSTGRADUATE MASTER'S DEGREE STUDENTSHIPS

The ESPCH studentships were advertised on-line, with multiple applicants applying for the studentship and six students shortlisted in accordance with the collaborating university's policies. Three were selected and the Society is proud to welcome these first postgraduate students to its membership and mission.



Manchester
Metropolitan
University

Cheshire Research Studentships

The academic supervisor of these two theses:
Professor Michael Loughlin
Chairman of the ESPCH SIG on Health Philosophy



Dr. Derek Mitchell BA(Hons)(Oxon) MA(UKC) PhD(UKC) PGDipHCE(Kings, London) PhD

One student, with an outstanding background in applied philosophy, Dr. Derek Mitchell, was selected as the first winner of this Award. The title of the approved thesis is as follows: "Putting Phenomenology into Practice - Towards an Epistemology of Person Centred Healthcare." Dr. Mitchell will use a Heideggerian/Havi Carel phenomenological type of approach, employing some of Gadamer's hermeneutic thinking in order to develop a philosophical ground or justification for person-centred healthcare. The Society is proud to welcome Dr. Mitchell as its first postgraduate student.

Dr. Derek Mitchell first studied philosophy at Oxford and subsequently at the University of Kent and King's College, London. He began work in the Health Service in 1986 and combined a successful career as a manager in every aspect of primary care, with a part-time academic career teaching and writing mainly within the Health Service, including workshops covering ethical topics for General Practice postgraduate work and Registrar training. As a manager Dr. Mitchell undertook groundbreaking work in primary care clinical effectiveness and clinical governance which led to the development of the Quality and Outcomes Framework for United Kingdom General Practice in 2003. Dr. Mitchell retired from the Health Service in 2004 due to a serious chronic illness. Following retirement he continued to teach and write philosophy as much as was permitted by his illness and, after surgery in 2009, now spends his time doing sessional teaching in philosophy and other work in support of the Health Service. Dr. Mitchell teaches philosophy for the Workers Educational Association, Canterbury Christchurch University in Kent, and privately. He also works as a volunteer patient representative for stoma patients with the Health Service in East Kent. Dr. Mitchell was the chairman of the East Kent Hospitals Trust Patient and Public Advisory Forum from October 2012 to March 2014.

Dr. Mitchell's first book "Heidegger's Philosophy and Theories of the Self" was published in 2001 and his second "Everyday Phenomenology" in 2012. He has also had work published on evidence based medicine and person centered healthcare. Apart from philosophy He enjoys recreational cycling and growing prize winning flowers, fruit and vegetables.

Dr. Leila Eccles BSc(Hons) MCouns DClinPsy

Dr. Eccles was selected as the winner of the second studentship. The working title for her thesis is: "A critical examination of the conceptual foundations of person-centred healthcare and the development of a distinctive philosophy of PCH, to support the progress of mental health practice in this area." Leila plans to explore what we know about PCH, how we apply it and whether the aspirations of its application are even possible in a setting dominated by evidence-based medicine. Her work has convinced her both of the need for a 'formulation driven' approach to mental health - starting with the person, her/his specific experiences of their current difficulties, considering their attachment styles from being a child to the present day, their life experiences, relationships, education, job roles - and of the constraints upon applying such an approach in practice. In current mental health settings, the pressure is to adopt a diagnostic-driven approach, with associated risks of losing the complex and unique reality of the person within diagnostic categories. A key goal of the research is to use philosophical methods to critique and develop current ways of working and informing policy.

Dr. Leila Eccles works as a Senior Clinical Psychologist in Advanced Care and Dementia in patients at The Harbour in Blackpool for Lancashire Care NHS Foundation Trust. Leila gained her Doctorate from The University of Liverpool and has since worked in the Community and in patients with older adults. She also holds a Master's Degree in Counselling Studies from The University of Manchester. Leila is an experienced clinician and researcher, with previous studies including "Improving the psychological wellbeing of older adults", and "Approach and avoidance goals in depression and anxiety".

choicesupport
make life more interesting

University of
Kent
Tizard
Centre

The academic supervisor of this project:
Professor Roger Ellis OBE
Chairman ESPCH SIG for Learning Difficulties



Ms. Juli Carson

The European Society for Person Centered Healthcare is delighted to announce its collaboration with Choice Support, the leading British Charity for the care of people living with learning disabilities, in the support of this postgraduate studentship at the University of Kent UK, at which Ms. Carson is completing the MA in Intellectual and Developmental Disabilities. The course is operated by the Tizard Centre which specialises in Learning Disabilities and is based at the University of Kent in Canterbury, England. This programme aims to provide graduates with detailed knowledge of intellectual and developmental disabilities and experience of conducting research in this field. Candidates will acquire knowledge and understanding of:

- Definitions and epidemiology of intellectual disability
- Cognitive, communicative and social characteristics of people with intellectual disabilities
- Biological, social and environmental causes of intellectual disability
- Behaviour analysis
- Challenging behaviour and other special needs
- Ideology, policy and service development
- Definition and measurement of service quality
- Relationships between service organisation and quality
- Research methodology

Ms. Juli Carson has worked in the Social Care field for 23 years. For the last 20 years her focus has been on managing and developing new services for people with learning disabilities and challenging behaviour. Recently, she had taken on the new challenge of creating behavioural interventions and support plans for people that challenge services. Her other roles have included managing the closure of campus provision for people with learning disabilities in the South London area and supporting the closure of the last long stay hospital in England.

Ms. Carson joined Choice Support in 2007 as an Area Manager and created a process of replacing night wake provision in services with Sleep-ins in Southwark. She was also part of the team that facilitated the division of an existing large block contract to create ISF's for many individuals. In 2013, she won the Best Front Line Leader Category in the Great British Care Awards.



THE CONFERENCE DINNER

CONFERENCE DINNER

Note

The European Society For Person Centered Healthcare and the University of Francisco de Vitoria welcome their guests to the Conference Dinner. The President will make a brief Address and an act of thanksgiving when the first plates have been laid.

Primer Plato

(First Course)

Ensalada de queso de cabra con nueces
(Goat's cheese salad with walnuts)

Served with Nuviana Chardonnay, Vino de la Tierra Valle del Cinca, Aragón, Spain.

Segundo Plato

(Second Course)

Dados de salmón al vino blanco con patatas duquesa
(Cubes of salmon in white wine served with duchess potatoes)

Served with Verdejo Legaris de Rueda, Castilla y León, Spain

Postre

(Dessert)

Tarta de manzana con helado
(Apple tart with ice cream)

Served with Moscatel Lágrimas de Jabalón from Valencia, Spain

Café y bombones
(Coffee with digestive and chocolates)

Served with Cognac Torres 10 from the Penedés Region of Spain

Close and transport to central Madrid



THE INAUGURAL MEETING OF THE COUNCIL OF THE SOCIETY – 19 JUNE 2015

**Opening of the Inaugural Meeting of Council**

The Inaugural Meeting of the Council of the Society was held in the Professorial Suite of Francisco de Vitoria University, Madrid, Spain on Friday 19 June 2015, shortly following the Close of Day Two of the Second Annual Conference and Awards Ceremony of the Society.

Professor Sir Jonathan Asbridge DSc (*hc*), President of the Society, acting as Chairman of Council, called the meeting to order and welcomed those present to the inaugural meeting of Council. The Council, Sir Jonathan said, should function as the Governing Body of the Society. Current Council membership, he noted, was constituted by all of the chairmen of the Special Interest Groups (SIGs) of the Society. Given that there were already over 30 of these and given that their numbers would rise to over 80 as SIG chairs were appointed over the remaining course of 2015 and during 2016, the Society would need, Sir Jonathan said, for reasons of streamlined decision-making, to move in his view towards a more nuclear Council Membership. Such a membership, limited to perhaps 25 colleagues derived from the Society's active geographical regions, would comprise colleagues elected from among the chairmen of the SIG Network and would also include a limited number of appointed members and observers. Elected Members from the SIG Network and Appointed Members (e.g. colleagues from key collaborating institutions of the Society and also from the Society's rapidly growing ordinary membership) would be entitled to vote and the majority of decisions would be agreed by simple consensus. The Council's remit, Sir Jonathan said, would be necessarily wide and fully democratic.

Given the worldwide location of the SIG chairmen and the pressures of everyday institutional work and responsibilities, Sir Jonathan said that he envisaged that the Council would meet ordinarily on an annual basis, usually following the Annual Conference and Awards Ceremony of the Society, but with the flexibility to call an extraordinary meeting whenever such a meeting was judged essential. In the interim, a properly constituted Management Board would be created, meeting quarterly, either in Madrid or in London, with minutes from such meetings being made available to all duly elected Council Members. Such Council Members would have the usual right to comment and/or express any concerns and ideas after having studied such minutes and feed these back

to the Society Executive. Council would also, Sir Jonathan said, examine matters of concern to the wider fellowship that were communicated to it, enabling a proper response. It was a *sine qua non*, Sir Jonathan confirmed, that the Council would ensure that the Society operated in accordance with the highest professional and ethical standards.

**Agendum for the First Meeting of Council**

Sir Jonathan informed Council that he had judged that its first meeting should not follow an *Agendum* that had been pre-determined by the Executive, but rather that those Council Members present should assist him in co-creating, as it were, the focusses of discussion for the inaugural meeting. Thus, Sir Jonathan asked members to advance a range of items for discussion to form the basis of the subsequent proceedings. Individual members duly provided their thoughts and Sir Jonathan noted these for subsequent discussion using a flipchart. The perspectives generated



were academic, clinical and also geopolitical in their nature, with valuable advice being given by the Council Members present, deriving, as they did, from five Continents.



The Entitling of the Society

The first issue advanced for discussion was the name of the Society. Many members articulated their concern with the prefix 'European', which they felt was descriptively inaccurate and potentially exclusionary. They pointed to the fact that the greatest number of speakers at the Society's First and especially Second Annual Conference were from non-European countries as were the chairmen of the rapidly growing Special Interest Group Network. A continued use of the prefix 'European', it was argued, would continue such descriptive inaccuracy and potential exclusion and would be likely to limit, rather than advance, the Society's overall mission. Sir Jonathan invited Professor Miles, Senior Vice President and Secretary General of the Society, to address Council on this matter.

Professor Miles confirmed that the initial entitling of the Society had been the result of the mid-2013 discussions on whether a new institution should be created to add to the work of a plethora of bodies already working in the field and, if so, what should be the character, aims and scope of such a new institution. When it had been decided, following a range of key consultative meetings in London, that a new institution with highly specific aims and scope would benefit, rather than disadvantage, the progress of the field, the geographical prefix 'European' had been adopted in the naming of the new Society as a 'first step' in defining the remit of the new Society. Professor Miles confirmed that the invitation of a wide range of non-European colleagues to the work of the Society over the last two years had been envisaged as a means of harnessing their non-European expertise for the specific purpose of advancing the development of person-centered healthcare within European countries and that it had been imagined that such colleagues would be prepared to act and contribute in this way and in a sustained fashion. Professor Miles conceded, however, that in reality the reverse had proved the case, with many non-European colleagues having written to the Society strongly advocating a change in appellation to symbolize, as well as operationally enable, a complete inclusivity.

Noting the same, Sir Jonathan counselled against any immediate changes in advance of a wider consultation with Society members than those present at the Council meeting and asked members present whether they would collectively assent to retain the prefix 'European' until a wider consultation on its use or otherwise could be conducted. Such a consultation could take place in advance of the next meeting of

Council in 2016 and changes agreed with Council prior to or at the next Council meeting itself. Those present agreed with Sir Jonathan's thinking and it was decided by Council to retain the prefix 'European' pending a wider consultation on the implications of retaining, detaching or replacing the 'European' prefix.

Special Interest Group Network of the Society

The second issue advanced for discussion was the role and function of the Society's Special Interest Group (SIG) Network, with members present asking for a clarification of the role of the Society's SIGs. Sir Jonathan asked Professor Miles to address Council on this matter.

Professor Miles pointed out that the role of the SIGs had been set out within a paper published on the Society within the 20th Anniversary Issue of the Journal of Evaluation in Clinical Practice [1]. Basically, the SIGs are, Professor Miles explained, the 'intellectual powerhouses' of the Society', currently numbering over 83 and spanning an extensive range of clinical, academic, managerial, policy and political areas of study of direct and immediate relevance to the advancement of PCH. Although each SIG is focused on a highly specific area of study, Professor Miles explained, each one engages, as appropriate, in cross working with other SIGs in a classical interdisciplinary manner.

Professor Miles confirmed that the chairmen of the Society SIGs had a very great degree of autonomy to organize and energize their SIG within the broad remits and aims and scope of the Society. The Society made only one initial request of SIG chairmen: that they invest their first efforts into the production of a clinical or academic handbook (depending on the nature of study of the given SIG) which, once published, could be updated every one or perhaps two years, depending on the rate of progress in the given field). Here, Clinical SIGs would engage in the development a clinical handbook that is specifically designed to provide a practical guide for clinician education in the person-centered care of the given condition, acting also to assist patient education, literacy and empowerment and thus to foster shared decision-making between clinician and patient. Academic SIGs would engage in the development of an academic handbook that represented a concise state-of-the-art account of the thinking and progress in the relevant field of learning. Handbooks would typically be multi-authored, and edited by the chairman of the given SIG, co-opting, as appropriate, other co-editors to the production and editing tasks. The legal contracts for these publications had already been signed with the Publisher.

Reflecting on the number and designations of the Society SIGs, one member of Council expressed his concern that the proliferation of many single disease-specific SIGs, among the other multi-disciplinary SIGs, risked a codification of the reductionism in modern healthcare that PCH was generally seen to oppose, given that co- and multi-morbid, socially complex illnesses, were the defining challenges for modern healthcare systems and societies. Sir Jonathan asked Professor Miles to respond to this expressed concern. Professor Miles explained that, at its inception, the Society had an option. The Society could create one 'mega', multi-specialty, multi-disciplinary SIG with an essentially 'impossible' remit to consider every possible disease or illness in combination with every other possible diseases or illnesses. Or it could create a given number of highly specific SIGs via a demarcation of principal diagnoses (which may indeed be complicated by a secondary or multiple pathologies), but where the principal diagnosis represented the major concern of the patient and/or his or her attending physician(s). Members of Council acknowledged the validity of this approach, but suggested that SIGs should contain, in their entitling, the words 'the person with' and not simply be entitling with the name of the disease or illness entity. Many of the members of Council present were also chairmen of given SIGs and Professor Miles confirmed that *Notes of Guidance for SIG Chairmen* would be circulated to existing and new SIG chairmen in due course to facilitate SIG functioning.

Governance of the Society

Sir Jonathan, addressing Council, emphasized that an effective Society would need an effective governance and that a draft of a **Constitution**

and Terms of Reference for the Society was currently being progressed. The draft would be completed in due course and subsequently circulated to Council Members. This would be accompanied by the draft **10 Year Strategic Plan of the Society** which would set out the Society's ambitions and activities and their associated timings/deadlines and against which the Society's ongoing progress could be measured and assessed.

Communications and Public Relations Strategy of the Society

Sir Jonathan confirmed to Council that the writing of a formal Society **Communications and Public Relations Strategy** had commenced. The Society already communicated via its official journal, the European Society for Person Centered Healthcare and a major Newsletter was also in the final stages of launch, named the e-Bulletin of the European Society for Person Centered Healthcare. These two methods of communication, published quarterly, differed in nature and purpose, but sat well alongside each other. The Society had also created a Facebook account, a Twitter Account and a YouTube account. The **Communications and Public Relations Strategy** would include all of these initiatives and more and would be factored into the **10 Year Strategic Plan of the Society**. Council strongly endorsed the need for such actions of governance.

Society Website

The official website of the Society was discussed. Council Members believed that there was a need to develop the website and to create a platform within it to host the working community of SIG chairmen and the Society's rapidly growing membership. Professor Miles confirmed that this was in hand and that this was yet another item for inclusion in the **10 Year Strategic Plan of the Society**.

Close of the Inaugural Meeting of Council of the Society

Following the conclusion of discussions and interchange, and with no other business arising, Sir Jonathan thanked Council Members present for their time in attending the meeting and in contributing so much valuable advice. He looked forward, he said, to remaining actively in contact with Council Members during the intervening year, until Council met for its second meeting in 2016. The Society had much to achieve, Sir Jonathan said, but he was more than confident that the dedication and enthusiasm he had seen during the Conference itself and indeed at the Council Meeting, was more than sufficient to allow the Society to move forward swiftly in the pursuit of its aims.

Sir Jonathan then provided a Concluding Summary of the Inaugural Meeting of Council. Sir Jonathan said he was delighted that so many questions had been raised and so much discussion generated. This was, he said, a sure sign of dynamic growth within a new and inclusive democratic body of scholars, clinicians and others. This characteristic had classically underpinned the success enjoyed by so many well established clinical and academic associations within global healthcare. More discussion, more ideas, more argument, not less, Sir Jonathan asserted, was to be actively encouraged, representing real signs of an organisation fully alive and fully thriving. Yet discipline too, Sir Jonathan said, was necessary, and he strongly advocated the importance of the **10 Year Strategic Plan of the Society** in this context and the need for SIGs to collaborate with one another, when and where appropriate, to create and sustain a solid academic infrastructure.

Sir Jonathan stressed that the work of the Society, if it were to be successful and achieve the necessary impacts, would not be easy. There were many pressures within international health systems that militated against a person-centered approach in favour of a technocratic, conveyor belt, factory style processing of healthcare users/clients/consumers within a quasi-industrialized setting that was, by its nature, doomed ultimately to fail, leaving clinicians to pick up the pieces. Rigorous efforts now, by clinicians and other advocates of patients, including the voices of patients themselves, would be vital to encourage politicians and policymakers and some clinicians, particularly within secondary and

tertiary healthcare settings, of the vital necessity of a person-centered healthcare environment.

Following these comments, Professor Sir Jonathan Asbridge DSc (hc), President and Chairman of Council of the Society, formally declared the inaugural Council Meeting closed.

Reception

A cava reception followed the close of the Council Meeting at which Council Members were able to interact and discuss Council Proceedings and Next Steps.

Reference

[1] Miles, A., & Asbridge, J. E. (2014). *The European Society for Person Centered Healthcare (ESPCH) – raising the bar of health care quality in the Century of the Patient. Journal of Evaluation in Clinical Practice 20* 729–733.



ESPCH APPOINTMENTS

Officers of the European Society for Person Centered Healthcare



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



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

Regional Vice Presidents



Vice President (Northern Europe)
Professor Linn Okkenhaug Getz
MD PhD



Vice President (Southern Europe)
Dr. Marco Bregni
MD

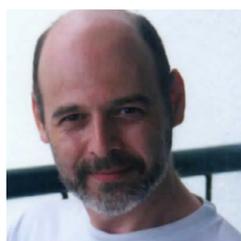


Vice President (Western Europe)
Dr. Thomas Fröhlich
MD PhD



Vice President (Eastern Europe)
Professor Drozdstoj St. Stoyanov
MD PhD

Logistic Officers



Senior Production Editor of the *European Journal for Person Centered Healthcare* & Director of Finance and Operations at the European Society For Person Centered Healthcare
Mr. Andrew Williamson



Senior Project Manager at the European Society for Person Centered Healthcare & Senior Production Editor of the e-Bulletin
Dr. Vivian Mounir

ESPCH APPOINTMENTS

The Special Interest Group (SIGs) Network of the Society

The SIGs have been designed to enable the rapid advancement of research, scholarship and teaching in the specific field of study.

The following are the current chairmen of the SIGs Network.

Applications are welcomed for the Chairmanships of the SIG Network and more information is available at the following link [<click>](#)

To apply for a Chairmanship of a Society SIG [<click>](#)

Special Interest Group on Bioethics and PCH



Professor Gonzalo Miranda
Professor and Dean of Bioethics, Pontifical Athenaeum 'Regina Apostolorum', Rome, Italy

Special Interest Group on Burnout Syndrome and PCH for Patients and Professionals



Professor Drozdstoj St. Stoyanov
Professor of Psychiatry, Medical Psychology and Person-centered Medicine, Faculty of Medicine, Medical University of Plovdiv, Bulgaria

Special Interest Group on Case-based Decision-Making and PCH



Dr. Mark Tonelli
Professor of Medicine, University of Washington, Seattle, USA

Special Interest Group on Child and Family-Centered Care



Professor Linda Shields
Professor of Nursing, James Cook University, Townsville, Queensland, Australia

Special Interest Group on Communication and Communication Skills for PCH



Dr. Roger Ruiz Moral
Professor of Medicine and Medical Education, Universidad Francisco de Vitoria, Madrid, Spain

Special Interest Group on Complexity Theory, Non-Linearity and PCH (Co-chairmen)



Dr. Carmel Martin
Associate Professor of General Practice, Menzies University, Australia

Special Interest Group on Clinical Pharmacy



Professor Amanda Wheeler
Registered Pharmacist and Professor of Mental Health, Deputy Director of Population and Social Health Research Program, Menzies Health Institute Queensland, School of Human Services at Griffith University, Australia



Dr. Joachim Sturmberg
Associate Professor of General Practice, Monash University, Australia

Special Interest Group on Traditional, Complementary and Alternative Medicine



Professor Paolo Roberti di Sarsina
Specialist in Psychiatry & President, Charity for Person Centered Medicine (Moral Entity), Bologna, Italy & Member, Observatory and Methods for Health & Coordinator Master's Course "Health Systems, Traditional and Non-Conventional Medicine, University of Milano-Biocca, Milano, Italy

Special Interest Group on Evidence-based Medicine, Patient-centered Care and PCM (Co-chairmen)



Dr. Peter Wyer
Associate Clinical Professor of Medicine, Columbia University, New York and Chairman, Section on Evidence-based Healthcare, New York Academy of Medicine, USA

Special Interest Group on PCH of Drug and Alcohol Addiction



Professor Michael Musalek
President, European Society on Treatment of Alcohol Dependence and Related Disorders, Chairman, EPA Section of Psychopathology & Vice-chairman, WPA Section for Clinical Psychopathology, Anton Proksch Institute, University of Vienna, Austria.



Dr. Suzana Alvez de Silva
Consultant Cardiologist, Federal University of Rio de Janeiro, Brazil, Co-ordinator, Brazilian Workshop of Evidence-based Practice for Decision-Making

Special Interest Group on Health Philosophy (General) and PCH



Professor Michael Loughlin
Professor of Applied Philosophy, Manchester Metropolitan University, UK, & Guest Editor, Annual Philosophy Thematic Edition of the Journal of Evaluation in Clinical Practice

Special Interest Group on Epistemology and Ontology of PCH



Professor Lin Getz
Professor in Biopsychosocial Medicine, General Practice Research Unit, Department of Public Health and General Practice, Norwegian University of Science and Technology, Trondheim, Norway

Special Interest Group on Health Politics, Policy and PCH



Dr. Sandra Tanenbaum
Professor of Health Policy, College of Public Health, Ohio State University, USA

Special Interest Group on Health Impact Analysis



Professor Jack Dowie
Emeritus Professor of Health Impact Analysis, London School of Hygiene and Tropical Medicine, London, UK

Special Interest Group on Medical Humanities and PCH



Dr. Stephen Post
Director, Centre for Medical Humanities, Compassionate Care and Bioethics, Stony Brook University, New York, USA

Special Interest Group on Mental Health (General Considerations) (Co-chairmen)



Professor Abraham (Rami) Rudnick
Professor in the Department of Psychiatry and Behavioural Neurosciences and an Associate Member in the Department of Philosophy at McMaster University, Psychiatrist-in-Chief and Staff Psychiatrist at St Joseph's Healthcare Hamilton, Ontario, Canada, Senior Editor of the Canadian Journal of Community Mental Health



Dr. Wilma Boevink
Senior Researcher at the User Research Center at Maastricht University, The Netherlands, Social Scientist and Experiential Expert in Psychiatry at Trimbos-Institute (The Netherlands Institute for Mental Health and Addiction), Utrecht, The Netherlands

Special Interest Group on Person Centered Healthcare for People Living with HIV/AIDS (+/- HCV/HBV)



Ms. Michelle Croston
Senior Lecturer and HIV Specialist Nurse, Department of Nursing, Manchester Metropolitan University, UK

Special Interest Group on Neurophenomenology



Dr. Hillel D. Braude
Director of Research at the Mifne Center (Early Intervention and Treatment of Autism for the Infant and the Family), Israel, Research Affiliate, Religious Studies Faculty, McGill University, Montreal, Canada

Special Interest Group on PCH for Learning Difficulties



Professor Roger Ellis OBE
Director, Social and Health Evaluation Unit & Emeritus Professor of Psychology, Universities of Chester and Ulster, UK

Special Interest Group on Patient Behavioural Studies



Mr. Kevin Dolgin
Associate Professor, University of Paris, France & President 'Observa', Paris, France

Special Interest Group on Health Technologies Assessment in PCH



Dr. Carlos Martín Saborido
Director, Health Technology Assessment Unit, Faculty of Medicine, Francisco de Vitoria University, Madrid, Spain

Special Interest Group on Health Disparities and Under-served Populations



Dr. John McKinlay
Senior Vice President of the New England Research Institutes (NERI) & Co-Director, NERI Health Services and Disparities Research Unit, Massachusetts, USA

Special Interest Group on Shared Clinical Decision-Making for PCH



Professor Alan Cribb
Centre for Public Policy Research, Department of Education and Professional Studies, King's College, University of London, UK

Special Interest Group on People-Centered Public Health and PCH



Professor Gualtiero Walter Ricciardi
Vice Dean, Faculty of Medicine and Professor of Public Health, National Catholic University of Italy at the Policlinico Gemelli Rome, Italy & President, European Public Health Association, Utrecht, The Netherlands

Special Interest Group on Postgraduate Medical and Clinical Training for PCH



Professor Ed Piele
Professor Emeritus of Medical Education, University of Warwick UK, Visiting Research Professor, School of Medicine, Dentistry and Biomedical Sciences, Queen's University Belfast Northern Ireland & Inaugural Ronald Harden Visiting Professor, International Medical University, Malaysia, Editor-in-Chief, Education for Primary Care.

Special Interest Group on Lesser Heard Groups



Dr. Michelle Pyer
Senior Researcher in the Institute of Health and Wellbeing at the University of Northampton, UK

Special Interest Group on Chronic Illness and PCH (General Considerations)



Dr. Ross Upshur
Canada Research Chair in Primary Care Research, Professor, Department of Family and Community Medicine and Dalla Lana School of Public Health, University of Toronto, Canada

Special Interest Group on Personalized (Translational) Medicine



Professor Emanuela Signori
Lead, Laboratory of Molecular Pathology and Experimental Oncology, National Research Council of Italy Institute of Translational Pharmacology & Professor of Pathology, Università Campus Biomedico, Rome, Italy

Special Interest Group on Undergraduate Medical and Clinical Education for PCH



Dr. Fernando Caballero
Director of Medicine, Francisco de Vitoria University, Madrid, Spain

Special Interest Group on Personhood and The Dynamics of Healing Relationships in PCH



Professor Brian Broom
Consultant Physician (Clinical Immunology), Department of Immunology, Auckland City Hospital and Adjunct Professor, Department of Psychotherapy, Auckland University of Technology, New Zealand

Special Interest Group on Chronic Illness: PCH and Dementia



Professor Claire Surr
Professor of Dementia Studies, Leeds Beckett University, Leeds, UK

Special Interest Group on Person-Centered Health Records



Dr. Rajeev Chaudhry
Associate Professor of Medicine, Mayo Clinic, Rochester, Minnesota, USA

Special Interest Group on Research Methods for PCH



Dr. Stephen Buetow
Associate Professor and Director of Research, Department of General Practice and Primary Health Care, University of Auckland, New Zealand

Special Interest Group on Spiritual and Religious Care



Dr. Christina Puchalski
Director, Institute for Spirituality and Health & Professor of Medicine and Health Sciences, George Washington University, Washington DC, USA

Special Interest Group on Chronic Illness: PCH, Diabetes and Nutrition



Professor Paolo Pozzilli
Professor of Diabetes and Clinical Research, Centre for Diabetes and Metabolic Medicine, Institute of Cell and Molecular Science, Bart's and The London School of Medicine and Dentistry, London & Professor of Endocrinology and Metabolic Diseases, Università Campus Biomedico, Rome, Italy

ESPCH APPOINTMENTS

Recent Membership Appointments



Professor Abraham (Rami) Rudnick BMedSc MD MPsych PhD CPRP FRCPC CCPE
Elected Distinguished Fellow of the ESPCH and appointed Co-Chairman of the S.I.G on Mental Health

Dr. Abraham (Rami) Rudnick is a certified psychiatrist and a PhD-trained philosopher. He is a Professor in the Department of Psychiatry and Behavioural Neurosciences and an Associate Member in the Department of Philosophy at McMaster University. He is the Psychiatrist-in-Chief as well as a staff psychiatrist at St Joseph's Healthcare Hamilton, Ontario, Canada. He is an Adjunct Professor at Royal Roads University in Victoria, British Columbia, Canada, and an Adjunct Research Professor at the Arthur Labatt Family School of Nursing in the Faculty of Health Sciences and a member of the Rotman Institute of Philosophy, both at Western University in London, Ontario, Canada. He is a Canadian Certified Physician Executive and a Certified Psychiatric Rehabilitation Practitioner. He is a Senior Editor of the Canadian Journal of Community Mental Health. He is the founder of the Canadian Unit of the International Network of a UNESCO Chair in Bioethics, and the recipient of a national pioneer award in recovery research granted by Psychosocial Rehabilitation (PSR) /Readaptation Psychosociale (RPS) Canada. One of his main foci of interest is person-centered care for people with mental illness, on which he has published many papers, chapters and books, and presented and taught across the world, as well as led and provided consultation for service development and quality improvement initiatives.



Professor Amanda Wheeler PhD PG Cert Public Health (Effective Practice) PGDip (Psych Pharm) BPharm BSc (Biochem)
Elected Distinguished Fellow of the ESPCH and appointed Chairman to S.I.G on Clinical Pharmacy

Amanda Wheeler is Professor of Mental Health at Griffith University. She is a registered pharmacist who has worked as a health practitioner, educator and researcher in mental health and pharmacy practice for almost 20 years. She is nationally and internationally recognised for her expertise in these areas. Her research focuses on quality improvement, professional practice, workforce development and capacity building. These themes come together with the common goal of improving outcomes for consumers and carers and are integrated across the full scope of her work. Professor Wheeler was awarded her PhD late in her professional career (in 2009) whilst working full-time and followed a non-traditional career path, establishing a highly successful research centre in a public health service in NZ that she directed for over 10 years. The centre was primarily self-funding from the award of competitive and consultancy research grants of over \$2.5 million NZD. Since moving to Australia in December 2010 Professor Wheeler's international profile and reputation has contributed to ongoing success in securing highly competitive national research funding with three grants totalling almost \$4 million.



Dr Michelle Pyer BA (Hons) PhD FRGS FHEA
Elected Fellow of the ESPCH, and appointed Co-Chairman to S.I.G on Lesser Heard Groups

Dr. Michelle Pyer is a Senior Researcher in the Institute of Health and Wellbeing at the University of Northampton, UK. Dr. Pyer has completed over thirty research projects on a variety of topics aligned to health and wellbeing and has published on a wide variety of topics including researching with groups deemed 'vulnerable', childhood disability, cancer screening and diagnosis and teenage pregnancy. Her particular research interests are in research with 'lesser heard' groups, health services research and research ethics. Dr. Pyer has worked on a number of research projects focussing on the needs of carers and families of disabled people; her background in geography led her to undertake a PhD on the impact of particular spaces on the leisure and wellbeing of teenage wheelchair users. She is currently co-editing a book on Children, Young People and Care for Routledge. Prior to undertaking her current role at the University of Northampton, Dr. Pyer acted as a consultant on involving children and young people in service design and provision. As part of her current role Dr. Pyer co-ordinates doctoral provision in the School of Health at UoN, overseeing discipline based development for researchers. Dr. Pyer is also course lead for the Doctorate of Professional Practice in Health and Social Care and is currently supervising six doctoral candidates, on such topics as participatory research with people with dementia. She has a particular specialism in research ethics, having acted as an expert member of an NHS Research Ethics Committee.



Dr. Hillel D. Braude MD PhD
Elected Fellow of the ESPCH, and appointed Chairman to S.I.G on Neurophenomenology

Dr. Hillel D. Braude studied medicine at the University of Cape Town Medical School (1988-1993) and obtained a PhD in philosophy cum laude with The University of Chicago's Committee for the History of Culture (1998-2006). He completed a Fellowship at the MacLean Center for Clinical Medical Ethics (2001-2003), and has worked as a clinical medical ethicist in Paris and Montreal. Dr. Braude also completed Postdoctoral Fellowships in Neuroethics with McGill University's Biomedical Ethics Unit and Religious Studies Faculty (2008-2011). His book manuscript entitled "Intuition in Medicine: A Philosophical Defense of Clinical Reasoning" appeared through The University of Chicago Press (2012). His multidisciplinary research interests include phenomenology, cognition and clinical reasoning. He is currently Director of Research at the Mifne Center in the North of Israel for the treatment of infants with autism and their whole families.



**Professor Brendan McCormack D.PHIL (OXON.) BSC (HONS.) FRCN FEANS PGCEA RMN RGN
Elected Distinguished Fellow of the ESPCH**

Head of the Division of Nursing, Queen Margaret University, Edinburgh, Professor II, Buskerud University College, Drammen, Norway; Extraordinary Professor, Department of Nursing, University of Pretoria, South Africa; Visiting Professor, Maribor University, Slovenia; Resident Scholar, Dalhousie University, Halifax, Canada. Professor McCormack'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-centered practice, gerontological nursing, and practice development and he serves on a number of editorial boards, policy committees, and development groups in these areas. He has a particular focus on the use of arts and creativity in healthcare research and development. Professor McCormack has more than 600 published outputs, including 180 peer-reviewed publications and 8 books. Until this year he was the founding Editor of the "International Journal of Older People Nursing". Professor McCormack 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. In 2015 he was recognized as an 'Inspirational Nursing Leader' by Nursing Times (UK nursing magazine).



**Dr. Michel Accad MD
Elected Distinguished Fellow of the ESPCH**

Dr. Accad received his medical degree from the University of Texas Medical School in Houston and obtained his cardiology training at the University of California San Francisco (UCSF). He has been in practice for over 20 years and previously served as Director of the Cardiac Catheterization laboratories at Kaiser San Francisco. Prior to opening his private practice, Dr. Accad was member of the clinical staff at the San Francisco Heart and Vascular Institute. Dr. Accad holds a position as Assistant Clinical Professor of Medicine at UCSF and is part of the clinical cardiology staff at the San Francisco General Hospital. He contributes actively to new knowledge in the field of medicine through publications in medical journals and through work in therapeutic device development. He also holds a certificate with distinction from the National Catholic Bioethics Center.



**Dr. Sarah Neill PhD MSc BSc (Hons) PGDE PGC Res. Deg. Sup. RGN RSCN RNT
Elected Fellow of the ESPCH**

Associate Professor Sarah Neill is an academic children's nurse with over twenty years of experience in higher education. Awarded the role of Associate Professor in Children's Nursing in 2013, her research centres on the patient experience in child health and children's nursing, with a specific focus on parents' decision making during acute childhood illness and the development of interventions to support parents. Methodologically her expertise is in qualitative research and, within that, grounded theory. Dr. Neill is committed to working collaboratively with children & families in research projects. She believes that interventions will only be effective when developed with the people for whom they are intended. Dr. Neill set up a panel of parents with children under 5 years for a research project 5 years ago and now leads this work in collaboration with the lead parents. She also acts as Patient and Public Involvement Lead with the Institute of Health and Wellbeing at the University of Northampton, UK. Dr. Neill is keen to further develop patient-centred care in the field of child health through research and education in collaboration with colleagues nationally and internationally.



**Dr. Wilma Boevink PhD
Elected Fellow of the ESPCH and Co-Chairman to S.I.G on Mental Health**

Mrs. Wilma Boevink (1963) is a social scientist and an experiential expert in psychiatry. She is working at Trimbos-Institute (The Netherlands Institute for Mental Health and Addiction) and as a senior researcher and at the User Research Center at Maastricht University. She is the founder of a user-led training and consulting company in the area of recovery, empowerment and experiential expertise of persons with psychiatric disabilities and has been chair of the Dutch Hearing Voices Network and a Board Member of the European Network of Users/Survivors of Psychiatry (ENUSP). In 2006 she received the Douglas Bennett Award for her work in the recovery movement and in 2015 she was honoured by the Dutch Foundation for Mental Health. She was Professor of Recovery at Hanze University Groningen (2008-2013) and is currently finishing her doctoral thesis on the life art of people suffering from severe mental problems who are also patients in long-term psychiatry. Recent publications include:

- 'Ausweg aus der Schizophrenie: von einer psychischen Störung als Lebensidentität zur Auseinandersetzung mit dem Leben' in Amering M Krausz M Katschnig H (eds) Hoffnung Macht Sinn. Schizophrene Psychosen in neuem Licht. Wien, Facultas Verlags- und Buchhandels AG 2008.
- 'Life beyond Psychiatry' in Rudnick A (ed) Recovery of people with mental illness. Philosophical and related perspectives. Oxford: Oxford University Press, 2012.
- 'L'expertise d'expérience des usagers de la psychiatrie' in Greacen T et Jouet E (eds) Pour des usagers de la psychiatrie. Acteurs de leur propre vie. Toulouse : Éditions érès 2012.
- Risk and recovery' in Sadler J, Werendly van Staden C, Fulford B (eds) The Oxford Handbook of Psychiatric Ethics, Volume 1. Oxford: Oxford University Press,
- And with D. Corstens : 'My body remembers; I refused: Childhood trauma, dissociation and psychosis' in Geekie J, Randal P, Lampshire D, Read J (eds) Experiencing psychosis. Personal and professional perspectives. East Sussex: Routledge, 2012.



Ms. Michelle Croston RGN RHV
Elected Fellow of the ESPCH, and appointed Chairman to S.I.G on Person Centered Healthcare for People Living with HIV/AIDS (+/- HCV/HBV)

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



Dr. Martyn Queen BEd (Hons) PGCE (HE) MA PhD
Elected Member of the ESPCH

Dr. Martyn Queen is a Senior Lecturer and Qualitative Researcher in Health and Physical Activity at the University of St Mark and St John in Plymouth, UK. Dr. Queen has taught in higher education for the past twelve years and developed undergraduate degree programmes in Coaching & Fitness, Sports Therapy and Health, Exercise and Physical Activity. He received his PhD from the University of Gloucestershire UK in March 2014, entitled "The impact of an exercise referral scheme on patients and health professionals: A longitudinal qualitative study". His PhD focused on two interrelated themes: the role of physical activity in managing chronic lifestyle diseases and the impact of the health professional referral on the take-up of physical activity interventions. Martyn has a profound interest in the use of physical activity as social medicine. He has recently published papers on the person-centred approach to healthcare that focus on the effectiveness of long-term engagement with exercise referral schemes, and tactics used by health professionals to engage hard-to-reach patients. Dr. Queen is currently working on a project that focuses on gender perceptions and their impact when referring obese patients for exercise. He has just completed a 12 month study for Macmillan Cancer Support UK on the impact of physical activity on recovery from cancer.



Ms. Galia Barhava-Monteith MPsych (hc)
Elected Member of the ESPCH

Galia Barhava-Monteith is a PhD candidate and the recipient of the Vice Chancellor scholarship in Auckland University of Technology School of Health and Environmental Studies. Her research is entitled: Being Seen as a 'Whole': What can clinicians learn about caring for chronic illness from persons' experiences of non-dualistic healthcare in a biomedical setting? Ms. Barhava-Monteith has chosen to undertake this research following her own experience as a CSV patient who had undergone both extensive 'bio-medical' treatment as well as experiencing the Whole Person Therapeutic Approach first hand. Professionally, Ms. Barhava-Monteith holds a Master's Degree in Developmental Psychology from Auckland University in New Zealand with First Class Honours. Prior to her diagnosis she worked in a range of corporate roles in New Zealand including managing the ethics and community relations function for New Zealand's largest company: Fonterra Co-operative Group. She has also been involved in governance roles including co-designing and coordinating Fonterra's Board candidate assessment panel, being appointed by the Minister for Women to deputy chair New Zealand's National Advisory Council on the employment of women and she is a member of the advisory Board to AUT's Dean of Business and Law. Ms. Barhava-Monteith is an advocate for person-centered healthcare and for diversity and wellbeing in the workplace.



Dr. Rani Lill Anjum BA MA PhD
Elected Member of the ESPCH

Dr. Rani Lill Anjum is a Research Fellow (Dr. Art.) and Director of The CauseHealth at the School of Economics and Business, Norwegian University of Life Sciences (NMBU). Dr. Anjum is a philosopher, working mainly on causation. She obtained her doctoral degree from University of Tromsø in 2005 within philosophy of logic and language, followed by a 3 year Postdoctoral Fellowship during which she wrote the book Getting Causes from Powers (Oxford University Press 2011) with Stephen Mumford at Nottingham University, UK. After returning from Nottingham, she has been Principal Investigator of the research project 'Causation in Science' at Norwegian University of Life Sciences (www.nmbu.no/causci). Her newest research project, 'Causation, Complexity and Evidence in Health Sciences' (CauseHealth), is a 4 year interdisciplinary project that invites philosophers, medical researchers and practitioners to critically examine the ontological and methodological foundation of medicine. All of her research since 2001 has been funded by the Research Council of Norway's FRIPRO Scheme for Independent Projects.



Dr. Alexandra Pärvan BSc MA PhD
Elected Member of the ESPCH

Alexandra Pärvan is Lecturer in the Department of Psychology at the University of Pitești, Romania. She has degrees in Psychology (BSc), Philosophy (MA, PhD), and is licensed for independent practice in experiential counselling. She held post-doctoral fellowships in St Andrews (UK), Edinburgh (UK), Tübingen (Germany) and Princeton (USA), doing cross-disciplinary research in Augustinian Studies, philosophy and psychotherapy, and philosophy of medicine, with a focus on the metaphysical concept of "evil" and persons' experiences of "harm", in the form of violence or disease. Her work advances the concept of metaphysical care, arguing that there is an ignored metaphysical dimension to persons' experiences of their medical or psychological condition and showing how metaphysical views (on deprivation, substance, self, agency and action) can be turned into practical tools which clinicians could use in order to address unmet health needs in this dimension and improve therapeutic outcome. She takes an active interest in promoting humanities-informed education for clinicians, mostly through her teaching of future clinical psychologists and nurses, and attempts to hasten the day when medical schools in Romania will cease to remain impermeable to courses that support such an education.



Ms. Sarah Wieten MA
Elected Student Member of the ESPCH

Sarah Wieten is a Postgraduate Student/University Instructor, and is completing her PhD in Philosophy at Durham University, UK. Her project makes use of methods from epistemology and the philosophy of science to study medicine, specifically the "Evidence-Based Medicine" movement. She is also interested in the place of values and causes in medicine, developments in medical education and palliative care delivery and the relationship between personhood and patient status. Ms. Wieten has experience in the methods of "Evidence-Based Medicine" and in Clinical Ethics consultation.



Dr. Monique Lhussier PhD
Elected Member of the ESPCH

Dr. Monique Lhussier, Reader in Public Health Research, had undertaken all of her formal education in France, and has been working at Northumbria University (UK) since 2001. During this time, Dr. Lhussier has worked on a variety of research projects articulated around the lives of people with long-term conditions and the service delivery models most apt at meeting whole person needs, as well as care at the end of life. She developed a particular interest and level of expertise in quality of life measurement and conceptualisation through her doctoral work. Methodologically, Dr. Lhussier's career spans a broad horizon, as she was originally trained as a biomolecular engineer and completed her PhD ten years later using a postmodern framework, which highlighted the societal and cultural influences upon the quality of life of people with long term conditions. She had also used variations of soft system methodology and realist evaluation and synthesis, which have been useful in the analysis and articulation of complex health improvement issues. Dr. Lhussier is particularly keen on methodological developments that enable the articulation of knowledge that is contextually sensitive and most readily translatable to practice improvement. She supervises a range of PhD and professional doctorate students whose studies focus on older age, palliative care and health improvement generally.

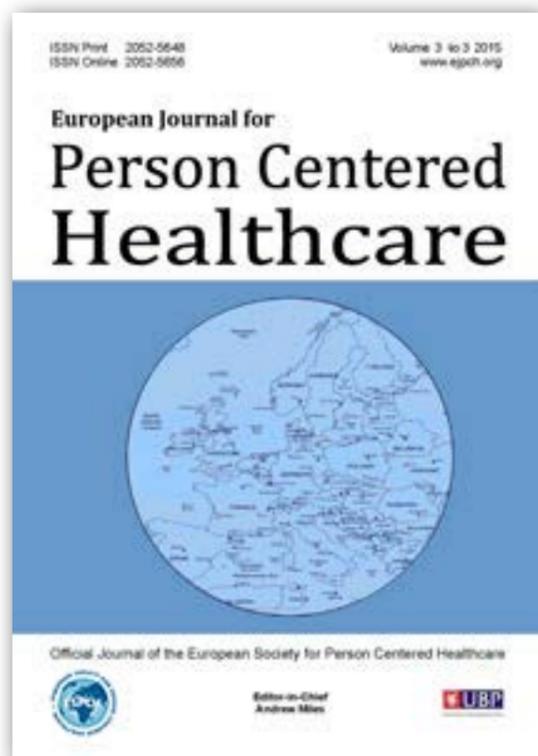


Dr. Marie Chollier BS MPsych (Clin) MD
Elected Associate Member of the ESPCH

Dr. Chollier moved from France to work on her PhD thesis, at the Manchester Metropolitan University, UK, on the ability to relate to different disciplines regarding stigma and HIV. Simultaneously, Dr. Chollier is a part-time Clinical Psychologist at Crir-Avs Paca (Regional Resources Center for Professional Working with Sex Offenders) and at Sainte-Marguerite Teaching Hospital, Marseille, France, where she is involved in prevention, supervision, research and education projects in the field of sex offending. Dr. Chollier's training, work and research is involved in the intensive understanding of the psychology of sex offenders and how it impacts the victim's life. She led and was involved in multidisciplinary approaches to crisis intervention to the victims of sexual offenses and their families, focusing on support groups and therapy and consultations for sex offenders themselves. Her work has also extended within the socially vulnerable sectors; suicidal females, prostitutes and the follow up of transsexual people within gender reassignment protocol teams, all for providing support, therapy and education for the subjects and their families.

ESPCH

ACADEMIC & CLINICAL PUBLICATIONS



EUROPEAN JOURNAL FOR PERSON CENTERED HEALTHCARE

EJPCH

Publisher: University of Buckingham Press, UK
ISSN (Print): 2052-5648
ISSN (Online): 2052-5656
Website: www.ejpch.org
Editor-in-Chief: Professor Andrew Miles

The European Journal for Person Centered Healthcare (EJPCH) is the official journal of the European Society for Person Centered Healthcare [1]. The Journal, which was launched in September 2013, has become the preeminent academic periodical in the field of person-centered healthcare globally, attracting publications from distinguished contributors and institutions all over the World (see Figure). Typically publishing 20 papers per quarter in all formats, including original research articles, literature reviews, rapid communications, letters and book reviews, etc., the EJPCH entered its 4th Volume in January 2016, with a substantial number of papers awaiting publication, and is currently being indexed by PubMed.

A feature of the EJPCH in 2017 will be the publication of Special Supplements of the Journal, deriving from the Society's condition and illness-specific conferences - those activities which are aimed at developing person-centered models of care for given conditions and illnesses. Where possible, the supplements will be made Open Access on-line as a major contribution to the given field, providing a solid academic resource for teaching and research and accompanying the publication of the Society's Clinical Handbooks in these given areas, which are aimed at providing guidance for 'hands on' person-centered care approaches.

[1]. Miles, A., & Asbridge, J. E. (2013). The European Journal for Person Centered Healthcare. European Journal for Person Centered Healthcare 1 (1) 1 - 3.

Theory and Practice of Person Centered Healthcare
Narrative-based / Informed healthcare
Values-based / Informed Healthcare
Preferences-based / Informed Healthcare
Spiritual & Religious Care, Culturally Sensitive Care
Person-centered undergraduate & postgraduate education

Table: Aims and Scope of the EJPCH

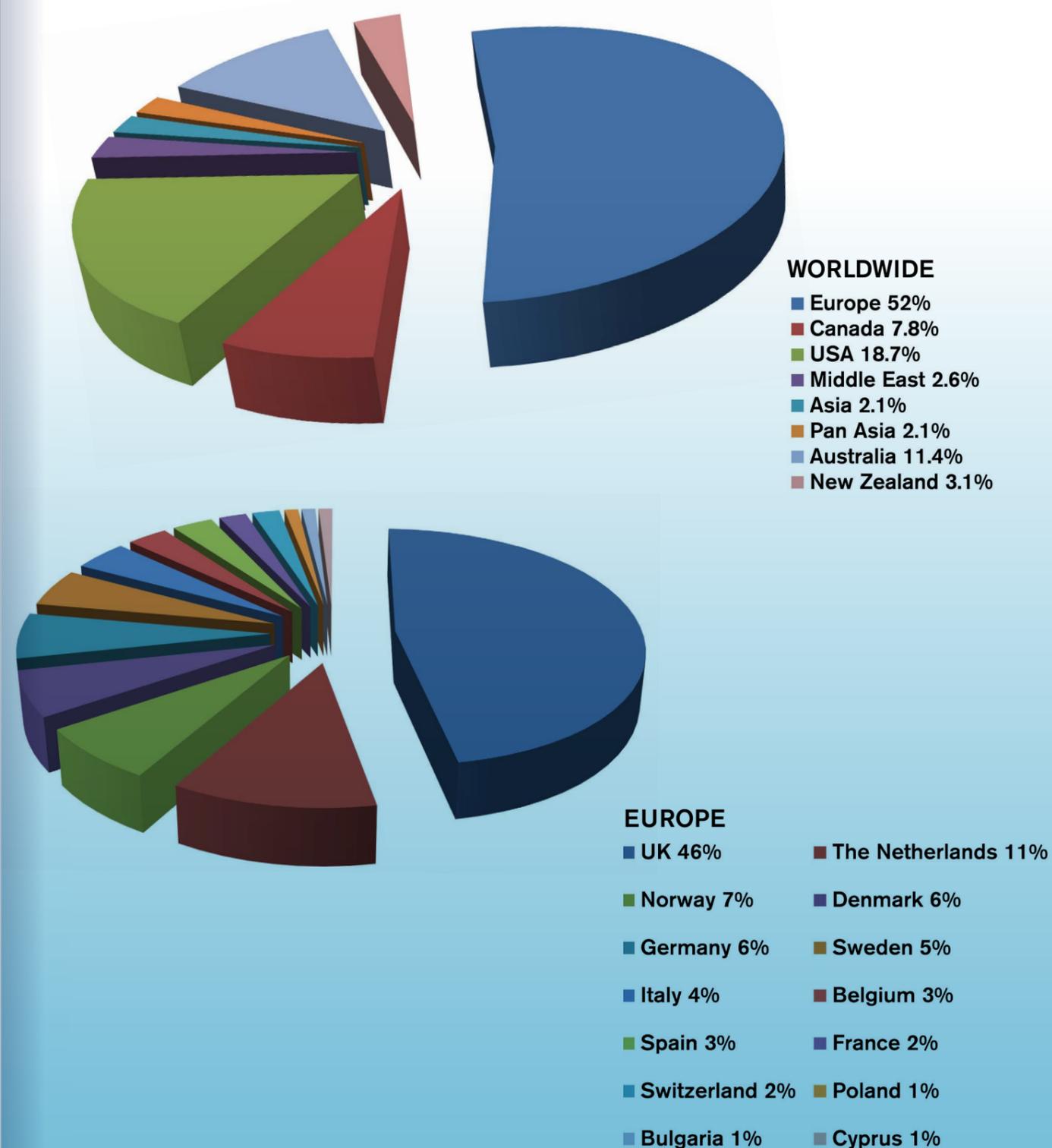


Figure: Pie charts illustrating article submissions for the EJPCH 2013-2015

UPCOMING PUBLICATIONS OF THE ESPCH

**PERSON-CENTERED
HEALTHCARE**

How to Practise and Teach PCH

Edited By
Andrew Miles



**Person-Centered Healthcare:
How to Practise and Teach PCH**

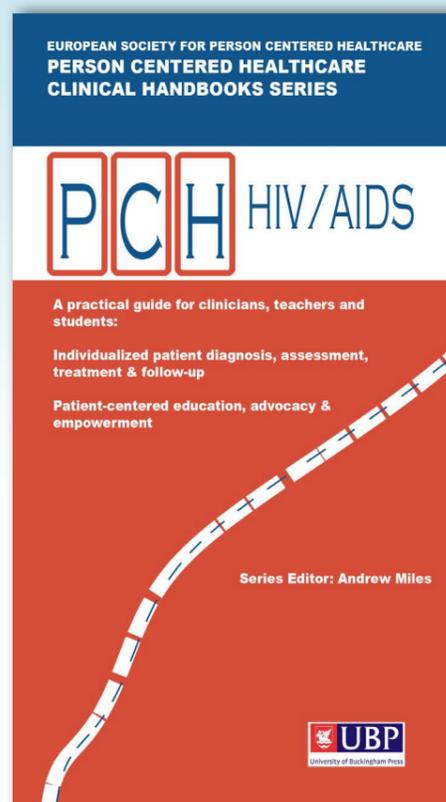
Editor: Andrew Miles
Publisher: European Society for Person Centered Healthcare & University of Buckingham Press Ltd
ISBN 978-1-908684-27-1
55 chapters. pp. 800 (approx.)
Publication: 2017, UK

A further major initiative within the Publications Programme of the Society will be the production of an important and substantial text for the study, practice and teaching of person-centered healthcare. This major academic/clinical textbook is designed specifically to guide person-centered clinical practice and to provide material for undergraduate and postgraduate person-centered teaching the design of educational courses and "hands on" clinical practice. The Editor of the volume is Professor Andrew Miles, with senior colleagues drawn internationally acting as Section Editors within the text.

**Person-Centered Healthcare:
Clinical Handbooks Series**

Publisher: European Society for Person Centered Healthcare & University of Buckingham Press Ltd.
Publication: 2017, UK

The *Clinical Handbook Series* of the Society (the forthcoming HIV Handbook is shown here) is a major initiative of the ESPCH designed to increase the person-centeredness of current clinical practice. The Series will examine current European clinical guidelines published by European medical and clinical societies and associations and, in collaboration with those bodies and acknowledged experts in the given field, make a range of suggestions for how person-centered actions can be added into the guidance, while removing none of the biomedical and technological prescriptions contained within them. Along with this 'superimposition' of person-centered suggestions, the handbooks will incorporate an Audit Proforma and a Patient Satisfaction Questionnaire to allow clinicians and audit specialists to quantitatively measure and qualitatively describe resulting quality improvements. Alongside the Clinical Handbook Series, the Society will publish an Academic Handbook Series focussing on non-clinical areas of study, such as person-centered health policy and politics, IT, health economics, etc.



ESPCH

NEWS
&
PLANNED
EVENTS



70th Anniversary of Foundation Celebrations of the Medical University of Plovdiv, Bulgaria

Professor Andrew Miles, Senior Vice President of the ESPCH, was a guest of honour at the 70th Anniversary of Foundation Celebrations of the Medical University of Plovdiv, Bulgaria: 20 – 23 May 2015. Professor Miles was honoured to receive the award of the Honorary Token of the University from the Rector of the Medical University in recognition of his work in advancing the person-centeredness of clinical care across Europe and indeed internationally. Professor Miles, a Visiting Professor to the Medical University, has been involved in a multiplicity of activities at the University over many years and has worked closely with Professor Drozdov St. Stoyanov in developing a series of lectures on PCH which have now been implemented within the undergraduate medical curriculum.



Innovations and Challenges in Medical Education, Madrid, Spain

Professor Miles delivered a KeyNote lecture on PCH and the Society to the "Innovations and Challenges in Medical Education" conference at El Escorial, Madrid, Spain, part of the celebrated Cursos de Verano at the historic Palace-Monastery of Philip II of Spain, organized in collaboration with Universidad Complutense, on 6 July 2015. Professor Miles' lecture was entitled 'Educación Médica centrada en el paciente: un concepto formativo diferente' (Medical education centered on the patient: a new and different concept). The conference was attended by 200 senior clinicians from across the length and breadth of Spain, the majority with special responsibilities for progress in medical and professional education. The lecture was one of three in the late morning session, others focussing on person-centered clinical communication (Professor Roger Ruiz Moral) and on emotional competence training in medical education (Dr. José Antonio Gutiérrez Fuentes). The concept of person-centered medical education and the suggestion that medical schools should move towards such teaching was well received, as illustrated by the nature and number of questions to the Round Table chaired by Dr. José Antonio Sacristán del Castillo, Director of the Lilly Foundation, Spain.



PATIENTCENTRICITY: Defining Our Role, London, UK

A One-day Thought Leadership Forum was held on the 17th March 2016, at the Royal College of Physicians, London, UK. The forum was the concluding event of the "Renaissance Series" organised by Adelphi Group UK, and designed for stakeholders across the spectrum of the healthcare industry to engage in thought leading debate on the role of the pharmaceutical industry in bringing the claim of "patientcentricity" to life. Participants in the forum were senior pharmaceutical executives, leaders of various patient advocacy groups, and clinicians involved in the delivery of person-centered healthcare to patients. On behalf of the European Society for Person Centered Health Care, Professor Miles, discussed the interface between pharma's notion of patient centricity, which he believed unduly reductionist, and clinical understandings of person-centered healthcare.

Adelphi Group is unique in the world of pharmaceutical consultancy and service provision. Adelphi's offerings span the lifecycle of pharmaceutical development, with comprehensive services in Strategic Product Development Consultancy, Health Economics and Outcomes Research, Real World Disease Understanding, Marketing Research, Medical Communications and Post-meeting Brand Support Services.



**ESPCH HIGHER DEGREE
FEE SPONSORSHIPS - January 2016
(For research expected to commence in
January 2017):
Invitation to Submit an Expression of Interest**

The Society now invites registrations of interest from professionally qualified doctors, nurses and other health service professionals, including health policy and management colleagues, for a range of 2-year part-time Master's degree fee studentships to be offered by the Society with the Society's collaborating European university partners. The winners of the 2016 Studentships will be announced at The Third Annual Conference and Awards Ceremony of the Society in London, in September 2016.

Interested colleagues, both students and potential supervisors, are invited to write to the Society (via the contact details below) with specific areas of research interest and outline proposals. Expressions of Interest should consist of an introductory letter to Professor Andrew Miles MSc MPhil PhD DSc (hc), the Senior VP & Secretary General, attaching a circa 1,000 word outline of the project proposal, the student's Curriculum Vitae and the Curriculum Vitae of the proposed first and second supervisors. Letters should be signed by the prospective student and supervisors. A clear statement of how the proposed research is likely to contribute to the theory and practice of humanistic healthcare is essential.

In addition to primary research as the basis of the higher degree, the Society is equally prepared to consider applications for secondary research, for example, structured and systematic reviews of the literature.



**ESPCH INTENSIVE 7-DAY
RESIDENTIAL TRAINING COURSES
IN PERSON-CENTERED HEALTHCARE
(PCH) - 2017:
Invitation to Submit an Expression of Interest**

About the Courses

Course types

(1) Course A (Basic). For clinical practitioners working in everyday practice and service institutions
(2) Course B (Advanced). For advanced practitioners/service directors wishing to become mentors, teachers and leaders in PCH

Aim

To equip course participants with a through working knowledge of the principles and practice of person-centered healthcare through expert teaching and interaction with internationally distinguished clinicians and academics working in the field of PCH.

Content

Modern understandings of the nature of clinical knowledge. The lexicon and vocabulary of PCH. The differences between person and patient-centered care. A review of the global literature on PCH. The multiple components of the PCH approach – what are they and how do they piece together? What is the relationship between PCH and EBM/P? How to implement relationship-centered care. The evidence for PCH – qualitative and empirical. Costing and measuring PCH. Communication skills, active listening and non-directive counselling. Teaching self-help and management to patients and their families. Empowering the patient. The methods and processes of making shared clinical decisions with the patient. Methods for accompanying the patient along the trajectory of illness. Methods to increase adherence to therapy. Developing and using person-centered health records Transformational and servant leadership in PCH. Clinical services re-configuration and re-design to facilitate the

implementation of PCH and provide value-added services. Increasing the person-centeredness of the clinical team. Regional and global health policymaking and policy developments in PCH. The politics of PCH. Using PCH to manage co- and multi-morbid long term, socially complex illness. Research in PCH – who is doing what and where to start yourself. Building person-centricity into scientific studies and clinical trials. (etc).

Who should attend?

Consultant Physicians and Trainees in primary and secondary care across all medical specialties. Clinical Nurse Specialist and Nurse Consultants. Colleagues working within the Professions allied to Medicine. Directors and Managers of Patient Advocacy Groups and Organizations. Directors and Associate/Assistant Directors of healthcare services delivery across primary, secondary and tertiary care. Health services managers and health academics. Healthcare services commissioners. Healthcare policy-makers Members of the Pharmaceutical Industry with special responsibilities for patient education, empowerment and advocacy.

Which course will suit me?

If you fit one of the professional categories immediately above, but have a limited knowledge of the principles and practical techniques of person-centered care, then you are advised to apply for Course A. If you already have a good working knowledge of the principles and practical techniques of patient-centered care, then you are advised to apply for Course B.

Structural and related aspects

Each week long training course (whether Course A or B) commences on a Saturday and ends on a Sunday. Participants will arrive between 15.00 - 18.00 hours on the commencing Saturday (Day 1), in time for check-in, registration, group and faculty introductions (19.00 hours) and a communal supper (20.00 - 22.00 hours). Study begins on Sunday morning (Day 2) at 08.00 hours [breakfast at 07.00 hours, lunch at 13.00 - 14.00 hours + working tea/coffee breaks] and concludes each weekday at 18.00 hours [supper at 19.00 hours]. Each study day consists of formal lectures and also tutorial-style small groupwork and a case-based interactive Masterclass with videos. Written materials and books will be provided. Relaxation and meditation time is incorporated within the training days, along with time for personal study and group interaction. Visits to notable local monuments and attractions are included in the overall programme. Participants may also take advantage of a 1-2-1 meeting with a member of faculty of their choice (by arrangement outside of the formal study periods). Participants will check-out following breakfast and a farewell session [09.00 hours] on the following Sunday. The courses have been designed to achieve maximum education and training (54 hours) within a minimum annual leave/study leave period away from the workplace (5 working days). Places are limited to a maximum of 25 participants per course, dividing into five, 5-participant member groups for tutorials/groupwork.

CPD and Certification

The courses will be CPD accredited and formal Certificates of Attendance will be issued.

Locations and Dates of the Courses

London, Rome, Madrid or Sofia - 2017. Dates and locations to be announced in late September 2016.

Costs

£1,250.00 per participant. The fee includes single accommodation, all meals and refreshments, all educational materials and a free copy of the major 55-chapter volume 'Person-centered Healthcare. How to Practise and Teach PCH'. Participants are eligible for a 50% discount on first year membership of the European Society for Person Centered Healthcare and with it free access to the European Journal for Person Centered Healthcare and discounts on all of the Society's conference initiatives.

Submit an Expression of Interest to Professor Andrew Miles DSc (hc) by 1st September 2016: andrew.miles@phealthcare.org.uk

On receipt of an Expression of Interest, the Society will provide further information to guide formal applications.



European Society For Person Centered Healthcare & CAUSE HEALTH Project & UFV The Person-Centered Care of Medically Unexplained Symptoms

SEPTEMBER 2016, LONDON, UK

One Day Symposium in collaboration with The CauseHealth Project



This one day symposium is being organized as a collaborative project between the European Society for Person Centered Healthcare and the CauseHealth Project, a four year research project funded by the Research Council of Norway and conducted from the Norwegian University of Life Sciences (NMBU).

The CauseHealth Project is set to study the increasing incidence of so-called medically unexplained symptoms (MUS) and conditions such as chronic fatigue syndrome, irritable bowel syndrome, low back pain, multiple chemical sensitivity and fibromyalgia. These conditions, and others like them, are reported to constitute 40 percent of the symptoms currently reported to doctors, with each presenting patient demonstrating a largely unique combination of symptoms and illness profile. Typically, these chronic conditions are often depicted as outliers: atypical illnesses where standard causal explanation fails, and not as opportunities to study causation more effectively in order to better comprehend the causes of health and illness more generally. As such they represent a real methodological challenge for medical and health services research.

Given the nature of MUS and of co- and multi-morbid, socially complex chronic illnesses more generally, EBM-type clinical thinking has only partial value and it is increasingly recognized that far more complex approaches to the investigation and management of these conditions are urgently required. Indeed, complex disorders are difficult to study and treat because they have multiple causes: genetic, environmental and lifestyle factors (many not yet elucidated) and because each patient presents with a unique combination of biological, psychological, spiritual and social characteristics. It is here that person-centered healthcare approaches, in both theory and practice, retain a vital place in assisting both clinicians and patients to better understand and deal with their illness experiences.

In order to debate these issues and to generate further in-depth insights into the problem of MUS and chronic illness management more generally, the symposium will bring together a wide range of distinguished clinicians from primary and secondary care responsible for the investigation and care of such symptoms and conditions, together with senior academics from the philosophy of science and medicine, clinical psychology, and medical sociology of key relevance to this area of clinical practice, health services provision and basic and applied research.

For further information and contacts:

To register interest in the Conference and to receive more detailed information, please e-mail Dr. Vivian Mounir at: vivian.mounir@phealthcare.org.uk

For clinical and academic queries and queries related to sponsorship and commercial exhibition, etc., please contact Professor Andrew Miles DSc (hc) at: andrew.miles@phealthcare.org.uk



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE

THE THIRD ANNUAL CONFERENCE AND AWARDS CEREMONY

SEPTEMBER 2016
London, UK

For further information and contacts:

To register interest in the Conference and to receive more detailed information, please e-mail Dr. Vivian Mounir at: vivian.mounir@pchealthcare.org.uk

For clinical and academic queries and queries related to sponsorship and commercial exhibition, etc., please contact Professor Andrew Miles DSc (hc) at: andrew.miles@pchealthcare.org.uk



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE

FIRST EUROPEAN CONFERENCE ON INCREASING THE PERSON CENTEREDNESS OF THE CARE OF THE FRAIL ELDERLY



October 2016
Central London, UK

FIRST EUROPEAN CONFERENCE ON INCREASING THE PERSON CENTEREDNESS OF CARE FOR PEOPLE LIVING WITH HIV/AIDS



November 2016
Central London, UK

For further information and contacts on both events:

To register interest in the Conference and to receive more detailed information, please e-mail Dr. Vivian Mounir at: vivian.mounir@pchealthcare.org.uk

For clinical and academic queries and queries related to sponsorship and commercial exhibition, etc., please contact Professor Andrew Miles DSc (hc) at: andrew.miles@pchealthcare.org.uk

SOCIETY INTERVIEWS

Every e-Bulletin of the Society will carry comprehensive interviews with leading figures in the world of person-centered healthcare.

In this, the inaugural e-Bulletin of the ESPCH, we publish the first interview with Professor Andrew Miles, the Society's Senior Vice President and Secretary General (London and Madrid).

In the next e-Bulletin we are delighted to publish an interview with the Society's President, Professor Sir Jonathan Asbridge DSc (hc) (Oxford and London UK), Professor Brendan McCormack (Scotland UK) and an interview with Professor Amanda Wheeler (Australia), both of whom were recently elected to the Distinguished Fellowship of the Society. Subsequent e-Bulletins will carry interviews from other prominent figures working in PCH from across the Globe.

Dr. Margot Lindsay RGN MPhil PhD MCLIP

Librarian to the European Society for Person Centered Healthcare (University College London, UK)



“...assisted suicide is the administration of death, not care or compassion...”

MARGOT'S Q&A with...

PROFESSOR ANDREW MILES

**SENIOR VICE PRESIDENT AND SECRETARY
GENERAL OF THE EUROPEAN SOCIETY FOR
PERSON CENTERED HEALTHCARE**

**Andrew: I decided against
clinical medicine..... I was a
bench scientist, completely.**

I'm interested to learn why and how someone finds themselves working within this rapidly emerging and increasingly powerful world of person-centered healthcare. But I would also like to gain some insight into you as one of the leaders in this field and so I would like to mix my questions, both professional and personal. Do you mind?

No, not at all, please do so and thank you for your invitation.

Where were you born and what were the circumstances of your early life?

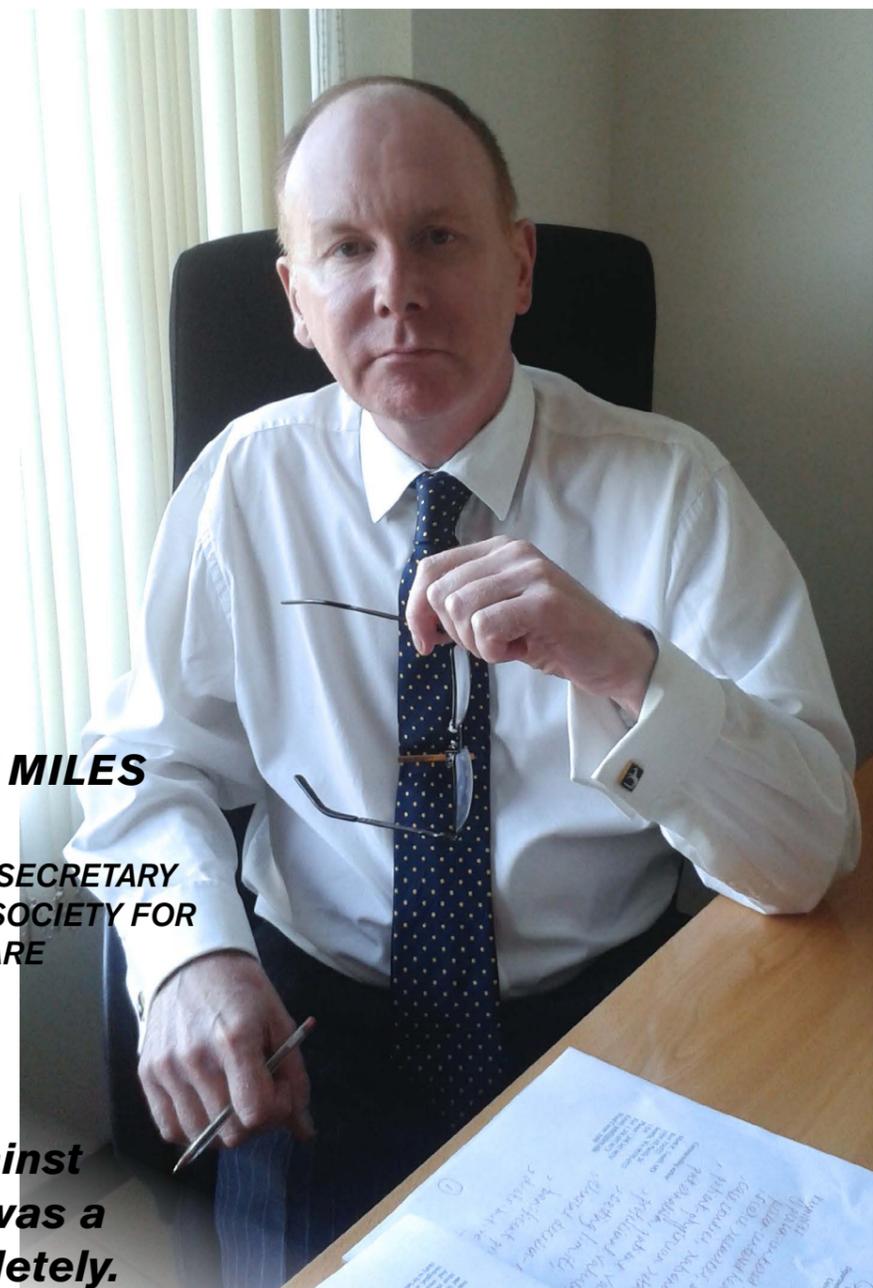
I was born, in 1963, in the general hospital of a small town in the South Wales valleys called Aberdare, some twenty miles from Cardiff, the Welsh Capital. I was an only child, no brothers or sisters. I went to a local primary school and after that won admission, following examination, to an elite school called a boys' grammar school, which taught us not only the usual secondary school curriculum, but also Latin, Greek, ancient history, classical music appreciation, even manners, etiquette and self-discipline. From there I went to Cardiff to study for my first degree.

What was your earliest ambition in life, as a maturing adolescent or university student?

To give, I think, some sort of meaningful service to humankind - perhaps as a doctor, scientist or a priest or an educator/ scholar, that type of thing. I was never, for example, interested in becoming a businessman or a banker or a lawyer or a politician or anything like that. I was taught by my Mother and my Aunt (Italian sisters) the distinction in one's short life between giving and taking, between altruism and selfishness, and the importance of sustained contribution to the Society in which we live, whether such a contribution is to turn out large or small.

Would you give me a 'potted' account of your early university years?

Sure. On moving to Cardiff to study for my first degree I applied for a Medical Research Council (MRC) Undergraduate Research Studentship within the Medical School, based in the MRC Biological Psychiatry Research Group at a local psychiatric university teaching hospital. I was successful and was given a



programme of research, on pineal gland indoleamines, to conduct alongside my undergraduate studies. This meant going to the laboratory after my university lectures during the week and spending all of my weekends in the laboratory. It was tough, but a challenge I relished, and somehow I managed to publish about twelve articles in peer reviewed journals, before graduating, as a result. It was this undergraduate studentship that fuelled, I think, my early enthusiasm for research, scholarship and academic life.

And what happened after your first graduation?

I decided against clinical medicine in favour of academic medicine and I won a postgraduate research studentship within the Medical School looking at the diagnostic and prognostic significance of human prostate specific antigen (PSA) and I contributed to the early work on the value of PSA screening. After completing my MSc on that subject I was invited by the Department of Human Physiology at Cardiff to return to my earlier work on melatonin, which I did, and that led to my PhD on

a postdoc, by studying the physiological significance of circadian rhythms in cell surface melatonin receptor expression within the anterior pituitary gland and also to screen for such receptors and receptor behaviour on target organs elsewhere in the human body. It proved impossible to win a grant to do so, despite continued attempts. I guess like a lot of young researchers at the time with the same experience I felt a sense of disillusionment and I guess that prompted a career re-think. Wind forward just a little, so to speak, and I was appointed by a Cardiff university teaching hospital to design a rigorous system of medical audit and to implement this across all operational medical specialties in the institution, which I did. The system was commended by the UK Audit Commission who had seen it working as part of their inspection of Radiology Services in the hospital and about a year after that I was headhunted to set up a well-resourced department of clinical audit in a major London teaching hospital. So, at 30, I moved from Cardiff to the 'megalopolis' to take up what was really my first senior position and I appointed a total of



“Fiction is just someone else’s imagination.”

the clinical significance of the pineal gland hormone melatonin. While writing my PhD I was approached by Oxford University Press with an invitation to edit a multi-author international volume on the subject which I did and this was my first book, at 24 years of age.

So your grounding was entirely scientific?

Yes, completely. I was a bench scientist, completely. The laboratory was my comfort zone, I virtually lived there. At that time, as a young man in my twenties, the notion of medical humanism didn't really enter my head. I lived for basic biomedical research. I literally used to go to sleep thinking biomedical science and I would wake up thinking biomedical science. That is how it was back then.

So when did things begin to change?

After the award of my PhD I wanted to continue the research, as

17 staff from what was a pretty big budget to assist me in that work. This work brought me directly into day-to-day contact with a wide range of consultant physician and surgeon colleagues and returned me to the clinical milieu. I also gained my first full professorship in London around this time, at age 30, on, in fact, 4 July 1994.

And what then?

We started refining and implementing, at the hospital, the method I'd developed in Wales and we commenced large scale audits on the adequacy of care of patients with myocardial infarction, prophylaxis of deep vein thrombosis and pulmonary embolism, psychiatric services, palliative care services, etc. The work came to the attention of Blackwell Science Ltd (now Wiley-Blackwell) and I was invited to edit a book on the evaluation of clinical services. This was published under the title Effective Clinical Practice and it sold extensively. It was also at this time, in 1994,

that the same publishers asked me to found an academic journal in the field and so we launched the Journal of Evaluation in Clinical Practice which is now in its 22nd volume and of which I remain the Editor-in-Chief.

Your later chairs, at Bart's and The London Medical School and then King's College School of Medicine were in public health science. The key tenets of public health are quite removed from humanistic medicine. How and when did you make the transition from population health to the person-centered vision with which you are now so strongly associated?

It certainly wasn't a damascene conversion, more a gradual appreciation that classical public health, and the discipline of clinical epidemiology, out of which evidence-based medicine has grown, were radically insufficient models of practice for the care of individuals. I gradually became more and more convinced that the idea that statistical effect sizes, derived from highly limited epidemiological study designs, that these were of immediate use in the clinic, well, I became more and more convinced that that was a complete and utter nonsense, since the focus was on the biological body, not on the patient's subjective experience of illness as a human person, loving and loved, existing in

“When you look at medicine and healthcare using this 'outside in' perspective, it becomes obvious where some things have gone wrong over the last one hundred years or so and therefore what needs to be done to put these specific things right again. For sure, modern clinical practice has become de-personalised, de-humanised, and in order to reverse this, we need new dialogues between biomedicine and the medical humanities, between the objective and the subjective in medicine and between practitioners and patients in exploring the adequacy, or otherwise, of practice.”

relationship with others in Society and with a comprehensive range of needs that extend, typically, well beyond the biological body.

Your work, in part, makes recommendations to practising clinicians about how to become more person-centered. But you yourself have never practised clinically, so do you think that sets a limit, as it were, to the authority with which you, as a medical school academic, can speak to practising clinicians?

I, myself, realized fairly early on in my undergraduate years that 'hands on' clinical practice wasn't for me, but as time moved on, I became, as we touched on earlier, far more interested to study clinical practice objectively, from a standpoint where I was one step removed from it, so to speak. The entitling and work of the Journal of Evaluation in Clinical Practice is, perhaps, illustrative here – it's not and never has been a journal of clinical practice *per se*, but rather a journal that has, for 22 years now under my leadership, been concerned instead with the objective evaluation of clinical practice. It's recognised, I think, ever since the advent of clinical audit, that clinicians can't be the sole evaluators and judges of their work and that this responsibility also falls to governments, academics and increasingly to patients and patient organisations themselves. After all, it's Society that provides the licence to practise, clinicians don't award it to themselves. So, there's a great value, I think, in looking at current clinical practices from the outside in, from a 'ringside seat', sort of thing, from which to observe. When you look at medicine and healthcare using this 'outside in' perspective, it becomes obvious

where some things have gone wrong over the last one hundred years or so and therefore what needs to be done to put these specific things right again. For sure, modern clinical practice has become de-personalised, de-humanised, and in order to reverse this, we need new dialogues between biomedicine and the medical humanities, between the objective and the subjective in medicine and between practitioners and patients in exploring the adequacy, or otherwise, of practice. Far from insulting or weakening modern medicine, such dialogues greatly, I'm convinced, enrich it. And this is what the PCH movement is doing. And that's precisely what I'm doing. It's just this, essentially, just this, enabling such dialogues to take place and then acting on their results. So my role in modern medicine and my authority to speak to practising clinicians is certainly limited, indeed it is – limited to objective observation of modern clinical practices and to suggesting to my clinical colleagues how the wonderful things that they are already doing can be enriched even further.

Is it true to say that you've articulated that view, in one way or another, consistently, for twenty years in the Journal of Evaluation in Clinical Practice? And that this journal has had a substantial impact on the direction of the global EBM debate?

Well, yes, the JECP has published extensively for more than two decades on the futility of the EBM thesis, for sure. And, yes, I think it is probably true to say that our work has forced consecutive shifts in the EBM thesis so that, as we speak here, now, EBM has changed its thesis five times in those twenty years, yet it is still, I think, quite unfit for purpose as a model of authentic clinical practice.

So what, then, is PCH, in contradistinction to EBM?

Sir Jonathan, the President of the Society, and I, have described it as a 'new way of thinking and doing' in healthcare, one which aims to return to clinicians an ambition to treat patients as persons. So we can say, then, that, overall, it is therefore a philosophy and a method. For sure, some conceptual deficits remain and the methodology with which to realize PCH in operational practice is still very much being worked out, not least by the Society. A working definition might be as we have already advanced, which is that PCH is "a philosophy and method which enables affordable biomedical and technological advance to be delivered within a humanistic framework of care that recognises the importance of applying science in a manner which respects the patient as a whole person and takes full account of his values, preferences, aspirations, stories, cultural context, fears, worries and hopes and which thus recognises and responds to his emotional, social and spiritual necessities in addition to his physical needs". That's the framework, now we need to develop models to operationalise it. EBM, by focussing on the patient as a complex biological machine, rather than a person, radically short

changes the patient and fails to respond to his comprehensive needs.

A common criticism of PCH is that it takes too much time to do, time that clinicians within busy modern health systems just don't have, even if they have the motivation. What is your view?

This, in fact, is a frequently stated objection, but the matter is complex. As I've said before, PCH is intuitively the right way to practise clinically. But there is more to it than simple intuition. Rapidly accumulating empirical evidence, for example, now shows, increasingly, that PCH approaches to care improve clinical outcomes and contain or decrease healthcare costs. They are also associated with an increased adherence to both simple and complex medication regimens. They are positively correlated with patient satisfaction and they are negatively correlated with clinician burnout. Interestingly, while the initial consultations which build the clinician-patient relationship often involve more time than care as usual, the frequency of general practitioner and hospital consultant consultation then decreases so additional time spent at the beginning of the relationship is paid back down the line so to speak and is associated with all those other range of goods I just mentioned.

What is necessary to progress PCH in the wider world of health services and systems?

I think we need a multi-pronged approach, a detailed and highly rational strategy. Fundamental to this approach will be promoting an increased awareness of the benefits I mentioned in answer to your last question, an awareness of the empirical evidence that PCH works and works well for patients, clinicians and health services. Without that knowledge and awareness it will be impossible to convince healthcare policymakers and politicians and indeed the clinical workforce to invest, in their different ways, in this new approach. When these colleagues are able to see and indeed quantify and cost the benefits, we will then need to train and deploy transformational leaders to effect the re-configuration of clinical services that will be pivotal to enabling an operational realization of the new model of care. Of course, systems must also then be put in place to monitor, over time, the performance of the new model against a range of process and outcome criteria.

What would you say to a newly admitted medical or clinical student about PCH?

Actually, I have been asked this question before and my reply then was something like this: "You have been admitted to your

“EBM has changed its thesis five times in those twenty years, yet it is still, I think, quite unfit for purpose as a model of authentic clinical practice.”

“EBM, by focussing on the patient as a complex biological machine, rather than a person, radically short changes the patient and fails to respond to his comprehensive needs.”

“PCH is intuitively the right way to practise clinically. But there is more to it than simple intuition. Rapidly accumulating empirical evidence, for example, now shows, increasingly, that PCH approaches to care improve clinical outcomes and contain or decrease healthcare costs. They are also associated with an increased adherence to both simple and complex medication regimens. They are positively correlated with patient satisfaction and they are negatively correlated with clinician burnout.”

“...I always have had and still retain what I would call a 'healthy scepticism' of CAM...”

course because you have been judged to have an enthusiasm for the care of individual patients. Keep it". Of course, medical and clinical schools must assist such a retention and there is much discussion at the moment about how best this can be done. Certainly, heads, so to speak, are not enough, we needs hearts in our students as well. Screening procedures to identify students who have these dual attributes, declining those who are intellectual but who do not, perhaps, have the ability to care, are vital here and, of course, Francisco de Vitoria University in Madrid has and uses such a screening tool.

Francisco de Vitoria University (UFV) in Madrid. That's where the Society is partially based isn't it? Why UFV? How do the values of these respective institutions match and to what extent?

Actually, one half of the Society is currently based at UFV in Madrid and the other half is in London, so it's split site, so to speak. In Madrid, we have over the last two years delivered the Society's conference programme and other educational initiatives, and our publications programme is based in London. Strategy is agreed between London and Madrid and the Society has full time paid staff in both locations, but it's all a cohesive whole. The medical school at UFV is new, its first cohort of doctors graduate in July 2016 and it's completely committed to the person-centered ideal, having been built on the principle of marrying the applied scientist to the medical humanist, by Dr Fernando Caballero Martinez and his team. I mean, given this, this philosophy, the values of the medical school and the values of the Society, are highly coincident and our ongoing collaboration continues to work very well indeed.

What paper or book should every student and clinician read?

As Alan Richens, who was our Professor of Clinical Pharmacology and Materia Medica in the Medical School at Cardiff, always said: "When I want to read a good paper or book I write one"! I'm certainly not going to recommend any of mine! Two foundational publications come immediately to mind: Francis Peabody's 'The Care of the Patient' and Edmund Pellegrino's 'The Philosophy of Medicine Reborn'

What are you currently working on in PCH?

I'm currently completing various book chapters one of which reflects on the current conceptual deficits in the PCH thesis and how we can move forward to attempt to address them. And then there is the 'Lexicon and Dictionary of Terms for PCH' which is becoming enormous. Also,

there is a major work on the Theory and Practice of PCH, again growing startlingly. Additionally, there is what we are calling the Big Book or Bible of PCH – a 55-chapter volume on PCH which the American market in particular, I am told, is keenly awaiting. Then there are the forthcoming projects on increasing the person-centeredness of the care of the frail elderly, which BUPA have sponsored, and the CAUSEHEALTH project on the person-centered care of Medically Unexplained Symptoms. And alongside all of this, of course, there are the Society's 2016 and 2017 conferences, the Society's 7-day intensive residential training courses and the rapidly growing official journal of the Society, the *European Journal for Person Centered Healthcare*. And the new e-Bulletin of the Society. Oh, and then there is the continuing editorship of the *Journal of Evaluation in Clinical Practice*. So, as the expression goes, 'There's no peace for the wicked'!

As we sit here in London, legislation was recently introduced into the House of Commons to legalize Assisted Suicide and also into the House of Lords, the Upper Chamber of the British Parliament. The Motion in the Lower House failed, but efforts remain to re-introduce the legislation over time. Do you support assisted suicide? You surely have a view on this?

Yes, I have a personal view, for sure. I have been asked this very same question many times before when lecturing in Europe and elsewhere. The core question is usually preceded by a rhetorical question which goes something like this: "Surely, if PCH is about compassionate care, then it is compassionate to assist the dying of people in misery or who have forms of intractable pain?" Then we have the question: "So do you, then, as a protagonist of PCH, support assisted dying?" I always empathize with such feelings, but my clear, personal view is that assisted suicide is the administration of death, not care or compassion, and that no clinician of any type should therefore engage or be expected to engage in it. What we need in my view is assisted living, not assisted dying. There is, then, an urgent need for person-centered clinicians, and others, to engage very actively in this debate.

Some people say that complementary medicine and alternative medicine are fully part of person-centered healthcare. Do you have a view on this also?

Yes, I do, again a personal one. These therapies are the subject of considerable and ongoing debate. My only real personal encounter with the world of CAM was when I was DVC (Deputy Rector/President) of the University of Buckingham UK and where I had to take the difficult decision to order that the university's CAM course be shut down – there were as many political considerations involved in this decision as there were academic ones at the time. I think it would best summarize my position to say that I always have had and still retain what I would call a 'healthy scepticism' of CAM, though my mind remains open. Certainly, when I said this to a distinguished breast surgeon over lunch in London one day, about six years ago, he said to me: "Andrew, make sure your head isn't so open that your brains fall out". Good advice, for sure. But one cannot discard the relevance of the increasing empirical research on mind-body interactions, likely to be mediated in part by the psychoneuroimmunological axis and other such systems and also the apparent effects of CAM that patients attest to through patient-reported outcome measures and qualitative investigations more broadly. As always, a spirit of critical enquiry is the way forward, and for this reason, among its many special interest groups, the Society has one SIG dedicated to this aim.

If you weren't heading up the European Society for Person Centered Healthcare, then what would you be doing instead?

Living a life of broad contemplation in an Italian Monastery in the Lazio countryside, with easy access to Rome.



What 'non-PCH' reading are you reading at the moment?

Several books. I tend to read things in parallel, rather than in sequence. It's a boredom thing. So I have three books on the 'go' at the moment. I've almost finished *The Making of the Middle Sea* authored by Cyprian Broodbank, and I'm about a third through *The Book of Gomorrah* which is highly entertaining as well as rather shocking, and I am about halfway or so through a second reading of the *Confessions of St Augustine*.

Not exactly light or relaxing reading?

No, for sure. But I never read fiction, I've never really seen the point. I mean, for me, fiction is just someone else's imagination, it's just time consuming entertainment. But time is precious and I've always thought that there are better uses of time than reading non-fact which is what fiction, to me, is. So given the

time it takes to read it, it works out as a very expensive form of entertainment if, that is, you value your time. If I settle down with the Rise and Fall of the Roman Empire, for me that's likely to give me some improvement. But a Cartland summer romance? That's a valueless distraction. Of course, as always, each to his own, one man's meat is another man's poison and all that, but, for me, made up stories have little appeal.

How would you describe your personality? In, perhaps, four of five words?

Perhaps my closest friends – or nemeses – should answer that (!) I think I am passionate, committed, determined, sometimes impulsive and certainly empathic/compassionate, in both my professional and indeed personal life. I was once forced to do one of those management style assessments when I was a new postgraduate and I came out of it as a benevolent autocrat (!) Things have, perhaps, changed a little since then. By which I don't mean I am now a non-benevolent autocrat (!) No, I value democracy and teamwork more now than I ever did when I was much younger. One learns a lot over time.

“But the single biggest (mistake) in recent years, I think, some six years or so ago, was to accept the position of Deputy Vice Chancellor (Deputy Rector/President) of a British university.”

Everyone makes a mistake or mistakes in their careers. What was your biggest mistake?

Well, there is certainly more than one mistake to which I would lay claim or admit! But the single biggest in recent years, I think, some six years or so ago, was to accept the position of Deputy Vice Chancellor (Deputy Rector/President) of a British university. I was very flattered to be asked and was intrigued by the notion of executive power. Up to that point, I'd only been an academic, albeit having spent a very brief time as a senior NHS manager. But when I suddenly found myself sitting in a grand office at the centre of the University I found I had no time to do anything other than attend meetings, no time to read and to think innovatively and all my time was spent in meetings and in so called firefighting. Colleagues in various Ivy League UK universities said to me, when they heard I'd taken that role, that the closer one comes to the Office of the Vice Chancellor/President of a University, the closer one comes to the epicentre of madness. I discovered that this was a truism indeed. After a year in the job I arranged to demit Office to set up the European Society for Person Centered Medicine with my very good colleague and mentor Professor Sir Jonathan Asbridge DSc (hc). Agreeing to become a DVC back then was, I think, part of my midlife crisis and one from which I have learnt much!

What are your most valued possessions?

My life, my Catholic faith, my health and my father (who is my last remaining close family) and my friends. I have a pile of Italian art and furniture and old books, etc., inherited from my family, and it is comforting to have these around me, but they are entirely peripheral to the first things I mentioned.

What are you doing to reduce your carbon footprint? Are you a 'green' person?

I don't travel professionally unless I absolutely have to do so, not unless I'm convinced that it is necessary for an aspect of my work to be progressed. For relaxation I take European city breaks, though generally I add on days to professional travel for this purpose, rather than book entirely personal travel. But I'm absolutely not a 'green' person in the commonly understood use of the description, no, not at all. At the moment the science is hopelessly skewed. The predictive models simply cannot factor in all of the variables necessary to produce anything that is reliable. As Hans Eysenck, whom I had the honour to meet twenty years or so ago in London shortly before his death, when we were talking about the technique of meta-analysis, said: "Andrew, never underestimate the capacity of academics to take the simplest of ideas to the greatest extremes". I absolutely concur with his observation and I guard against falling into such traps myself. If anyone reading this interview finds my view politically incorrect, I would personally recommend that he or she listens to Professor Freeman Dyson's excellent interview which was conducted by Stuart McNish in "Conversations That Matter" and given from Stanford University in the USA on this matter for some much needed common sense.

“...but I'm absolutely not a 'green' person in the commonly understood use of the description...”

What part does food and alcohol play in your life? And music or other interests, hobbies, etc?

I adore French, Italian, Spanish, Greek and Portuguese cuisine. And robust reds and very dry whites. As for music, I adore 18th and very particularly 19th Century Russian orchestral and piano music and Italian, Spanish and Portuguese sacred polyphony. I am also heavily into Italian Renaissance and Counter-Reformation sacred painting.

Do you have what are called 'pet hates'?

For sure, as we all do. The modern lack of manners is number one. Number two is political correctness, which I find completely intellectually absurd. A third would be fashion. Fashion is pervasive. I agree with Oscar Wilde when he said that "fashion is frightful, that is why we keep changing it all the time". And, finally, the culture of so called 'celebrity'. On this last point, one of my heroes, Professor Raymond Tallis, has written magnificently in his article in The Times, entitled "Stop the sick, degrading culture of celebrity".

Who in your life is the person/s you would most like to thank?

My mother and father who had something to do with bringing me into this world of ours. My mother's sister, a stern teacher, who inculcated in me a strong work ethic. And a friend of mine, a Benedictine priest and monk, who brought me back to the Church after I had strayed a little too far into a spiritual emptiness during my early student years. There are also some key medical colleagues whose mentorship and wisdom during some difficult periods in my career and life who are also deserving of considerable gratitude.

Suppose, for a minute, that you could be invisible for 24 hours.

How would you use that invisibility? What would you do with it?
I certainly wouldn't want to use that time to listen to what other people think of me (!) I guess I would prefer to be invisible in wards and clinics and hospices and old people's homes across the world instead, to see and hear what was going on in the real world of life and clinical practice, not listening to backbiting and career advancement strategies in academic ivory towers.

If you won the EuroLottery, the EuroMillions, on the assumption you play it, what would you do?

I don't play it, I don't gamble with money. However, if I did play that Lottery and if I did win the jackpot, then I would use it to rapidly expand the work of the Society by creating new studentships and professorships and many other things to progress the field of person-centered, humanistic medicine and healthcare. Something that would last and grow and not be linked to individual personalities and interests.

So you wouldn't keep any of it for yourself? For a holiday home in Italy or a luxury car?

I might consider retaining 10% for investment in a property such as the one you suggest. As for a luxury car, no. I don't drive. My mother terminated my driving lessons when I was 18 year of age given my propensity for high speed! "Don't let Andrew drive", she would say, "Keep death off the roads!"

You wouldn't retire then?

Certainly not.

When will you retire?

Never! I don't believe in retirement for academics. We accumulate so much knowledge and experience and, hopefully, a little wisdom over long years, that we have in my view a duty to continue to dispense it, even if it is in a part-time/emeritized capacity and only to undergraduates. So I shall retire, Dr Lindsay, when I drop dead!

Professor Andrew Miles. It has been a privilege and an entertainment to hear everything you have said.

Dr Lindsay, that is very kind of you. Thank you once again for your invitation to interview.





What did Dr. Margot Lindsay say about this book?

REVIEWED BOOKS

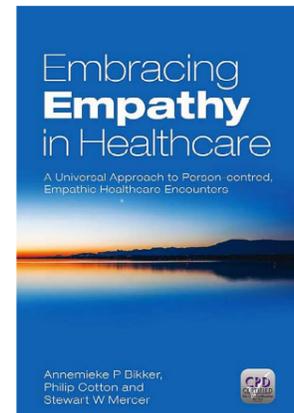
In this section of the e-Bulletin, we selected some of the latest publications in PCH, reviewed by Dr Margot Lindsay RGN BA MPhil MCLIP PhD. Dr Margot Lindsay is the Book Review Editor of the European Journal for Person Centered Healthcare (EJPCH) - the official journal of the European Society for Person Centered Healthcare. [Click Here](#) to read the whole review of each book.

In this section we selected recent publications exhibiting model ways of caring for the elderly, pre-adult people (children and adolescents), and for people living with dementia, intellectual disabilities, Alzheimer's Disease and receiving palliative care. All require tailored person-centered care models and teams of care givers with creativity, knowledge and experience, to break through communication barriers, and allow them to be more engaging with their environments and to overcome their incapacities and illnesses. We have also chosen a book of historical importance and a unique literature in its own field about the role of nursing and midwives in Nazi Germany.

Dr. Margot Lindsay regularly performs detailed and structured reviews in EJPCH on recent publications in PCH, in which she introduces the reader to the book, with a background overview on the author and the book's intended audience. She then proceeds to discuss the organisation of the book, reviewing each section in more detail. She continues by shedding light on the thesis of the book, and finally concluding with particular emphasis on the book's distinguished contributions to the PCH literature, and how it can encourage readers to apply many of its points into their daily practices and routines of PCH. In this section we have used parts of these reviews for the selected publications, together with information about the book and where to acquire it.

Dr. Margot Lindsay's career has encompassed both nursing and librarianship. After becoming a registered general nurse (RGN) in 1964 she acquired three GCE "A" Levels at the City of Westminster College in 1966 and a Certificate in Social Administration from the University of Southampton in 1968. While working as a Staff Nurse in the National Hospital for Neurology and Neurosurgery UK 1979-92 she published 14 papers on epilepsy in nursing journals and contributed chapters in books. "Migraine and Headaches" was published by Wessex Library and Information Services in 1981 and "Communicating with Neurological Patients: The Nurse's Role" was published by Scutari Press in 1990.

She received a BA (Hons) in Librarianship in 1977 and became a Member of the Chartered Institute of Library and Information Professionals in 1979 followed by a Diploma in Research Methods from the University of Surrey in 1982. She set up information services in four specialist medical centres from 1985-1993. Following an MPhil in Sociology in 1993 and a PhD in Librarianship in 1999 she published 18 papers on librarianship. Her librarianship career included a research assistantship in the British Library and library positions in four London hospitals. She provided an information service for the London Centre for Dementia Care in UCL during the period 1999-2008. She currently archives clinical research data in the Division of Psychiatry, University College London.



Embracing Empathy in Healthcare: A Universal Approach to Person-Centred, Empathic Healthcare Encounters
Authors: Annemieke P. Bikker, Philip Cotton, Stewart W. Mercer

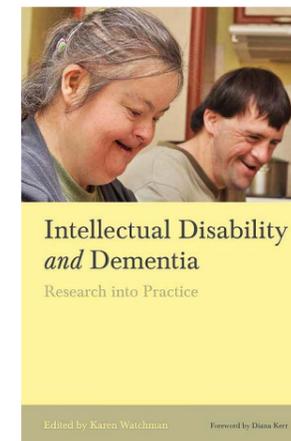
Publisher: Radcliffe Medical Press Ltd
Publication: July 2014
ISBN-10: 1909368180
ISBN-13: 978-1909368187

Get it at: [Amazon](#)

Book Review by Lindsay, M: Bikker, A.P., Cotton, P. & Mercer, R.W. (2014). Embracing Empathy in Healthcare. London: Radcliffe Publishing, 2014. ISBN 978190936-818-7. EJPCH, 2015; 3(3): 412-416.

"The CARE Approach aims to assist healthcare professionals in developing, practising and reflecting on empathic person-centered communication. This book, by describing the CARE Approach in detail represents a practical tool to help clinicians in their everyday endeavours. The authors hope the CARE Approach will inspire and support healthcare staff in their encounters with the people, their patients. This is much needed.

"Indeed, while it is tempting to think that experienced healthcare practitioners know all about: connecting, assessing, responding, compassion, attending, understanding, empowering, values, rapport and having a positive attitude, an overwhelming literature proves the opposite. In addition to the text, the video clips provide excellent examples of good communication. They are short and directly demonstrate verbal and non-verbal skills. This invaluable text is useful, in addition, for teaching, with the advantage of the large format enabling sections to be discussed in group work. In short, then, this text is highly recommended."



Intellectual Disability and Dementia: Research into Practice
Editor: Karen Watchman
Publisher: Jessica Kingsley Publishers
Publication: May 2014
Print Book ISBN: 978-1-84905-422-5
eBook ISBN: 978-0-85700-796-4
 Get it at: [Jessica Kingsley Publishers](#)

[Amazon](#)

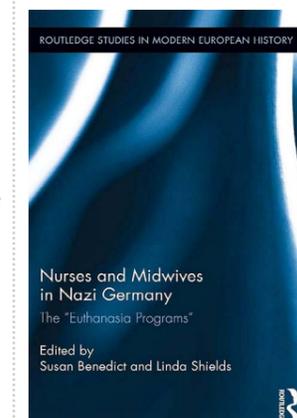
Book Review by Lindsay, M: Karen Watchman, (ed). (2014). Intellectual Disability and Dementia: Research into Practice. London: Jessica Kingsley Publishers. ISBN 978-1-84905-422-5. EJPCH, 2015; 3(3): 421-426.

"Pictures can speak louder than words as does the front cover of this book illustrating two happy disabled people. 'Learning disability' is the term that the Department of Health, UK uses within their policy and practice documents, but the term intellectual disability is now preferred by advocates and researchers in most English-speaking countries. This book concentrates on three themes in discussing intellectual disabilities and dementia. Firstly investigating what we know, secondly how we know and, thirdly, what we are going to do with such knowledge. Part 1 of the volume is entitled "The association between intellectual disabilities and dementia: What do we know?" and focusses on medication and non-pharmacological interventions such as psychology, environment design and communication. Throughout the book there is a focus on working with carers and families in relationship-centred care. Part 2 of the book "Experiences of dementia in people with intellectual disabilities: How do we know?" describes the experiences of dementia among a group of older people with intellectual disabilities who regularly meet together. These case studies provide invaluable learning tools for anyone involved in caring for people with these disabilities. Part 3 of the text, entitled "Service planning: What are we going to do?" discusses the difficult problem of sharing the diagnosis, breaking bad news, staff knowledge and training and descriptions of services provided in the UK and other countries."

"The targeted readership of this invaluable compendium is everyone working with people with intellectual disabilities and

dementia, including their families. As the contributors include internationally renowned experts the text provides excellent teaching material for practitioners and academics with reference to current practice and developments in this area. Dr Watchman's book is an essential tool for the health and social care sector."

"The current volume is an important contribution to the literature on intellectual disability and dementia. The individual chapters are well written, with accessibility of style and the volume is cohesively edited making the book a delight for the reader. The comprehensive nature of the volume in terms of its aims and scope make this publication highly recommended reading not only to all those colleagues involved in the health and social care of persons with intellectual disability and dementia, but also for the families and friends of those who suffer with these conditions."



Nurses and Midwives in Nazi Germany: The "Euthanasia Programs" (Routledge Studies in Modern European History)

Editor: Susan Benedict, Linda Shields
Publisher: Routledge
Publication: April 2014
ISBN-10: 0415896657
ISBN-13: 978-0415896658
 Get it at: [Routledge](#) [Amazon](#)

Book Review by Lindsay, M: Benedict, S. & Shields, L. (eds.). (2014). Nurses and Midwives in Nazi Germany; The "Euthanasia programs". New York: Routledge. ISBN 978-0-415-89665-8. EJPCH, 2015; 3(2): 267-273.

"Benedict and Shields have filled a very big gap in nursing and midwifery history by investigating the professional involvement of nurses and midwives in euthanasia programmes in the Nazi era in Germany. In Germany, Austria and occupied Europe, during the years 1939 to 1945, approximately three hundred thousand people became victims of the different forms of "euthanasia" killings under the National Socialists (NS) 'programme'. About seventy thousand of these people in psychiatric asylums, 60% of these 'patients' with the diagnosis of schizophrenia, were killed by carbon monoxide poisoning in six killing facilities. Nurses were a vital part of these

murders, making killing part of their everyday practice and participating in the execution of patients. Although nursing has traditionally been regarded as a caring profession, nurses actively and intentionally killed thousands of their most vulnerable patients - children and adults with mental and physical disabilities. While a large body of scholarship about the roles of doctors and medicine in these crimes exists, until now, nurses and nursing have been largely ignored. A small body of research in the history of nursing has explored how the caring professions of nursing and midwifery could become not only supporters of a government's murderous policy, but also its enthusiastic implementers."

"This book is a magnificent historical analysis. But it is more than that. Indeed, there is a perception that the modern world is free of the ethical dilemmas that the nurses discussed here faced and accepted or ignored. The authors suggest, however, that some things never change and dialogue about some present day nursing and midwifery actions is long overdue. An obvious choice for discussion is a practice against which bodies like the International Council of Nurses (2012) has fought robustly, that of nurses assisting with executions in countries that still have the death penalty. It is easy to see how this is wrong and how a moral stance can be made against it. However, there are other areas that require scrutiny. Maternal-foetal screening services, variously known as pre-natal diagnosis or pregnancy choice services, among other names, have, since the development of ultrasound as a screening tool during pregnancy, become commonplace. If a foetus is found to have a range of deformities, inherited diseases, or congenital conditions, mothers and fathers are given the choice of whether to continue with the pregnancy or have it terminated. While a condition known to be incompatible with life may be accepted as a reason for termination, sometimes terminations are being chosen for conditions that are far less severe, such as Down's syndrome or cleft lip and palate. According to a report by the Nuffield Council on Bioethics (2006), in 2006 in the United Kingdom, approximately eight hundred thousand pregnancies were recorded, and thirty-five thousand screened women were told that their foetus was at risk of a serious abnormality. Figures for terminations of pregnancy in developed countries such as the United Kingdom, US and Australia are difficult to find and so it is not possible to know how many pregnancies are terminated each year.

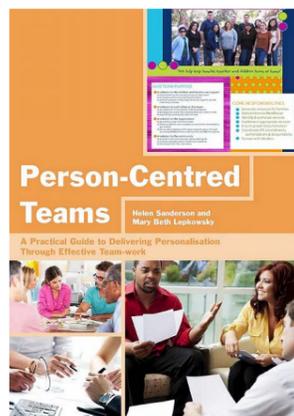
Rationing of healthcare is a well known term today. Escalating costs of healthcare and technology mean that some sort of reconciliation has to occur between what healthcare costs, what patients expect and what is deliverable within each country's budget. Examples of where this has become a battleground can be seen in the US with President Barack Obama's health reform, the Affordable Care Act (US Department for Health and Human Services 2012). The National Health Service in the United Kingdom has struggled for years to provide the 'free at

point of delivery' healthcare that has become so much a part of the UK Nation's psyche. Many lose their jobs when health budgets are cut; others work under increasing pressure from managers and policymakers to cut corners and minimize the standards of care they deliver. Nurses and midwives are caught up in this. Of course, those who suffer the most from such actions are ultimately the patients of the health service. Under the Nazis, rationing of health services took a sinister turn and people were killed if they were considered a burden on the State and expensive to care for. Nurses and midwives need to remember this when faced with dilemmas around rationing of services and aim to find the courage to resist if asked to do inappropriate things that will not best serve their patients.

The International Council of Nurses (2012) strongly decries the involvement of nurses in torture, but evidence exists that nurses have been complicit in force feeding prisoners at Guantanamo Bay, which constitutes torture. In 2013, a report from the Institute on Medicine as a Profession revealed the actions of these nurses (Task Force 2013). Such modern day events indicate the importance of studying history of nurses and midwives in Nazi Germany.

There may be a long moral distance between the health professionals of Nazi Europe and the health world now. Nonetheless, the authors are right to suggest that there is no room for complacency, nor is there any justification for thinking that such actions were only historical. In 2011, an American nursing student posted on Facebook a description of a young trauma patient who had sustained massive neurological damage. In response to this posting, a registered nurse provided advice on how to hasten the patient's death by slowly changing life-sustaining intravenous medications. Yet another nurse cheered on, "Do it, do it". Apart from the obvious privacy rights of the patient, which were so badly abrogated, one could imagine the nurses in the Nazi killing centres cheering each other on in a similar fashion.

One important aim of this book is to prevent the Nazi crimes happening again. As with many studies of the Holocaust and the Nazi era, the keys remain education and exposure to the reality of what occurred. History has slipped from many nursing and midwifery curricula and the history presented here receives little acknowledgement. Lobbying for the return of history as a permanent component of all curricula should be high on the agenda. Only by exposing and discussing them can we be confident we are doing our best to prevent their recurrence. In conclusion, then, this book is a landmark work, beginning as it does in an era of discovery and acknowledgment of the role of midwifery and it is hoped that further scholarship will ensue. We should all remember the words of the Irish politician, Edmund Burke (1729-1797): All that is necessary for the triumph of evil is that good men do nothing."



Person-Centred Teams: A Practical Guide to Delivering Personalisation Through Effective Team-work

Authors: Helen Sanderson, Mary Beth Lepkowsky

Publisher: Jessica Kingsley Publishers

Publication: February 2014

Print Book ISBN: 978-1-84905-455-3

eBook ISBN-13: 978-0-85700-830-5

Get it at: [Jessica Kingsley Publishers](#)
[Amazon](#)

Book Review by Lindsay, M: Sanderson, H. & Lepkowsky, M.B. (2014). Person-Centred Teams: A Practical Guide to Delivering Personalisation Through Effective Teamwork. London: Jessica Kingsley. ISBN 978-1-84905-455-3. EJPCH, 2015; 3(3): 417-420.

"The particular focus of this book is for teams working in health, social care, education and the voluntary sector. There is a drive towards personalisation, to make sure that people are at the centre of decisions about their lives and services and that they have as much choice and control as possible. No matter its designation, effective personalisation must be delivered by person-centred staff and teams across the entire organisation."

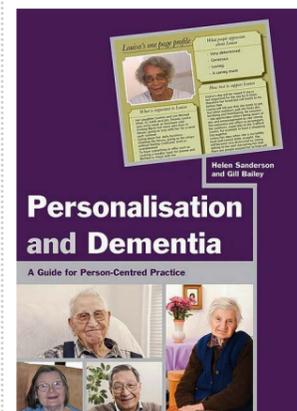
"This book is a very practical guide designed to provide a clear and well illustrated example of how to define effective team work with just five themes and examples from health and community services across the charity and public sector. The authors have clearly explained 'performance' and 'progress' in the context of team work. They have defined success as sharing learning and growing a community of practice around these ideas. The book takes the practitioner step-by-step through purpose, people, performance, process and progress and, for each, provides a range of ways to choose from and a means to check how people are doing."

An excellent example of involving individuals in teams is the one-page profile which is not only described but practical examples are also provided. One-page profiles are developed through conversations and using person-centred thinking tools, for example, talking about good days and bad days. The authors of the volume provide information about what is important to the individual staff and how he or she needs to be supported. A good one-

page profile will make the reader feel as if they have met the person, even before they meet them. The amount of detail is crucial. They can also be solely work focused, or broader, covering all areas of a person's life. Once everyone in the team has one-page profiles completed, they can begin a team one-page profile. A national organisation that provides support to people with learning disabilities uses one-page profiles as integral to performance management.

New staff members and their managers normally start their one-page profile during the induction training. Three times a year, in their 'one-to-ones' with their manager, staff update their one-page profile, if necessary and talk about whether they are getting the support described in their profile and how they are doing using the person's gifts and talents in the workplace. At the annual appraisal, both the staff member and the manager write what is working and not working from both of their perspectives and use this as the basis for review and action planning. Another organisation does the same and is using that information to contribute to its business planning in place of the usual staff satisfaction survey. At the appraisals, when staff have completed their working/not working points and acted on this, the manager asks for the top two working/not working themes. This information is collected for each staff member and used anonymously to identify the general themes that are working/not working for all staff. The information is then used within the business plan.

This essential manual is an invaluable resource for service providers, managers, practitioners and students involved in health and social care. In discussing multidisciplinary teamwork and those most effective components of this particular approach, this volume represents an important contribution to the person-centered healthcare literature and is, therefore, highly recommended to academics, clinicians and health policymakers alike."



Personalisation and Dementia: A Guide for Person-Centred Practice

Authors: Helen Sanderson, Gill Bailey

Publisher: Jessica Kingsley Publishers

Publication: October 2013

Print Book ISBN-10: 1849053790

Print Book ISBN-13: 978-1849053792

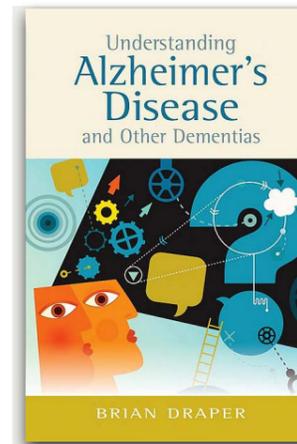
eBook ISBN: 978-0-85700-734-6

Get it at: [Jessica Kingsley Publishers](#)
[Amazon](#)

Book Review by Lindsay, M: Helen Sanderson and Gill Bailey. (2014). Personalisation and Dementia; A Guide for Person-Centred Practice. London: Jessica Kingsley Publishers. ISBN 978-1-84905-379-2 EJPCH, 2015; 3(2): 264-266.

"The person-centred practices outlined in this book show how to deliver genuine personalisation, where what is important for the person is balanced with what is important to the person's wellbeing. It is about the pre-requisites that make a life worth living: each person is an individual with his/her own needs, wishes and dreams to be recognised and met. This book shares the lives and journeys of people and their families. There are stories from people who have early-onset dementia and who live at home with support and from their families. The aim of the book is to look at the big picture and use the self-assessment tools to see how services are delivering personalisation. Proposals are more about changing routines or introducing one-page profiles and person-centred reviews for everyone (in care homes and domiciliary support). It is necessary to examine all aspects of the organisation, from where it is now, so what needs to change in order to make it more person-centred and able to deliver personalisation. In order to look at the big picture it is helpful to check progress in delivering personalised support for people living with dementia in care homes through a series of simple, practical self-assessments for providers who want to ensure they are delivering personalised services."

"Personalising services for people with dementia and enabling people to have as much choice and control in their lives as possible, builds on person-centred care approaches and also requires carers to think differently about dementia. Care providers can explore the dementia journey and learn how to change and develop care practices to focus continually on the importance of relationships, active citizenship and community membership. The approaches clearly laid out in this book, if followed, will help ensure the drive towards personal budgets takes place within the context of delivering improved and tailored outcomes for individuals. The very practical tools in this book for: self-assessment, policies, knowledge and skills, healthcare providers can develop person-centred practice. The usefulness of this guide is that there are many instruments which can be photocopied for use in direct care practice, including one-page profiles of individuals. In using these instruments staff will enjoy getting to know the individuals whom they are caring for, enhancing relationships and work satisfaction in a personalised care environment."



Understanding Alzheimer's Disease and other Dementias

Author: Brian Draper

Publisher: Jessica Kingsley Publishers

Publication: July 2013

Print Book ISBN: 978-1-84905-374-7

eBook ISBN: 978-0-85700-883-1

Get it at: [Jessica Kingsley Publishers](#)
[Amazon](#)

Book Review by Lindsay, M: Brian Draper, (2013). Understanding Alzheimer's Disease and other Dementias. London: Jessica Kingsley Publishers. ISBN 978-84905-374-7. EJPCH, 2014; 2(4): 539-544

"The book is directed towards relatives, carers and professionals involved in the care of a person with dementia. Case studies are used to illustrate the main points. Whether you know someone with Alzheimer's disease, are worried about your own memory, or just simply curious about the condition, this book is intended to meet your needs by providing an overview of Alzheimer's disease and other dementias."

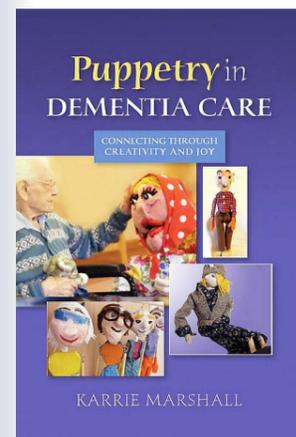
"The early chapters set the scene by describing the various causes of memory impairment. In recent years much has been learnt about the risk factors for Alzheimer's disease and other dementias to the extent that plausible action can now be taken by most people during their early to mid-adult life that may reduce their risk of developing dementia in old age. Family concerns about the genetic risk posed to children and grandchildren are common and examined in Chapter 3. The moderate stage of dementia is described in Chapter 4. The dementia assessment process in Chapter 6 should provide family members with the opportunity to come to grips with the diagnosis and start planning for the future. The treatments available for dementia are covered in Chapters 7 and 8. With the advent of drug treatments for Alzheimer's disease and some other dementias, it is important to understand their indications and limitations. Some drugs are only designed to treat some of the psychological symptoms associated with dementia, for example, depression, anxiety and hallucinations. Others may improve memory and concentration. The different types of drugs available are covered along with other naturopathic and herbal remedies."

There are many psychosocial treatments used in dementia care; most are designed to improve the quality of life of the person with dementia and their carer. The fundamental approach is to adopt person-centered care. An overview of these therapies is provided including reality orientation, aromatherapy and music therapy. If there are significant behavioural or psychological complications of dementia such as depression, hallucinations or aggression, various psychotropic drugs could be used or psychosocial treatments recommended. Interventions to prevent caregiver stress and depression are described, including the important role of the Alzheimer's Association and are the focus of Chapter 9.

The main types of services that are available in most developed countries are considered in Chapter 10. The numerous ethical and legal considerations for a person with dementia including: power of attorney, ability to make a will, guardianship and ability to drive a car are explained in Chapter 12. Staff of residential care face many of the same problems encountered by family caregivers - stress and frustration mixed with some job satisfaction as described in Chapter 11.

In many situations, early planning with the involvement of the person with dementia can avoid problems later. The person with dementia and their family should be encouraged to plan for the future by making sure that they have a valid will, enduring power of attorney and possibly enduring guardianship in place. The future of dementia care including the issues of prevention, early and pre-symptomatic diagnosis and disease-altering therapies such as gene therapy, stem cell grafts and vaccines are discussed in Chapter 13."

"In conclusion, Brian Draper's writing style provides a coherent, comprehensive guide to everything you ever wanted to know about dementia but were afraid to ask. It is full of useful information and advice. These are exciting times in the field of dementia care. Scarcely a week goes by without the publication of new research findings that provide a better understanding of some aspect of the early diagnosis, potential treatment or prevention of Alzheimer's disease and other dementias. We are on the cusp of being able to reliably identify people before they develop symptoms of dementia and, more importantly, being able to provide interventions that will significantly reduce or eliminate their risk of developing dementia. Just how far away this is and how effective the interventions may be are matters of speculation. Overall, the volume provides a clear and coherent account of the state-of-the-art of dementia care and on this basis is highly recommended to all those colleagues with an interest in or responsibility for the care of persons with dementia."



Puppetry in Dementia Care: Connecting Through Creativity and Joy

Author: Karrie Marshall

Publisher: Jessica Kingsley Publishers

Publication: July 2013

Print Book ISBN: 978-1-84905-392-1

eBook ISBN: 978-0-85700-848-0

Get it at: [Jessica Kingsley Publishers](#)

[Amazon](#)

Book Review by Lindsay, M: Karrie Marshall, (2013). *Puppetry in Dementia Care: Connecting Through Creativity and Joy*. London: Jessica Kingsley Publishers. ISBN 978-1-84905-392-1. EJPCH, 2014; 2(4): 545-549.

"This excellent book is aimed at carers of people with dementia at home and in residential care with a wide focus identifying practice from different counties. Regular communication can be charged with all sorts of tensions that overwhelm a person living with dementia. The world of puppetry can be an enjoyable meeting space between people who, for whatever reason, have difficulty engaging in the ways we are used to. The author describes different scenarios in which puppetry can help facilitate connections when words fail and in times of distress and conflict. There is something about creativity that releases people from the confines of a label. It does not mean that people are cured of disease, or miraculously change personalities."

"Each chapter begins with a story about puppetry with people who had experienced isolation. There are practical activities, hints and tips throughout the book. Chapter 1 briefly describes the different forms of puppetry we use with adults with dementia and refers to the puppet-making guides in the appendices. The puppet stories in Chapter 2 convey the importance of understanding individual needs and life preferences. In the story of Helen and the kitten, her preference was strong and clear. Other people may prefer a variety of activities. It is quite possible that someone might choose not to engage with puppetry at all. Each person's decision must be respected. There are still other ways to connect, other ways to care. Creativity has no boundaries.

Chapter 3 focusses on responding to changes in relationship. The puppet stories show opposite ends of the spectrum that relatives and carers find themselves in. One

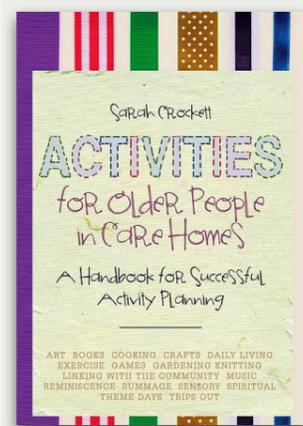
story involves a carer who wants everything to be back to the way it was, with everyone in their roles and all memory function restored. Another story is of a carer who found new and rewarding ways to be with her relative. This shifting of roles in relationship is undoubtedly one of the areas carers find most difficult to achieve. But when they do, the way opens for connecting more deeply in other ways. These carer stories contain complex issues about our human desire to 'fix' things, to make things better. Our cultural and personal values may feel challenged when someone behaves differently. Many people living with the late stages of dementia experience these challenges in their relationships. Through creativity we can discover new aspects of each other and ourselves.

Knowing how to communicate beyond words and memory is the subject of Chapter 4. Chapter 5 is about connecting in times of conflict or confusion. People respond to their changing situations in different ways. A meaningful life is the subject of Chapter 6. Chapter 9 brings us to the world of bed theatre and Chapter 10 explores how to use puppetry to highlight feelings of self, regardless of memories. Chapter 11 looks at enjoyable and relaxing memory experiences, including old puppets. Chapters 12-15 provide explanations of enhancing people's lives through simple acts of creativity and stimulation. Besides the five appendices explaining how to make puppets there are stimulating photographs of puppets."

"Carers at home say their relatives become more talkative after the puppet session. One man said he felt his brain was 'oiled' with the laughter and enjoyment. Clearly, stimulation is important, as is emphasized throughout this book. Having something interesting to consider or participate in helps raise pleasure levels, which increases self-esteem. When motivation strikes us, it seems as though our capabilities expand. We gain confidence and feel more energised, which stimulates more parts of the brain. Sometimes, people need time to become aware of the offer to engage with us and even longer to begin to participate. At other times, the response is immediate. Either way, the connection builds. Creativity begets itself.

The majority of the author's work is focussed on connecting with people who desire to be connected. She facilitates communication to express experiences, feelings and desires through the medium of puppetry. Helping people create their own puppet is deeply rewarding. The puppet can become an extension of the individual. It communicates or interacts with other puppets or people, often with great humour and insight. This is vividly demonstrated by the short case studies provided here. For example, two older ladies began communicating with each other through their puppets. They shared the same care home, but had not conversed before. Many people living in the home seemed self-contained. Not being disturbed by anyone has its merits for those of us who enjoy solitude. But through the puppets they discovered that people wanted to be in connection with other people.

Everyone in any way involved in caring for a person with dementia should use this book to stimulate the quiescent creativity in the person with dementia."



Activities for Older People in Care Homes: A Handbook for Successful Activity Planning

Author: Sarah Crockett

Publisher: Jessica Kingsley Publishers

Publication: July 2013

Print Book ISBN-10: 1849054290

Print Book ISBN-13: 978-1849054294

eBook ISBN: 978-0-85700-839-8

Get it at: [Jessica Kingsley Publishers](#)

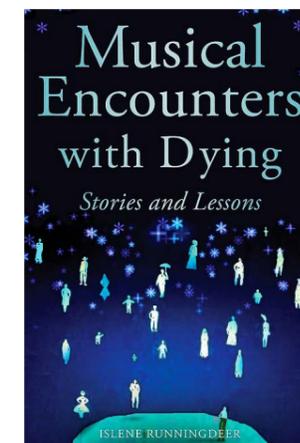
[Amazon](#)

Book Review by Lindsay, M: Sarah Crockett, (2013). *Activities for Older People in Care Homes*. London: Jessica Kingsley. ISBN 978-1-84905-429-4. EJPCH, 2014; 2(4): 550-553.

"This valuable book is aimed at staff caring for older people in Care Homes. The author, Sarah Crockett, provides lots of ideas and points care staff towards other resources which are available, in order to stimulate the provision of lively activity in residential care for older people in Care Homes. The experience of providing activities in residential care for over ten years is evident in Crockett's definition of activity. She explains that every moment can be an activity – whether someone is flicking through a magazine, out on a trip, using bathroom facilities, watching the cat, talking to someone or making a piece of artwork. Periods of inactivity can be turned into meaningful moments just by stopping to chat and really listening to what a person has to say."

"There are many reasons to suspect that this experienced activity co-ordinator's voice will inspire caregivers working in Residential Care Homes. The realistic and highly practical emphasis of the book and the way it is written in a very user-friendly style, means that everyone working in residential Care Homes would find this book an invaluable tool for their work. The relatively short chapters contribute to the book being a useful departmental tool to be consulted according to need. The book is carefully illustrated so that the figures explaining human needs are limited

to 3 very clear communications. Similarly, the illustrations for art work are clear and relevant. The diagrams showing how to perform chair exercises are particularly worthy of study. This book could comfortably replace endless shelves of notes on activities and is of course much more portable and compact than file pages. In conclusion, then, this book is a really excellent tool for every Care Home for Older People and is highly recommended to all those who are building a person-centered approach to dementia care."



Musical Encounters with Dying: Stories and Lessons

Author: Islene Runningdeer

Publisher: Jessica Kingsley Publishers

Publication: June 2013

Print Book ISBN-10: 1849059365

Print Book ISBN-13: 978-1849059367

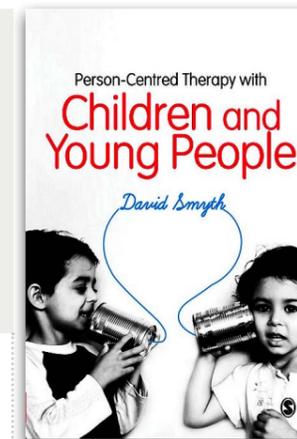
eBook ISBN: ISBN: 978-0-85700-748-3

Get it at: [Jessica Kingsley Publishers](#)

[Amazon](#)

Book Review by Lindsay, M: Islene Runningdeer. (2013). *Musical Encounters with Dying*. London: Jessica Kingsley. ISBN 978-184905-936-7. EJPCH, 2015; 3(2): 261-263

"At a time when someone is at the end of life, it is really important for them to review what their life has been about. The author concludes that in order to truly honour end of life and transition into death as the crowning developmental stage of each human being, we must talk about it more, teach about it more, offer more opportunities for people to experience death and dying in safe and well-supported places. All healthcare staff need to be able to explore their own personal issues with dying, their own deaths and the deaths of people in their care. The general cultural fear of death can be quieted simply by bringing it out into the open. There's nothing like direct exposure to the fearful experience for putting things in a more manageable and much less threatening perspective. The aim is for humanity to achieve a new and healthier relationship with death and the dying. This book is a very significant contribution towards fulfilling this ambition, it should be essential reading for everyone working in palliative or hospice care that wishes to increase the person-centeredness of the care that they and their institution provides."



Person-Centred Therapy with Children and Young People

Author: David Smyth

Publisher: SAGE Publications Ltd

Publication: February 2013

ISBN-10: 0857027603

ISBN-13: 978-0857027603

Get it at: [SAGE Publications Ltd](#) [Amazon](#)

Book Review by Lindsay, M: David Smyth. (2013). *Person-Centred Therapy with Children and Young People*. London: Sage Publications. ISBN 9 78057 027603. EJPCH, 2015; 3(3): 407-411.

"In his introduction to child-centred therapy in Chapter 2, Smyth feels that it is now time to give child-centred therapy its rightful place as a full member of the person-centred group of therapies. At any point in their lives, all people - irrespective of age - embody the sum of their experiences: personal; relational and environmental. As human beings, we 'accumulate' experiences and try to find a way of placing those events within a context that may permit us to continue with our lives. These experiences contribute to our individuality and have the capacity to influence the paths we might take. Occasionally, childhood experiences can be so traumatising that the events remain inaccessible to the adult conscious mind. Nevertheless, even if events cannot be cognitively recalled, they can profoundly influence an individual's capacity to make and maintain relationships. In other instances, there may be only a fragment of conscious memory available to an adult in relation to a painful childhood experience.

Even before undertaking research for this book, David Smyth had come to believe that person-centred therapy had been developed, characteristically, as an approach to facilitate therapeutic work with adult clients. He felt concerned that his early training, founded on adult psychotherapy practice, would not enable him to offer therapy to children and young people. It seemed as if the person-centred approach was unsuitable for young clients, especially since it was popularly described as a 'talking' therapy. How could children be 'made' to talk when this was unlikely to be their communication method of choice? Little did he then appreciate that children can comfortably converse within a therapeutic relationship using

a form of communication called 'play'.

This book is for students of counselling and qualified practitioners in other helping professions wanting to extend their training and thereby to contribute to their ongoing professional development. The author hopes that this volume will find its way to trainees and professionals in other fields, such as medicine, nursing and other allied health professions. Student teachers, trainee social workers, law officers (such as those working in the family courts) and others may find something here to enhance their professional and personal approach."

"The book is presented in two parts, beginning with theory and practice and continuing with professional issues."

"David Smyth considers a wide field of literature with a comprehensive bibliography. He explains personal solutions to issues raised in therapeutic encounters. The exercises throughout the text encourage readers to consider how they would respond to specific concerns in the therapeutic context. He considers the person-centred approach to be inherently holistic and believes it is reasonable to conclude that legal decisions directly affecting the emotional development of children and young people represents a legitimate area for the child-centred practitioner's practice. The book is not prescriptive: that individuals find a path or way of being that has meaning for them within a safe and effective therapeutic practice is central to person-centred values. The practitioner is a therapist who relies not upon tools and techniques with which to direct the patient, but who intuitively believes that offering appropriate conditions for emotional growth within the experience of the therapeutic relationship will enable patients to find a way that has meaning for them as individuals.

The author makes good use of visual images to clarify concepts, for example, the image of the iceberg that illustrates our consciousness (above the water's surface) and our subconscious state (below the waterline). The iceberg drawing is a metaphor describing the conscious and subconscious mind. These figures are only a glimpse of the intuitive personality of the author. The first two chapters on developing practice provide a very honest account of the therapist developing skills, strengthened by short anecdotes of interactions with young people. There is a delightful lack of jargon, to say the book is "user friendly" is inadequate, it is a delight to read. This excellent text is an invaluable tool for students and therapists of counselling and psychotherapy, as well as people involved in supporting the development of young people. It is therefore highly recommended."



Australian Government

Department of Health

The Pharmacy
Guild of Australia5th Community
Pharmacy Agreement

Exploring the health consumers' perspective on the burden of chronic illness and the role of community pharmacy in chronic illness management



Research & Development

Project Team

Lead Researchers

Professor Amanda J. Wheeler, Griffith University
 Dr Fiona Kelly, Griffith University
 Associate Professor Jennifer A. Whitty, The University of Queensland
 Dr Michelle A. King, Griffith University
 Professor Elizabeth Kendall, Griffith University

Research Team

Dr Adem Sav (Senior Research Assistant), Griffith University
 Sara S. McMillan (PhD Candidate), Griffith University
 Claire Campbell (Consumer Research Assistant)

Research Support

Ciara McLennan (Pharmacist Research Assistant)
 Nicholas Moir (Research Assistant), Griffith University
 Brittney Williams (Research Assistant), Griffith University
 Beth Hunter (Project Manager), Griffith University
 Rhonda Knights (Business Support Officer), Griffith University
 Gabor Mihala (Data Management), Griffith University

Introduction

Chronic health conditions

Chronic or long-term health conditions are characterised as having a complex causality, with long periods of illness and functional impairment or disability [1]. The World Health Organization defines chronic conditions as including non-communicable conditions (e.g. diabetes), persistent communicable conditions (e.g. HIV/AIDS), long-term mental health disorders (e.g. depression) and ongoing physical or structural impairment (e.g. blindness) [2]. Globally, chronic diseases are the leading cause of mortality [3], equating to more than 36 million deaths in 2008 [4]. The number of people with multiple chronic conditions is rising [4-6], particularly in the older population, with 8.0% of Australians over 65 years reporting more than four conditions [5]. For consistency, the term chronic conditions is used in this report.

Treatment burden

Despite significant advancements in healthcare, people with chronic conditions still experience *treatment burden*. This is defined as: *The consequences a person with a chronic condition or unpaid*

carer experiences as a result of undertaking or engaging in treatment, such as medications, therapies, medical interventions, etc. [7]. Learning about, adhering to and monitoring treatment and engaging with others are key aspects of burden, particularly medication use [8]. In 2010, 262 million medicines were prescribed in Australia, primarily to treat chronic conditions [9] and it is estimated that Australians aged 65-75 years, will be using on average six prescribed medicines by 2019. Treatment burden has received limited attention from researchers and health policy makers. Moreover there is limited knowledge about the ability of health professionals to recognise and respond when people feel overburdened. Research has neglected the experiences of those with more complex needs [10], and the issues unique to culturally and linguistically diverse populations, Aboriginal and Torres Strait Islander peoples and persons who are socially disadvantaged. Unpaid carers are another population that experience burden differently through their support of people with chronic conditions and greater insight is needed [11].

Patient centred care

Providing consumers with the opportunity to become involved in their own care is considered a core element of healthcare quality [12, 13] and an 'ethical imperative' [14]. Although there has been little consensus on the definition of patient centred care, there is some agreement on its key attributes and domains (Table 1.1) [15]. There is limited concrete evidence of the benefits of patient centred care and additional research is needed.

Table 1.1: Key domains of patient centred care

Holistic care	Responds to the true needs of consumers by valuing the entire person, considering the social context in which they live and recognising the interdependence of their parts.
Individualised care	Considers the unique history, specific needs, preferences and health concerns of an individual and customises health care to meet their needs.
Respectful care	Recognises and acknowledges consumer competence in their own care, respecting their right to choose and supporting their strengths and abilities.
Empowering care	Assists people to learn and obtain information about their healthcare and promotes self-confidence, self-determination and consumer autonomy to facilitate active participation in decision-making for their healthcare.

Source: Adapted from Morgan and Yoder [15] and McMillan et al. [16].

Role of community pharmacy

Increasingly, pharmacists are being expected to shift from a "product centred focus towards a patient centred focus" [17]. Furthermore, the Australian pharmacy profession endorses professional standards and policies that promote the delivery of patient centred services [18]. These include the Community Pharmacy Service Charter and also the Pharmaceutical Society of Australia's Code of Ethics which specifically states that pharmacists must encourage health consumers to actively participate in their health care, with informed consent [19]. Despite a drive towards more patient centred practice, scant data are available on the pharmacy services and attributes of patient centred care that people with chronic conditions and their carers expect, and/or want, from pharmacists and support staff. As medication is frequently used in the treatment of chronic conditions, pharmacy staff members are likely to have frequent contact with these consumers. The increasing rates of chronic conditions and comorbidities [4, 9], generated the overall question and aim of this study: *How can community pharmacy assist people with chronic health conditions to manage their health in a patient centred way?*

Project purpose and outline

The overall **project objectives** were to:

1) Undertake a literature review regarding the burden of chronic

conditions, the burden of treatment regimens and the benefits of using a patient centred approach to care;

2) Collect data that explores and measures: health consumer perspectives on the burden of chronic conditions and of multiple treatment regimens; health consumers' expectations of community pharmacy services and how these can assist with health management; and

3) Make recommendations on: the role community pharmacy can play in assisting consumers with their chronic conditions; strategies and/or models of care for community pharmacists to use when assisting consumers with chronic conditions and complex treatment regimens.

The specific aims were to:

- undertake a systematic literature review to identify current research on the burden of chronic conditions, related treatment, the benefits of patient centred care and tools to assess this;
- conduct stakeholder interviews to explore organisational perspectives of the burden of chronic conditions, perceptions of patient centred care, and the role of community pharmacy;
- conduct interviews and nominal groups¹ with health consumers and carers to fully explore the diversity of perspectives of the burden of chronic disease, consumer health care priorities and their perceptions of what patient centred care should be in the community pharmacy;
- develop a survey, including a discrete choice experiment (DCE) based on data collected during interviews and nominal groups, and use this to examine treatment burden, quality of life, and the potential value of selected services that pharmacy may deliver;
- explore the views of pharmacists and GPs on patient centred care, treatment burden and consumer healthcare priorities to reveal any disparities between consumer and health professional views and inform future training; and
- use the qualitative and quantitative research data to describe the significance of treatment burden and contextualise this with consumer views and experiences.

Project design

Commencing in November 2011, this 2.5-year project used a mixed methods approach over three stages (Figure 1.1). A total of 661 consumers with chronic conditions and their carers and 322 health professionals were recruited from four regions (Logan-Beaudesert and Mt Isa/North West in Queensland, Northern Rivers in New South Wales, Greater Perth in Western Australia) to participate in one or more stages of the research. Ethical approval was obtained from Griffith University and Queensland Health.

Stage One included a concept analysis, systematic review and 21 key stakeholder interviews from key consumer and professional organisations to identify their perspective of:

- patient centred care, treatment burden and the role of community pharmacy in assisting consumers to self-manage their illness(s)
- the health care priorities and needs for the consumers that they represent or support
- recruitment strategies for consumer engagement

The second and third stage involved consumers and health professionals in four key areas across 3 states: Logan-Beaudesert, Mt Isa and north-west area (QLD), Northern Rivers region (NSW) and the greater Perth area (WA). A minimum of 108 interviews and 16 focus groups with health consumers, their family members or carers were asked for their personal accounts on their:

- chronic illness, its treatment burden and impact on them and their family
- interactions with health providers, particularly community pharmacy services
- health care priorities and perceptions of what patient centred care should be in the pharmacy
- expectations of community pharmacy in assisting them to self-manage their illness(s)

¹ A discussion group using the Nominal Group Technique (a structured process that promotes the generation of ideas to a specific question(s). Participants discuss, clarify and prioritise (rank) the ideas raised).

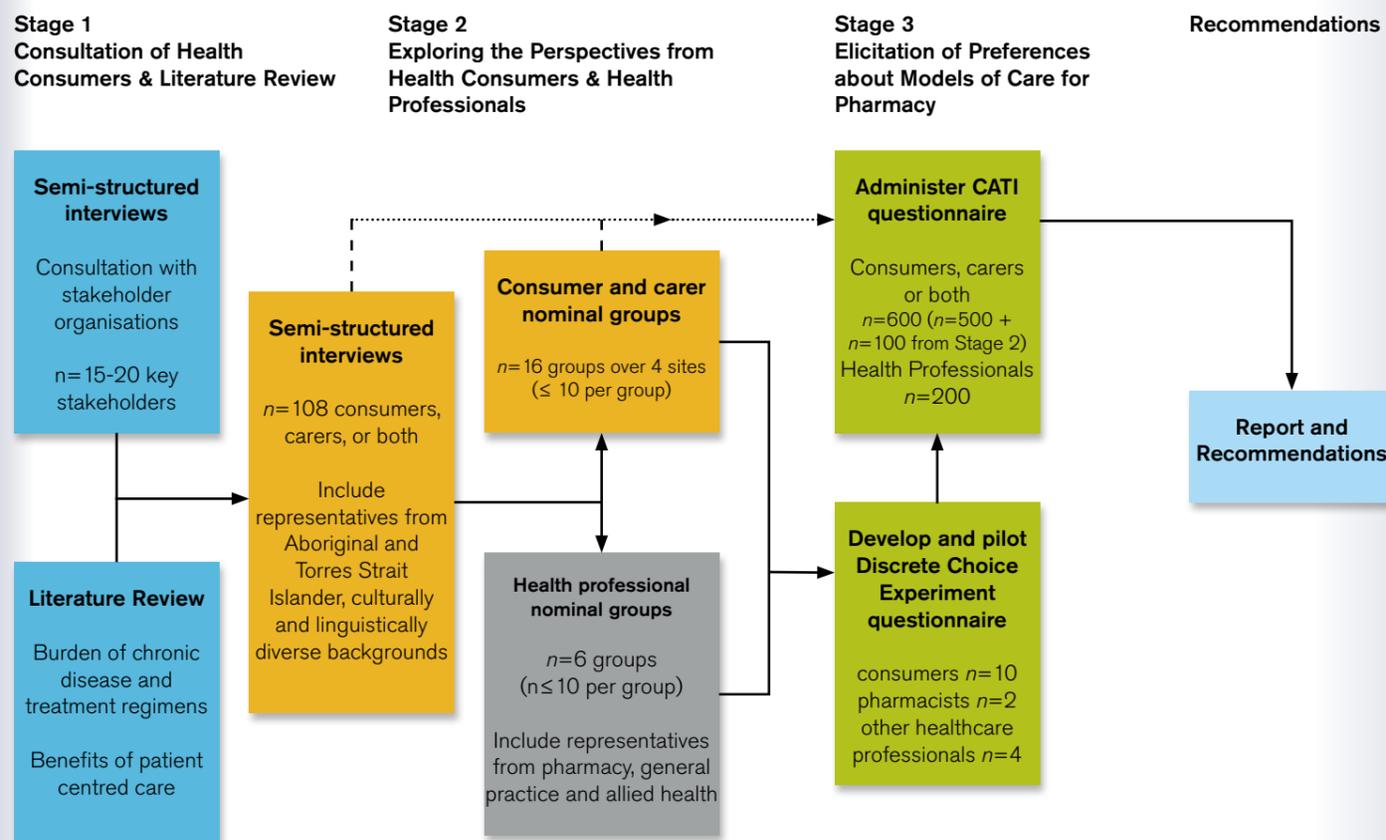


Figure 1.1: Project outline (2011)

Six focus groups were conducted with various health professionals (e.g. pharmacists, GPs, physiotherapists, diabetes educators) across the three states. This explored their views on patient centred care, treatment burden and patient health care priorities to reveal any disparities with the views of the consumer. This information provided insight into how current expectations are or are not met and formed the basis of recommendations for models of care for community pharmacies to assist consumers with chronic illness(es) and complex treatment regimes.

Stage Two included (i) interviews with 97 consumers and carers; (ii) discussion groups using the Nominal Group Technique (i.e. nominal group) with consumers and carers (n=103) and health professionals (n=61) to identify priorities for pharmacy services. Stage Two of the project surveyed a minimum of 600 health consumers and 200 health professionals to:

- quantify consumer preferences and the potential impact of selected pharmacy models of care
- statistically measure the burden of chronic illness
- compare the preferences of consumers and health professionals around what they expect would be important aspects of service delivery for consumers

Stage Three used a quantitative survey and discrete choice experiment to explore preferences about the nature of services (n=602 consumers and carers; n=297 health professionals).

The integration of findings from all three stages was used to develop a meaningful set of recommendations that inform the development of model(s) of care for community pharmacy.

Key Findings

A mixed methods approach was used to explore consumer and carer perceptions of their chronic condition(s), and choices or preferences about how to engage pharmacy in their management. In total, 661 consumers and carers and 322 health professionals participated in one or more of the research stages from four regions of Australia.

1. Whole-of-pharmacy patient centred services are of prime importance to consumers and carers and influence pharmacy choice and loyalty, satisfaction, perceived quality of service and treatment burden. Consumers value and benefit from patient centred services that are holistic, individualised, respectful and empowering. All stages of the research confirmed the central importance of patient centred services, revealing that it can influence choice and loyalty of pharmacy. Pharmacy is a critical intervention point to reduce medication-related treatment burden through informative, respectful relationships, clear communication and consumer engagement. Education and training about the continuum of patient centred care and nature of treatment burden will be required to ensure a whole-of-pharmacy approach to service delivery.

2. A continuous and reliable supply of medication and high quality advice achieved through creative, personalised, responsive, flexible and proactive services is highly valued by consumers and carers. A primary need for consumers and carers was access to a continuous, safe and quality supply of medications. This was described from two perspectives: continued supply of prescription medications from the pharmacist (without visiting the doctor); and convenient medication supply from the pharmacy. There was a strong preference for pharmacists to continue supply of regular medications for a predefined period and for medications previously used to relieve symptom flare-ups. Other suggestions for convenient supply included expanding home deliveries and extending opening hours.

3. Pharmacy is a convenient, accessible and trusted location that can act as a health hub or central point for appropriate referral, access to other health professionals and timely multidisciplinary information. Consumers and carers were frequent pharmacy users, which was associated with treatment burden and highlighted the important role of pharmacy. Access to pharmacy services was a key priority, particularly in relation to pharmacy as a safe health space where consumers and carers could be connected to relevant information and services based on their needs. Pharmacy services acting as a central hub were seen as a strategy for directing people to the multitude of available community organisation resources and support programs that could assist them.

4. Pharmacy is well placed to prevent or limit burden for specific populations, particularly for younger people who are more willing to adopt new initiatives, for carers, frequent pharmacy users and individuals experiencing financial distress or high levels of burden.

Several subgroups emerged as areas of opportunity where proactive pharmacy services could prevent or reduce treatment burden. These included younger people who were more likely to take up new services, middle-aged, low-income earners experiencing significant treatment burden, consumers with diabetes or an endocrine disorder and also carers, as recognition of their role and responsibilities was limited. Pharmacy is in a unique position to identify these groups and provide supportive and timely interventions if such initiatives are tailored to the specific needs of these populations.

5. Financial burden is inherently linked to medication use/non-use and in the absence of broader systemic changes can be identified and addressed by pharmacy. Affordability emerged as a key priority highlighting the need to decrease medication cost through low prices and prescription subsidies, maintain price consistency across pharmacies and develop responsive payment methods that alleviate financial stress. Financial burden was a key component of overall treatment burden with one-quarter of participants reporting that they delayed or neglected to purchase prescribed medication due to cost. Affordability influenced loyalty to a pharmacy, and cost was also a barrier to consumers and carers accessing new pharmacy services.

6. Pharmacy services need to be tailored to economic, personal, cultural and geographical circumstances of their customer base, as prevailing needs and values differ depending on the environment in which the pharmacy is accessed. No single model of pharmacy service will address the diverse needs of consumers and carers across Australia. Ideal pharmacy service did not reflect a particular model, but focused on timely and reliable coordination of relevant services within a patient centred and responsive relationship that was associated with pharmacy loyalty. Overall, this research revealed opportunities for pharmacies to support chronic condition management if pharmacy staff prioritise patient centred care and tailor services to the individual needs of consumers and carers.

Conclusion

There are clear opportunities for community pharmacy to support people with chronic conditions and carers and reduce treatment burden by streamlining access to information and medication, delivered in a patient centred manner. Advocacy for continued medication supply by pharmacists and strengthening collaborative practices between other health professionals and community organisations is a priority. Pharmacy provides a unique opportunity for targeted proactive intervention with particular groups of consumers and carers through extension of existing and innovative pharmacy services that deliver greater coordination of care and convenience for consumers and carers.

Financial Assistance:

The Research & Development (R&D) Programme is funded by the Australian Government Department of Health as part of the Fifth Community Pharmacy Agreement.

This report was produced with the financial assistance of the Australian Government Department of Health. The financial assistance provided must not be taken as endorsement of the contents of this report. The Pharmacy Guild of Australia manages the Fifth Community Pharmacy Agreement Research & Development Programme which supports research and development in the area of pharmacy practice. The funded projects are undertaken by independent researchers and therefore, the views, hypotheses and subsequent findings of the research are not necessarily those of The Pharmacy Guild of Australia.

Obtain The Full Report

References

- Australian Institute of Health and Welfare. Chronic disease. Australian Institute of Health and Welfare. 2013. <http://www.aihw.gov.au/chronic-diseases/>. Accessed 13 June 2013.
- World Health Organization. Innovative care for chronic conditions: building blocks for action. 2002. http://www.improvingchroniccare.org/downloads/who_innovative_care_for_chronic_conditions.pdf.
- World Health Organization. Noncommunicable diseases (NCD). 2014. <http://www.who.int/gho/ncd/en/index.html>.
- World Health Organization. Noncommunicable diseases country profiles 2011. World Health Organization, Geneva, Switzerland. 2011. http://www.who.int/nmh/publications/ncd_profiles2011/en/. Accessed 10 January 2013.
- Australian Institute of Health and Welfare. Australia's health 2012. Australian Institute of Health and Welfare, Canberra. 2012. <http://www.aihw.gov.au/publication-detail/?id=10737422172&tab=3>. Accessed 10 January 2013.
- Smith SM, Soubhi H, Fortin M, Hudon C, O'Dowd T. Managing patients with multimorbidity: systematic review of interventions in primary care and community settings. *BMJ* 2012;345:e5205. doi:10.1136/bmj.e5205.
- Sav A, King MA, Whitty JA, Kendall E, McMillan SS, Kelly F et al. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expect*. 2013. doi:10.1111/hex.12046.
- Gallacher K, May C, Montori V, Mair F. Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *Ann Fam Med*. 2011;9(3):235-43.
- Australian Institute of Health and Welfare. Australia's Health 2012. Australian Institute of Health and Welfare, Canberra. 2012. <http://www.aihw.gov.au/publication-detail/?id=10737422172&tab=3>. Accessed 10 January 2013.
- Caughey G, Vitry A, Gilbert A, Roughead E. Prevalence of comorbidity of chronic diseases in Australia. *BMC Public Health*. 2008;8(1):221.
- McNamara B, Rosenwax L. Which carers of family members at the end of life need more support from health services and why? *Soc Sci Med*. 2010;70(7):1035-41. doi:10.1016/j.socscimed.2009.11.029.
- Australian Commission on Safety and Quality in Health Care. Patient-centred care: Improving quality and safety through partnerships with patients and consumers. Sydney: ACSQHC2011.
- Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. National Academy Press, Washington, DC. 2001. http://www.nap.edu/openbook.php?record_id=10027. Accessed 10 January 2013.
- The Salzburg Statement on Shared Decision Making. Salzburg Global Seminar: The Greatest Untapped Resource in Healthcare? Informing and Involving Patients in Decisions about Their Medical Care 12 - 17 December 2010 Salzburg Global Seminar, ; 2011. p. Session 477.
- Morgan S, Yoder LH. A concept analysis of person-centered care. *J Holistic Nurs*. 2012;30(1):6-15. doi:10.1177/0898010111412189.
- McMillan SS, Kendall E, Sav A, King MA, Whitty JA, Kelly F et al. Patient-centered approaches to health care: a systematic review of randomized controlled trials. 2013. doi:10.1177/1077558713496318.
- Droege M. The role of reflective practice in pharmacy. *Educ Health*. 2003;16(1):68-74.
- Pharmaceutical Society of Australia. Professional Practice Standards - Version 4 - June 2010. ACT: Pharmaceutical Society of Australia; 2010.
- Pharmaceutical Society of Australia. Code of Ethics. Pharmaceutical Society of Australia. 2013. <http://www.psa.org.au/membership/ethics>. Accessed 13 June 2013.

Person-centred Care Around the World

The Health Policy Partnership

The Health Foundation

Publishing Institute

The Health Policy Partnership (www.healthpolicypartnership.com) is uniquely placed to understand the challenges facing healthcare systems and the people who use them, exposing gaps in prevention, treatment and care, and identifying new opportunities to improve the health and wellbeing of our societies. Health Policy Partnership specialises in:

- Policy research and analysis: Evidence-based policy reports, tools for engagement with policymakers, and publishing of peer-reviewed research to academic standards
- Intersectoral partnerships: Collaboration with patient groups, professionals, and the private sector to secure broad endorsement and consensus for change
- Action-oriented policy solutions: Translation of recommendations into sustainable policy change with major work in the public domain

Funding Institute

The Health Foundation (www.health.org.uk) is an independent charity working to improve the quality of health and health care in the UK.

- The Health Foundation's central premise is that patients are partners in their own health and health care, and that the person should be the focus of health care, not their illnesses or conditions.
- The Health Foundation wants a more person-centred health care system; one that supports people to make informed decisions about and successfully manage their own health and care, including choosing when to let others act on our behalf, and one that delivers care responsive to people's individual abilities, preferences, lifestyles and goals.

Project Authors

Ed Harding, The Health Policy Partnership
Suzanne Wait, The Health Policy Partnership
Jonathan Scrutton, The International Longevity Centre UK

Introduction

As it promotes health and wellbeing, integrated care, and true partnerships with patients, person-centred healthcare is a sustainable solution to many of the problems facing our fragmented, paternalistic and disease-focused health systems. However, the international field of person-centred care is complex, with many different schools of thought, terminologies, and sometimes conflicting messages from policy and research.

Objectives of the scan are summarized in two main points:

- To deliver a catalogue of key contributors, networks, and a global 'state of play' analysis of person-centred care as an evolving movement for change - who was doing what, what different people mean by person-centred care, and where this important global discussion might be going.
- To look at the future direction and gap analysis of each of these fields - highlighting key work, barriers and opportunities to progress.

Project Design

The project offers an overarching 'state of play' narrative in the research, implementation of measurement of person-centred care, illustrated through key examples of recent and ongoing work and materials.

A working definition for person-centered healthcare was a fundamental guide to the synthesis of this research, and was based on earlier work sponsored by with the Health Foundation:

- Principle 1. Being person-centred means affording people dignity, respect and compassion
- Principle 2. Being person-centred means offering coordinated care, support or treatment

- Principle 3. Being person-centred means offering personalised care, support or treatment
- Principle 4. Being person-centred means being enabling

This synthesis has been drawn together from a pragmatic search of recent literature, through Embase and PubMed search engines, with 8 core terms used to identify relevant publications for person-centered care. 15 excluding guidelines were placed to refine the outcomes of this search, resulting in 500 captured literature out of a total of 17,000 screened titles. A search through Google was executed using 18 core terms (figure 1) of 85 combinations, and identified 220 organisations worldwide advocating for person-centered healthcare. Calls for information were sent out, of which 85 responses were received. Interviews and written contributions about the perspectives of selected key commentators in the field were conducted and will be published in the report (figure 2).

Key Findings

An international community of key contributors recognised:

- Beyond some core principles, person-centred care is understood in many different ways by many different people.
- A substantial international body of work currently exists across a heterogeneous and evolving community, with complex synergy between 'person-centred care' and other associated groupings (e.g. 'patient centred-care', 'patient engagement', etc.)
- 'Person-centred care' is term rooted in culture and context. Diversity appears to reflect the different needs of different populations and healthcare settings.
- Commentators give different emphasis and priority to different qualities of person-centred care. These are not necessarily exclusive, but include:
 - A 'first order' grouping of concepts: person-centred care as an overarching framework which orders a number of distinct concepts and practices, such as shared decision making, care planning, information, and self-management support.
 - Personhood and anti-reductionism: promoting a deeper existential and philosophical understanding of personhood to better engage with the patient and address their unique needs.

Informed decision making	Enablement
Self-directed support	Re-ablement
Activation	Recovery
Collaborative care	Empowerment
Partnerships	Supported self-management
Involvement	Person-led care
Person-provider partnerships	Individualised care
Personalisation	Health literacy
Co-production	Shared decision making

Figure 1: Core Terms used to identify recent literature through Embase and PubMed

- **Partnership, mutualism, co-production:** an understanding that through partnership, mutual respect, and self-knowledge, medical expertise can combine with patient self-knowledge for maximum benefit.

Some strategic research issues identified by the scan:

- A lack of common definitions is frequently cited as barrier to the aggregation of research and replication of studies.
- Research 'hotspots' in different settings and diseases are encouraging but siloed activity may slow diffusion of good practice, and risk divergent concepts.
- Behind some promising evidence of impact there are still questions about differentiating processes, outcomes and indicators, and what is to be counted as 'success'.
- Patient involvement in helping to shape research priorities is rare.

Some strategic implementation issues identified by the scan:

- There is a significant presence of 'person-centred care' in health care policy in English speaking and Northern European countries, however implementation lags a considerable way behind.
- The implementation challenge will require a 'whole system response', for example organisational change models, formal education and training for healthcare professionals, but also efforts to tackle resistance and misunderstanding, and to connect and explore with deeper, ethical and personal values at the individual level.
- There appear to be major unanswered questions about how best to lead models of person-centred care in vulnerable and disadvantaged populations.

Some strategic measurement issues identified by the scan:

- Measurement is widely considered to be vitally important in embedding person-centred care in the mainstream.
- However, a number of practical and ethical concerns arise, including; the limitations of patient satisfaction and patient experience, a lack of validated models for measurement, uncertain psycho-metric instruments and the absence of the patient involvement in the design and validation of measurement tools.
- Those tools that exist have mostly been designed for research - i.e. to evidence the benefits of an intervention - and may be challenging for mainstream use.
- Setting and monitoring more personalised outcomes is regarded as important by key contributors, but models are largely experimental.
- Linking measurement to financial incentives and performance assessment seems rare, however this will need to navigate the issue of perverse incentives.
- Fears of measurement 'overload' and capacity issues in management and care professionals highlight the need for practical models in the everyday setting.

Appleyard, Prof. James. <i>International College of Person-Centred Medicine</i>
Boström, Eva. <i>Department of Nursing, Umeå University</i>
Britten, Prof. Nicky. <i>University of Exeter Medical School, UK</i>
Butow, Prof. Phyllis. <i>University of Sydney, Australia</i>
Collins, Dr. Alf. <i>GP UK</i>
Coulter, Dr. Angela. <i>Nuffield Department of Population Health, University of Oxford, UK</i>
Cribb, Prof. Alan. <i>King's College London, UK</i>
Curtice, Dr. Lisa. <i>Health and Social Care Alliance, Scotland</i>
Ekman, Prof. Inger. <i>University of Gothenburg, Sweden</i>
Elwyn, Prof. Glyn. <i>Dartmouth College, USA</i>
Epstein, Prof. Ronald. <i>University of Rochester Medical Center, USA</i>
Fooks, Cathy. <i>The Change Foundation, Canada</i>
Frosch, Dr. Dominick. <i>Gordon and Betty Moore Foundation, USA</i>
Gaudet, Dr. Tracy. <i>US Department of Veterans Affairs, Veterans Health Administration, USA</i>
Glover, Dr. Vaughan. <i>Canadian Association for People-Centred Health</i>
Härter, Prof. Martin. <i>University Medical Center Hamburg-Eppendorf, Germany</i>
Hibbard, Prof. Judith. <i>University of Oregon, USA</i>
Jacobs, Dr. Gaby. <i>Fontys University, The Netherlands</i>
Johnson, Beverley H. <i>Institute for Patient- and Family-Centred Care, USA</i>
Kersten, Prof. Paula. <i>Auckland University of in, New Zealand</i>
Kidd, Prof. Michael. <i>World Organisation of Family Doctors (WONCA), and Flinders University, Australia</i>
Kremer, Prof. Jan. <i>Radboud University Nijmegen Medical Centre, The Netherlands</i>
Légaré, Prof. France. <i>Université Laval, Canada</i>
Levack, Dr. William. <i>University Of Otago, New Zealand</i>
Löpare-Johansson, Lisbeth. <i>Vårdförbundet, Sweden</i>
Luxford, Prof. Karen. <i>Clinical Excellence Commission, Australia</i>
McCormack, Prof. Brendan. <i>Queen Margaret University, UK</i>
McPherson, Dr. Kathryn. <i>Auckland University of Technology, New Zealand</i>
Miles, Prof. Andrew. <i>European Society for Person-Centred Healthcare</i>
Montori, Dr. Victor. <i>Mayo Clinic, USA</i>
Rokstad, Prof. Anne Marie Mork. <i>Norwegian National Advisory Unit on Ageing and Health, Norway</i>
Morris, Susan. <i>Macmillan Cancer Support Wales, UK</i>
Osborne, Prof. Richard. <i>Deakin University, Australia</i>
Paterson, Michael. <i>Joining the Dots, NHS Scotland, UK</i>
Plass, Dr. Anne Marie. <i>NIVEL (Nederlands instituut voor onderzoek van de gezondheidszorg), the Netherlands</i>
Redding, Don. <i>National Voices, UK</i>
Sheridan, Susan. <i>The Patient-Centered Outcomes Research Institute (PCORI), USA</i>
Walsh, Tracy. <i>Planetree, USA</i>
Zimmerman, Prof. Sheryl. <i>University of North Carolina at Chapel Hill, USA</i>

Figure 2: Key individuals who contributed to the synthesis of The International Environmental Scan in person-centered healthcare

Conclusion

If person-centred care is indeed to enter a period of implementation and uptake into policy, much greater exchange will be needed, with a stronger emphasis on lessons learnt in practical delivery and application. Strategic thinking is needed to marry up these strengths and weaknesses, to push the boundaries across other elements of care. This work will make an important contribution to our understanding of how person-centred care can make health care systems more effective, and deliver better outcomes to people and their communities.

PCH RESOURCES

We have selected for our readership some of the recently published literature on Person Centred Healthcare.

The selection offers a wide range of topics on person-centered healthcare systems and guides to the provision of person-centered care.



With courtesy to
The Health Foundation
www.health.org.uk



A practical guide to self-management support: Key components for successful implementation

Authors: Anya de longh, Petrea Fagan, Julie Fenner, Lisa Kidd

Publisher: The Health Foundation

Publication: December 2015

Link to Download file:

<http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf>

Self-management support is when health professionals, teams and services (both within and beyond the NHS) work in ways that ensure that people with long-term conditions have the knowledge, skills, confidence and support they need to manage their condition(s) effectively in the context of their everyday life. A system of effective self-management support requires changes at every level from how and what services are commissioned, to how health professionals and people with long term conditions work together in a consultation, to how people are supported in between appointments. This guide provides an overview of self-management support and the key components for effective implementation. It will be useful both for those starting their self-management support journey and those building on and improving the support that they already provide. The guide explains what self-management support is and why it is important. It then looks at various aspects of putting it into practice, including planning and commissioning, building knowledge, skills and confidence, and measurement and evaluation. The guide also contains suggestions for further reading and case studies of self-management support in practice.

Building the House of Care

Authors: Angelina Taylor

Publisher: The Health Foundation

Publication: December 2015

Link to Download file:

http://personcentredcare.health.org.uk/sites/default/files/resources/buildingthehouseofcare_0.pdf

This paper explores how the House of Care, a coordinated approach to personalised care and support planning, can transform the health and care of people with long-term conditions (LTCs). It contains case studies of evolving practice in Leeds and Somerset and seeks to understand how two whole health economies – individuals, communities, health and social care services and others – are working to manage the rise in the number of people with multiple LTCs and enhance their care experiences. The paper is intended for clinical commissioning groups (CCGs), public health teams, other front-line providers and national bodies.

Person-centred care made simple: What everyone should know about person-centred care

Publisher: The Health Foundation

Publication: October 2014

Link to Download file:

<http://www.health.org.uk/sites/default/files/PersonCentredCareMadeSimple.pdf>

The challenges facing the NHS are well understood. There are growing numbers of older people and people living with long-term conditions and disabilities. At the same time, health and social care budgets are under increasing pressure. If we are to provide high quality care that affords people the best possible quality of life, we need to rethink the relationship between people and the services that provide their care. In person-centred care, health and social care professionals work collaboratively with people who use services. Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and health care. It is coordinated and tailored to the needs of the individual. And, crucially, it ensures that people are always treated with dignity, compassion and respect. This might seem a common sense vision for any form of health care, but it is not standard practice. Often, health care does 'to' or 'for' people rather than 'with' them, finds it difficult to include people in decisions, and views people's goals only in terms of particular clinical outcomes. Adopting person-centred care as 'business as usual' requires fundamental changes to how services are delivered and to roles – not only those of health care professionals, but of patients too – and the relationships between patients, health care professionals and teams. Despite the challenges in making this shift, person-centred care does exist, in a modest but growing number of services, with positive outcomes. It requires effort, but it certainly is possible. This guide seeks to provide a quick overview of person-centred care. It is written for anyone interested in health and health care, including health care professionals and those who use the NHS.

PCH LITERATURE

We have selected for our readership some of the recently published literature on Person Centered Healthcare.

The selection presents a wide range of topics on person-centered healthcare systems and guides to the provision of person-centered care.



Appreciative Healthcare Practice: A guide to compassionate, person-centred care

Authors: Gwilym Wyn Roberts, Andrew Machon

Publisher: M&K Publishing

Publication: July 2015

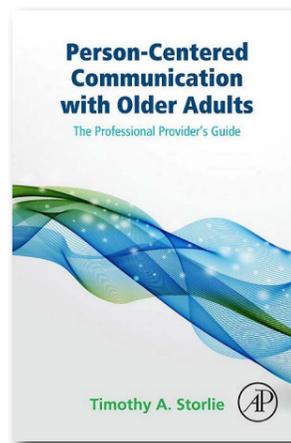
ISBN: 9781907830-93-8

Get it at: [M&K Publishing](#) [Amazon](#)

Written by a leading healthcare academic and an accredited international business coach, this book takes a new approach to one of the most crucial issues in healthcare – how to care for patients appreciatively, responsively and compassionately. In the light of the findings of the Francis Report (2013), and at a time when healthcare services are under enormous pressure, there is a clear and urgent need for such a book.

Despite the challenges of ill health, the authors demonstrate that the opportunity is there for any healthcare practitioner to draw out what the patient needs and desires, in line with the patient's own values, purposes and beliefs. This approach seeks to alleviate suffering and allows the patient to be more empowered and motivated to change, discovering choice and possibility in times of adversity. In this way, the practitioner can help the patient increase their own resilience and resourcefulness. At the same time, the practitioner discovers their own ability to self-care and self-manage.

Aimed at healthcare students and practitioners at all levels, Appreciative Healthcare Practice will provide a valuable and supportive learning resource for a wide range of individuals involved in caring.



Person-Centered Communication with Older Adults: The Professional Provider's Guide

Author: Timothy A. Storlie

Publisher: Academic Press - Elsevier

Publication: June 2015

Print Book ISBN: 9780124201323

eBook ISBN: 9780128004333

Get it at: [Elsevier Store](#) [Amazon](#)

Providers serving older adults face a growing problem. Older adults are becoming increasingly dissatisfied with service quality citing deficits in provider communication and relationship skills. The author argues this dissatisfaction is largely related to three widespread issues: ageism, use of professional jargon, and age-related changes in the older adult. To address these concerns, Dr. Storlie advocates adoption of an evidence-based, person-centered approach to communication.

The benefits of person-centered communication are many. They can increase older adult satisfaction with provider services, enhance mutual respect and understanding, improve accuracy of information exchanged, positively impact service outcomes, increase compliance with provider recommendations, and reduce the frustration and stress often experienced by both provider and older adult.

Rare to this genre, readers are introduced to several under-explored topics within the field of communication, along with methods for applying concepts from research findings into these topics to enhance the quality of interpersonal communication. Topics include the role of mental imagery in the communication process, the influence of neurocardiology on relationships, and controversial findings from research into quantum physics. The book concludes by highlighting progress made in narrowing the interpersonal communication gap and forecasts how communications-oriented technological advances might improve quality of life for 21st century older adults and the providers who serve them.

Utilizing interdisciplinary case studies to illustrate common problematic situations, this book provides detailed exercises that explain how providers can integrate person-centered communication into their practices to improve provider-older adult interactions. Written in a style designed to maximize learning, it helps providers find the information they need, understand what they read, and apply what they've learned to improve professional communication.

Person-Centered Communication with Older Adults is an essential guide for today's healthcare professionals and other aging-services providers, and also for the educators who help to prepare the providers of tomorrow.

- Presents a conceptual framework for understanding respect-based, person-centered communication
- Teaches specific communication skills to

aging services providers and educators to assist in effectively communicating with older adults

- Includes numerous case studies to help in identifying common problematic situations and describing practical ways to integrate positive communication
- One of the first books to integrate scientific, evidence-based findings with a personal approach that includes important new information on neurocardiology



Using Person-centered Health Analytics to Live Longer: Leveraging Engagement, Behavior Change, and Technology for a Healthy Life

Author: Dwight McNeill

Publisher: Pearson Education

Publication: April 2015

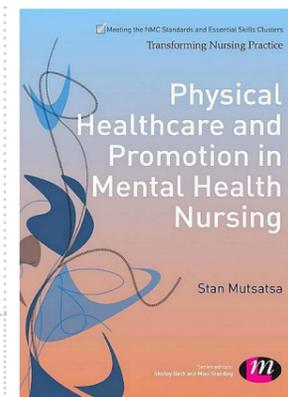
ISBN-10: 0133889971

ISBN-13: 978-0133889970

Get it at: [Amazon](#)

This book provides a framework for providers, payers, governments, and people to partner in the co-production of health. McNeill's new approach recognizes the centrality of prevention, focuses on behavior change as the reliable pathway to improved outcomes, and uses information technologies to empower people as the primary agents of change. Synthesizing powerful new trends and research, he reviews emerging approaches that are already working in other fields, and formulating a powerful "workbench" of essential analytics tools for health production. You'll discover how business intelligence can be refocused to improve health outcomes as well as financial performance; and how to re-engage people from care processes, both when they're sick and when they're well. You'll learn how to use technologies to empower people with information, applications, and connectedness – borrowing successful strategies from other industries to achieve powerful positive impacts in healthcare.

McNeill's insights will be valuable to all professionals, leaders, policymakers, researchers, and strategists engaged in health promotion, healthcare delivery, prevention, public health, health insurance, and life sciences – and everyone interested in managing their own healthcare.



Physical Healthcare and Promotion in Mental Health Nursing

Author: Stanley (Stan) Mutsatsa

Publisher: Learning Matters

Publication: March 2015

ISBN-10: 1446268187

ISBN-13: 978-1446268186

Get it at: [Amazon](#)

It is essential for mental health nurses to understand the physical health needs of people with mental health disorders in order to provide holistic care. Yet these people often have their physical health needs unrecognised or poorly managed. This book is a practical and informative guide to the physical health care of people with mental health illnesses. It covers a range of health-promotion strategies, including exercise, diet and oral health, and assessment, intervention and skills for common physical disorders found in people with mental-health problems. It takes a recovery perspective and emphasises the importance of communication and collaborative care for adherence to healthy lifestyles.



Developing Person-Centred Practice: A Practical Approach to Quality Healthcare

Author: Jaqui Hewitt-Taylor

Publisher: Palgrave Macmillan

Publication: March 2015

Print Book ISBN-10: 1137399783,

ISBN-13: 9781137399786

eBook ISBN-10: 1137399791

ISBN-13: 9781137399793

Get it at: [Vital CourseSmart](#)

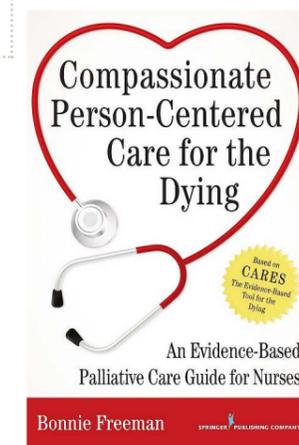
Person-centered care is the idea that the healthcare professional shifts their focus from routine tasks and processes to the individual

needs of the patients. It has been highlighted as the cornerstone of high quality care. But whilst few practitioners intend to work in a non-person-centered way, for reasons such as priorities, organisational policies, workplace culture and resources, a person-centered approach can be very difficult to achieve.

This book provides a practice-focused exploration of how the ideas of person-centeredness can be developed and incorporated in to everyday practice:

- It forms each chapter around an engaging case study, with examples from adult and child health, mental health, learning disabilities and many more.
- It introduces the theoretical basis of person-centered care, including the benefits it has for working environments, staff and patients.
- It demonstrates how meaningful practice development partnerships can be made with patients, including who to involve and how to involve them.
- It takes the reader through the steps of developing a person-centered ethos- from encouraging people to participate in the development, to evaluating the progress and sustaining it in the long run.

With clear and accessible guidance through the use of chapter overviews, key points, activities and web-based resources, this is an important book for anyone interested in developing a person-centered approach to care.



Compassionate Person-Centered Care for the Dying: An Evidence-Based Palliative Care Guide For Nurses

Author: Bonnie Freeman

Publisher: Springer Publishing Company

Publication: February 2015

ISBN-10: 0826122477

ISBN-13: 978-0826122476

Get it at: [Springer Publishing Company](#)

[Amazon](#)

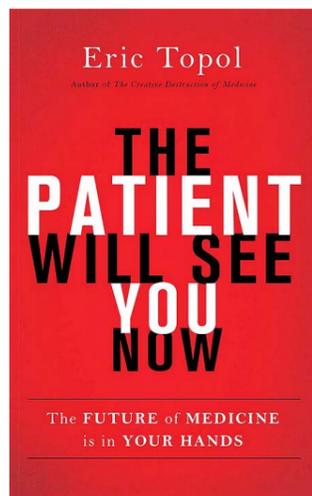
This groundbreaking reference for palliative care nurses is the first to provide realistic and achievable evidence-based methods for incorporating compassionate and humanistic care of the dying into current standards of practice. It

builds on the author's research-based CARES tool; a reference that synthesizes five key elements demonstrated to enable a peaceful death, as free from suffering as possible: comfort, airway management, management of restlessness and delirium, emotional and spiritual support, and self-care for nurses. The book describes, step by step, how nurses can easily implement the basic tenets of the CARES tool into their end-of-life practice. It provides a clearly defined plan that can be individualized for each patient and tailored to specific family needs, and facilitates caring for the dying in the most respectful and humane way possible.

The book identifies the most common symptom management needs in dying patients and describes, in detail, the five components of the CARES paradigm and how to implement them to enable a peaceful death and minimize suffering. It includes palliative care prompts founded on 29 evidence-based recommendations and the National Consensus Project for Palliative Care Clinical Practice Guidelines. The resource also addresses the importance of the nurse to act as a patient advocate, how to achieve compassionate communication with the patient and family, and barriers and challenges to compassionate care. Case studies emphasize the importance of compassionate nursing care of the dying and how it can be effectively achieved.

Key Features:

- Provides nurses with a clear understanding of the most common needs of the dying and supplies practical applications to facilitate and improve care
- Clarifies the current and often complex literature on care of the dying
- Includes case studies illustrating the most common needs of dying patients and how these are addressed effectively by the CARES tool
- Based on extensive evidence as well as on the National Consensus Project for Palliative Care Clinical Practice Guidelines



The Patient Will See You Now: The Future of Medicine is in Your Hands

Author: Eric Topol
Publisher: Basic Books
Publication: January 2015
ISBN: 0465054749

Get it at: [Amazon](#)

A trip to the doctor is almost a guarantee of misery. You'll make an appointment months in advance. You'll probably wait for several hours until you hear "the doctor will see you now"—but only for fifteen minutes! Then you'll wait even longer for lab tests, the results of which you'll likely never see, unless they indicate further (and more invasive) tests, most of which will probably prove unnecessary (much like physicals themselves). And your bill will be astronomical.

In *The Patient Will See You Now*, Eric Topol, one of the nation's top physicians, shows why medicine does not have to be that way. Instead, you could use your smartphone to get rapid test results from one drop of blood, monitor your vital signs both day and night, and use an artificially intelligent algorithm to receive a diagnosis without having to see a doctor, all at a small fraction of the cost imposed by our modern healthcare system.

The change is powered by what Topol calls medicine's "Gutenberg moment." Much as the printing press took learning out of the hands of a priestly class, the mobile internet is doing the same for medicine, giving us unprecedented control over our healthcare. With smartphones in hand, we are no longer beholden to an impersonal and paternalistic system in which "doctor knows best." Medicine has been digitized, Topol argues; now it will be democratized. Computers will replace physicians for many diagnostic tasks, citizen science will give rise to citizen medicine, and enormous data sets will give us new means to attack conditions that have long been incurable. Massive, open, online medicine, where diagnostics are done by Facebook-like comparisons of medical profiles, will enable real-time, real-world research on massive populations. There's no doubt the path forward will be complicated: the medical establishment will resist these changes, and digitized medicine inevitably raises serious issues surrounding privacy. Nevertheless, the result—better, cheaper, and more human health care—will be worth it.

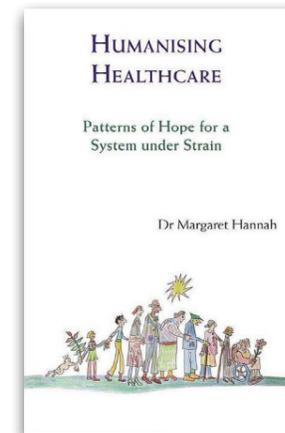
Provocative and engrossing, *The Patient Will See You Now* is essential reading for anyone who thinks they deserve better health care. That is, for all of us.

rampant. There is an explosion of research projects using MI or adaptations of MI in the behavioral health medicine field in the past decade. Hospitalizations can't make people change. How marvelous is it that an evidence-based health behavior change approach (MI) can help people change the outcomes of their illnesses and the course of their lives.

This therapeutic approach is not a form of psychotherapy and is not the stuff of cobwebs and old leather couches. MI is readily integrated into regular ward rounds and office visits and provides an effective and efficient approach to patients' clinical encounters.

Written by experts in the field and medical trainees across medicine, this is the first MI guide of its kind. It explores how MI enhances contact with patients from every level of training, following an accessible, succinct approach. This book covers the application of MI method and skills into practice and also includes numerous clinical scenarios, personal reflections and online animated clinical vignettes (video clips) that share the challenges and successes the authors have focused. Main features:

- Strong emphasis on clinical application, with vignettes and personal reflections as commentary on skills and challenges
- Specialized chapters cover a diverse of topics including Motivational Interviewing in challenging medical encounters, primary care, pediatric populations, family settings, and special populations.
- Board-style questions are included at the end of each chapter
- Eight animated case vignettes are included on OxfordMedicine.com, based on actual clinical encounters. Dialogue between a "trainee" and a "mentor" outlining the various Motivational Interviewing skills is included



Humanising Healthcare: Patterns of Hope for a System Under Strain

Author: Margaret Hannah
Publisher: Triarchy Press
Publication: December 2014
Print Book ISBN: 978-1-909470-44-6
eBook ISBN: 9781909470514

Get it at: [Triarchy Press](#) [Amazon](#)

A practical strategy for transforming the UK and other healthcare systems, offering an affordable, sustainable and compassionate alternative to the present mess.

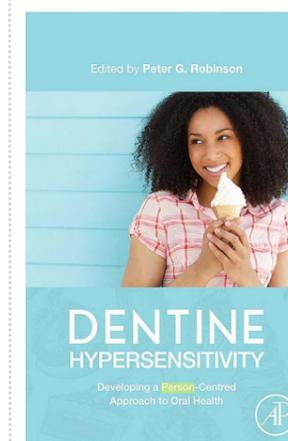
Healthcare systems across the developed world are in trouble. Changing patterns of disease, an ageing population and advances in drugs and technology feed an inexorable rise in costs outrunning our best efforts to contain them. At a human level the system is coming under intolerable strain. Demands for cost savings squeeze out the time and humanity needed for good care and quality relationships. Safety suffers. Staff become demoralised, stressed and burned out.

In the first two parts of *Humanising Healthcare* and focusing on the UK's National Health Service, Dr Hannah explores the fundamental assumptions which have brought us to this point and which likewise inform our current inadequate responses. She dissects the burgeoning regime of regulation and inspection that tries to impose ever tighter controls on a healthcare system that needs to be freed to serve its citizen patients.

In the final part of the book, 'Another Way Is Possible', Dr Margaret Hannah offers a practical alternative strategy based on numerous examples of transformative practice from the UK and around the world. It promises a sustainable culture of healthcare that will enable us all to live healthy, fulfilled lives at a fraction of the current cost.

Chief among Dr Hannah's case studies is the 'Nuka' model of care in Alaska. Healthcare in the Nuka system is based on reconnecting people into the web of life. Don Berwick, a former health adviser to President Obama and a founder of the highly respected Institute for Healthcare Improvement, has

declared that Nuka "is probably the leading example of healthcare redesign in the world. US healthcare suffers from high costs and low quality. This system has reversed that: the quality of care is the highest I have seen anywhere in the world, and the costs are highly sustainable. It's extraordinary. It is surely leading healthcare to its new and proper destination."

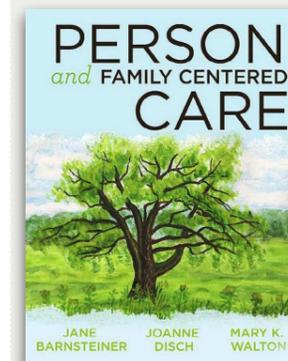


Dentine Hypersensitivity: Developing a Person-centred Approach to Oral Health

Author: Peter Glenn Robinson
Publisher: Academic Press - Elsevier
Publication: October 2014
Print Book ISBN: 9780128016312
eBook ISBN: 9780128016589

Get it at: [Amazon](#) [Elsevier Store](#)

Dentine Hypersensitivity: Developing a Person-Centred Approach to Oral Health provides a detailed and integrated account of interdisciplinary research into dentine hypersensitivity. The monograph will be of interest to all those working on person centred oral health related research because it provides not only an account of the findings of a series of studies into dentine hypersensitivity drawing on the research traditions of epidemiology, sociology psychology, and dental public health but an integrated study of the benefits of exploring a single oral condition from this range of disciplines.

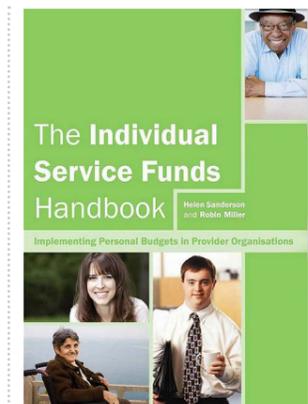


Person and Family Centered Care

Authors: Jane Barnsteiner, Joanne Disch, Mary Walton
Publisher: Sigma Theta Tau
Publication: June 2014
ISBN-10: 1938835077
ISBN-13: 978-1938835070

Get it at: [Amazon](#)

Person and Family Centered Care offers a new approach that begins with the person, embraces the family, and encompasses all care delivery locations. At the forefront of this movement are authors Jane Barnsteiner, Joanne Disch, and Mary K. Walton, who present a surprisingly practical clinical reference covering a vast array of patient-care scenarios, together with effective strategies for achieving optimal outcomes. This groundbreaking text is a complete resource that ensures the needs of patients, families, and caregivers are met.

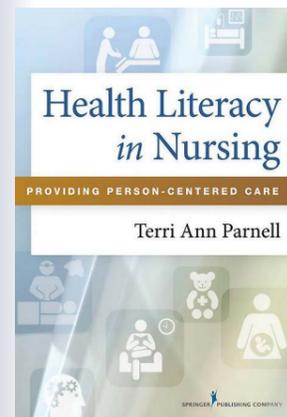


The Individual Service Funds Handbook: Implementing Personal Budgets in Provider Organisations

Authors: Robin Miller, Helen Sanderson
Publisher: Jessica Kingsley Publishers
Publication: September 2014
Print Book ISBN: 978-1-84905-423-2
eBook ISBN: 978-0-85700-792-6

Get it at: [Amazon](#)

The Individual Service Funds Handbook is the definitive guide to one of the most innovative forms of personal budget in health and social care. It gives a clear explanation of what Individual Service Funds (ISFs) are, how to use them effectively and includes all the information you need in order to implement them in your organisation. The Handbook spans a range of settings, including a dementia care home, supported living and residential homes for adults with learning disabilities and people who use mental health services. It also sets out guidelines and templates which can be used when implementing ISFs, addressing key practical concerns including: how to put together effective support plans, and how to ensure that ISFs are delivered in a person-centred way, how to overcome organisational complexities in implementation and supporting managers. A one-stop resource for anyone wanting to understand the potential of ISFs, the Handbook is required reading for service providers, commissioners, and those engaged in person-centred practice and personalisation, including user-led organisations.



Health Literacy in Nursing
Author: Terri Parnell
Publisher: Springer Publishing Company
Publication: August 2014
ISBN-10: 0826161723
ISBN-13: 978-0826161727
Get it at: [Springer Publishing Company](#)
[Amazon](#)

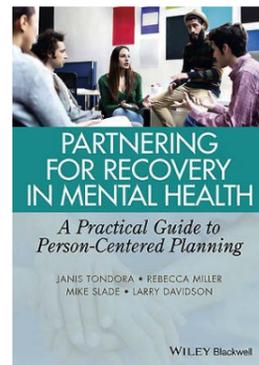
Promoting the health literacy of patients across all settings is an essential component of prevention, wellness, and effective medical treatment. This health literacy textbook provides an overview of health literacy, discusses the magnitude of the issue, and explains implications of low health literacy. It details strategies to enhance effective communication between patients and nursing practitioners. Through case-based examples, this textbook and clinical guide assists nurses in developing the requisite skills needed to communicate effectively so that patients can truly make informed health decisions and enhance health outcomes.

Health Literacy in Nursing promotes verbal and written communication strategies that nurses can use to effectively meet the individualized needs of an increasingly diverse patient population in an effort to enhance patient-provider communication across the entire continuum of care. It provides strategies for creating culturally appropriate written materials in plain language that patients can read and follow when they arrive home.

Nursing professionals can build upon the basic tools offered in the text throughout their career to stay abreast of methods to effectively communicate and educate a culturally and linguistically diverse demographic. Additionally, the material can easily be incorporated into course content regarding "unique populations" (pediatrics, older adults, research participants, and those managing mental health and end-of-life care decisions) for whom health literacy is often overlooked. The book will be valuable to undergraduate and graduate nursing students studying to meet advanced nurse practice competencies and is an essential resource for practicing nurses who must stay abreast of evolving standards and regulations related to the provision of safe and effective patient and family-centered care.

Key Features:

- Provides a solid foundation for developing skills that foster health literacy among all patients and practitioners
- Assists in meeting the regulatory requirements for providing culturally and linguistically appropriate patient education
- Includes guidelines for improving health literacy according to increasingly evolving regulatory standards
- Includes case-based examples to illustrate the purpose and effectiveness of enhancing patient and provider health literacy skills
- Addresses both oral and written communication strategies

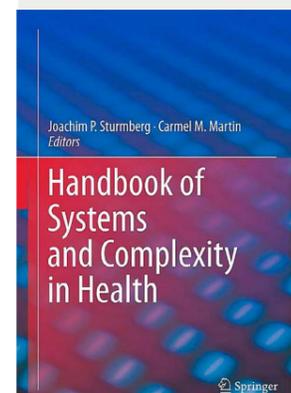


Partnering for Recovery in Mental Health: A Practical Guide to Person-Centered Planning
Authors: Janis Tondora, Rebecca Miller, Mike Slade, Larry Davidson
Publisher: Wiley-Blackwell
Publication: August 2014
ISBN: 978-1-118-38857-0
Get it at: [Wiley](#) [Amazon](#)

"Partnering for Recovery in Mental Health" is a practical guide for conducting person and family-centered recovery planning with individuals with serious mental illnesses and their families. It is derived from the authors' extensive experience in articulating and implementing recovery-oriented practice and has been tested with roughly 3,000 providers who work in the field as well as with numerous post-graduate trainees in psychology, social work, nursing, and psychiatric rehabilitation. It has consistently received highly favorable evaluations from health care professionals as well as people in recovery from mental illness.

This guide represents a new clinical approach to the planning and delivery of mental health care. It emerges from the mental health recovery movement, and has been developed in the process of the efforts to transform systems of care at the local, regional, and national levels to a recovery orientation. It will be an extremely useful tool for planning care within the context of current health care reform efforts and increasingly useful in the future, as systems of care become more person-centered. Consistent with other patient-centered care planning approaches, this book adapts this process specifically to meet the needs of persons with serious mental illnesses and their families.

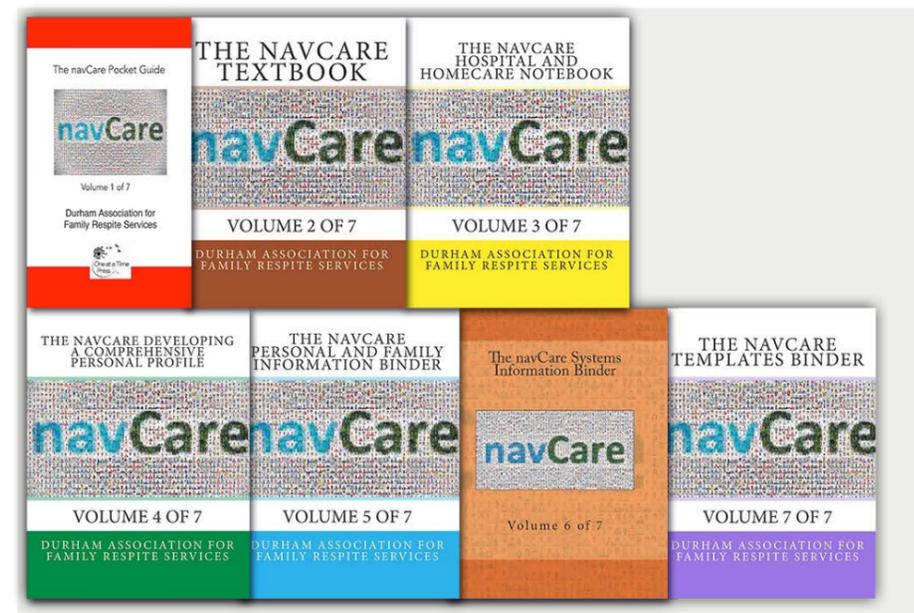
"Partnering for Recovery in Mental Health" is an invaluable guide for any person involved directly or indirectly in the provision, monitoring, evaluation, or use of community-based mental health care.



Handbook of Systems and Complexity in Health
Authors: Carmel M. Martin, Joachim P. Sturmberg
Publisher: Springer Press
Publication: May 2014
ISBN-10: 1461449987
ISBN-13: 978-1461449980
Get it at: [Springer](#) [Amazon](#)

This book is written by international experts from health services research, primary care, management studies, systems science, and organizational behavior. It applies systems science theory to population health and health care systems, with implications for health policy reform.

Handbook of Systems and Complexity in Health is an introduction to health care as a complex adaptive system, a system that feeds back on itself. The first section introduces systems and complexity theory from a science, historical, epistemological, and technical perspective, describing the principles and mathematics. Subsequent sections build on the health applications of systems science theory, from human physiology to medical decision making, population health and health services research. The aim of the book is to introduce and expand on important population health issues from a systems and complexity perspective, highlight current research developments and their implications for health care delivery, consider their ethical implications, and to suggest directions for and potential pitfalls in the future.



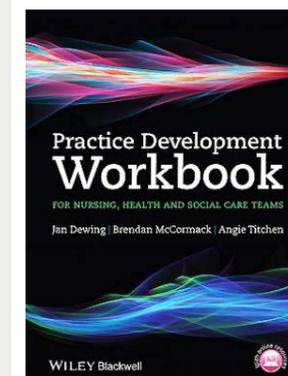
navCare Series
Editors: Harry van Bommel, Janet Klees
Publisher: One at Time Press
Publication: May 2014
Get it at: [Amazon](#)

NavCare is a collaborative project of 15 organizations from diverse professional backgrounds and volunteer members, committed to developing resources that make it easier for people and family caregivers to navigate healthcare and other systems: ALS Canada, Better Living Health and Community Services, Caregiver, Omnimedia Inc., Deohaeko Support Network, Durham Association for Family, Respite Services, Durham Family Network, Habitat Healing Hospice Toronto, Metropolitan United Church, Parkinson Society Central & Northern Ontario, Patients Canada, PSD Consultants, Saint Elizabeth Health Care, Syke, Assistance Service Corp, and WORDS: Solo Traveler.

The Navcare series of textbooks are for learners wanting to become Navcare Advisors, looking specifically at creating a comprehensive personal profile of a person so those advocating on their behalf have the most recent and detailed information possible. They provide insight on how to gather and record information on the various systems one has to deal with during their lives such as: health care, legal, financial, community and social services, insurance companies, governments, and more.

Key features:

- Navigate complex healthcare, legal, government, financial and other systems
- Negotiate the best care and services possible
- Mediate problems if they arise
- Reduce the stress on these systems by helping people use them more effectively.



Practice Development Workbook for Nursing, Health and Social Care Teams
Authors: Jan Dewing, Brendan McCormack, Angie Titchen
Publisher: Wiley-Blackwell
Publication: April 2014
ISBN: 978-1-118-67675-2
Get it at: [Wiley](#) [Amazon](#)

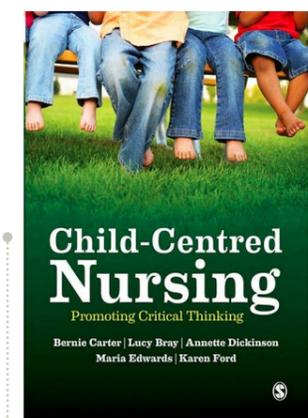
If you're looking to develop and improve your nursing, health or social care practice, either individually or as part of a team, the Practice Development Workbook for Nursing, Health and Social Care Teams offers a wide-ranging selection of activities, tools and resources covering vital aspects of practice development. Written as a companion volume to the latest edition of the best-selling Practice Development in Nursing and Healthcare, this new resource grounds practice development in day-to-day nursing and health and social care through accessible, informative learning activities. It also focuses on practical ways in which teams can make their workplace cultures more effective and person-centred, and enables practitioners to empower themselves to make compassionate care a fundamental part of effective health and social care systems.

Key features:

- Offers a full range of resources and tools to support all stages of learning and development towards person-centred practice, including learning activities,

templates, posters, tips and hints, information sheets, and checklists.

- Includes practical advice for teams to involve patients, clients and residents in the transformation of workplace cultures and bringing about sustainable change
- Perfect for use both by individuals or by those working in group settings
- Presents informative and accessible information through activities and key learning points rather than just theory
- Fully linked to Practice Development in Nursing and Healthcare, second edition, but can also be used as a stand-alone resource
- Includes access to a companion website featuring even more tools and resources, including: sample Powerpoint presentations, worksheets and reflection tools, questionnaires and checklists, evaluation tools, as well as a bonus chapter on 'Sharing and Celebrating'



Person and Family Centered Care
Authors: Bernie Carter, Lucy Bray, Annette Dickinson, Maria Edwards, Karen Ford
Publisher: SAGE Publications Ltd
Publication: April 2014
ISBN-10: 1446248607
ISBN-13: 978-1446248607
Get it at: [Sage Publications Ltd](#) [Amazon](#)

Child-Centred Nursing presents a unique approach by bringing children to the fore of the discussion about their health and health care. It encourages you to think critically about children, their families and contemporary practice issues. It promotes reflection on how you can develop innovative practice so as to improve children's health outcomes and their experiences of health care.

Clinical case studies and critical thinking exercises are included in each chapter, creating and sustaining a clear link between professional practice, research and theory.

The book is essential reading for all pre-registration and post-graduate students studying children's and young people's health care.

EDITOR'S PICK!

SUGGESTED READING
FROM THE RECENT PEER
REVIEWED MEDICAL
LITERATURE

1. Doolan-Noble, F. B., Gauld, R., Waters, D. L., & de le Barra, S. L. (2015). New Zealand health professional and patient perceptions of chronic illness care. *European Journal for Person Centered Healthcare* 3 (1) 4-10
2. Sidani, S., Collins, L., Harbman, P., Hurlock-Chorostecki, C., MacMillan, K., Reeves, S., Donald, F., van Soeren, M., & Staples, P. (2015). A Description of Nurse Practitioners' Self-Report Implementation of Patient-Centered Care. *European Journal for Person Centered Healthcare* 3 (1) 11-18
3. Kaltoft, M. K., Nielsen, J. B., Salkeld, G., & Dowie, J. (2015). Who should decide how much and what information is important in person-centred health care? *Journal of Health Services Research and Policy* 20, 192-195
4. Schwartzstein, R. M. N. (2015). Getting the Right Medical Students — Nature versus Nurture. *New England Journal of Medicine* 372, 1586-1587
5. Chandra, A., Khullar, D., & Lee, T. H. N. (2015). Addressing the Challenge of Gray-Zone Medicine. *New England Journal of Medicine* 372, 203-205
6. Tomkins, A., Duff, J., Fitzgibbon, A., Karam, A., Mills, E. J., Munnings, K., Smith, S., Seshadri, S. R., Steinberg, A., Vitillo, R., & Yugi, P. (2015). Controversies in faith and health care. *The Lancet* DOI: [http://dx.doi.org/10.1016/S0140-6736\(15\)60252-5](http://dx.doi.org/10.1016/S0140-6736(15)60252-5)
7. Atun, R. (2015). Transitioning health systems for multimorbidity. *The Lancet* 386 (9995) 721–722
8. Humphris, G. (2015). Improving health professionals' communication skills: A major global endeavour. *Patient Education and Counseling* 98, 1–2
9. Macey, K., Clarke, S., Golijani-Moghaddam, N., & das Nair, R. (2015). Evaluating a person-centered chronic pain service using indices of reliable and clinically significant change. *European Journal for Person Centered Healthcare* 3 (1) 19-25
10. Mott, J. M., Koucky, E. M., & Teng, E. J. (2015). The impact of patient preference on mental health treatment: a methodological critique and suggestions for future research. *European Journal for Person Centered Healthcare* 3 (1) 26-36
11. Lhussier, M., Forster, N., Eaton, S., & Carr, S. M. (2015). Care planning for long term conditions in primary care: indicators of embeddedness. *European Journal for Person Centered Healthcare* 3 (1) 59-64
12. Minami, C. A., Yang, A. D., Szmuiłowicz, E. (2015). Negotiating the Tensions in Patient-Centered Care *Journal of the American Medical Association* 314 (11) 1167-1168
13. Nath, P. A., Sharp, C. D. (2015). A User-Centered Design Approach to Information Sharing for Older Patients and Their Families. *JAMA Internal Medicine* 2015; 175 (9) 1498-1499.
14. Patricia A. Ganz, P. A. (2015). Delivering Patient-Centered Care in the Setting of Advanced Cancer: What Does a Clinical Risk-Prediction Model Have to Do With It? *JAMA Oncology* 1 (4) 430-432.
15. LeBlanc, A., Herrin, J., Williams, M. D., Inselman, J. W., Branda, M. E., Shah, N. D., Heim, E. M., Dick, S. R., et alii. (2015). Shared Decision Making for Antidepressants in Primary Care: A Cluster Randomized Trial. *JAMA Internal Medicine* 1-10. doi: 10.1001/jamainternmed.2015.5214
16. Kroenke, K. (2015). The Role of Decision Aids in Depression Care. *JAMA Internal Medicine* 1-2. doi: 10.1001/jamainternmed.2015.5243
17. McMullen, C. K., Safford, M. M., Bosworth, H. B., Phansalkar, S., Leong, A., Fagan, M. B., Trontell, A., Rumpitz, M., & Vandermeer, M. L. (2015). Patient-centered priorities for improving medication management and adherence. *Patient Education and Counseling* 98, 102–110
18. Carpenter, D. M., Elstad, E. A., Sage, A. J., Geryk, L. L., DeVellis, R. F., & Blalock, S. J. (2015). The relationship between partner information-seeking, information-sharing, and patient medication adherence. *Patient Education and Counseling* 98, 120–124
19. Dharmaratne, S., Razee, H., Ponnampereuma, G., Marambe, K., Dawson, A., & Balasooriya, C. (2015). Vignette-based Decision Point Analysis (VDPA): A novel method of exploring person-centered contextual influences on clinical decision-making. *European Journal for Person Centered Healthcare* 3 (2) 151-157
20. Carayon, P., Schoofs Hundt, A., Hoonakker, P., Kianfar, S., Alyousef, B., Salek, D., Cartmill, R., Walker, J. M., & Tomcavage, J. (2015). Perceived impact of care managers' work on patient and clinician outcomes. *European Journal for Person Centered Healthcare* 3 (2) 158-167
21. Rathert, C., Williams, E. S., McCaughey, D., & Ishqaidif, G. (2015). Patient perceptions of patient-centred care: empirical test of a theoretical model. *Health Expectations* 18, 199–209
22. Sav, A., King, M. A., Whitty, J. A., Kendall, E., McMillan, S. S., Kelly, F., Hunter, B., & Wheeler, A. J. (2015). Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations* 18, 312–324
23. Hansson, E., Ekman, I., Swedberg, K., Wolf, A., Dudas, K., Ehlers, L., & Olsson, L. E. (2015). Person-centred care for patients with chronic heart failure – a cost–utility analysis. *European Journal of Cardiovascular Nursing* doi:10.1177/1474515114567035
24. Nguyen, O. K., Chan, C. V., Makam, A., Stieglitz, H., & Amarasingham, R. (2015). Envisioning a Social-Health Information Exchange as a Platform to Support a Patient-Centered Medical Neighborhood: A Feasibility Study. *Journal of General Internal Medicine* 30 (1) 60-67
25. Johnston, B., Gaffney, M., Pringle, J., & Buchanan, D. (2015). The person behind the patient: a feasibility study using the Patient Dignity Question for patients with palliative care needs in hospital. *International Journal of Palliative Nursing* DOI: <http://dx.doi.org/10.12968/ijpn.2015.21.2.71>
26. Loughlin, M., Bluhm, R., Fuller, J., Buetow, S., Borgerson, K., Lewis, B. R., & Kioussis, B. M. (2015). Diseases, patients and the epistemology of practice: mapping the borders of health, medicine and care. *Journal of Evaluation in Clinical Practice* 21, 357–364
27. Thornquist, E., & Kirkengen, A. L. (2015). The quantified self: closing the gap between general knowledge and particular case? *Journal of Evaluation in Clinical Practice* 21, 398–403
28. Marcum, J. A. (2015). Caring for patients during challenging clinical encounters. *Journal of Evaluation in Clinical Practice* 21, 404–409
29. van Baalen, S., & Boon, M. (2015). An epistemological shift: from evidence-based medicine to epistemological responsibility. *Journal of Evaluation in Clinical Practice* 21, 433–439
30. Flores, L. (2015). Therapeutic inferences for individual patients. *Journal of Evaluation in Clinical Practice* 21, 440–447
31. Jackson, G. I., & Williams, J. Q. W. (2015). Does PCMH “Work”?—The Need to Use Implementation Science to Make Sense of Conflicting Results. *JAMA Internal Medicine* 175 (8) 1369-1370.
32. Friedberg, M. W., Rosenthal, M. B., Werner, R. M., Volpp, K. G., & Schneider, E. C. (2015). Effects of a Medical Home and Shared Savings Intervention on Quality and Utilization of Care. *JAMA Internal Medicine* 175 (8) 1362-1368
33. Wu, Chiung-Jung, Atherton, J. J., Chang, A. M., Courtney, M., Clark, A. M., Thompson, D. R., Ramis, M. A., & McPhail, S. M. (2015). Australian patients using a cardiac-diabetes web-based intervention program: contributions to person-centered clinical practice. *European Journal for Person Centered Healthcare* 3 (2) 168-174
34. Sturmberg, J. P. (2015). Health - Illness - Disease. A person-centered perspective. *European Journal for Person Centered Healthcare* 3 (2) 182-186
35. McCoy, R. G., Fan, J., Smith, S. A., Deming, J. R., Ziegenfuss, J. Y., Montori, V. M., & Shah, N. D. (2015). Patient experience with care and clinical outcomes in diabetes: a case for more person-centered measurement. *European Journal for Person Centered Healthcare* 3 (2) 187-195
36. Marcum, J. A. (2015). Healthcare personalism: a prolegomenon. *European Journal for Person Centered Healthcare* 3 (2) 228-232
37. Branch, W. T. (2015). Teaching professional and humanistic values: Suggestion for a practical and theoretical model. *Patient Education and Counseling* 98, 162–167
38. Malloy-Weir, L. J., Charles, C., Gafni, A., & Entwistle, V. A. (2015). Empirical relationships between health literacy and treatment decision making: A scoping review of the literature. *Patient Education and Counseling* 98, 296–309
39. Arora, N. K., Hesse, B. W., & Clauser, S. B. (2015). Walking in the Shoes of Patients, Not Just in Their Genes: A Patient-Centered Approach to Genomic Medicine. *The Patient* 8, 239-245
40. Miller, D., Gray, C. S., Kuluski, K., & Cott, C. (2015). Patient-Centered Care and Patient-Reported Measures: Let's Look Before We Leap. *The Patient* 8, 293-299
41. Kehl, K. L., Landrum, M. B., Arora, N. K., Ganz, P. A., van Ryn, M., Mack, J. W., & Keating, N. L. (2015). Association of Actual and Preferred Decision Roles With Patient-Reported Quality of Care: Shared Decision Making in Cancer Care. *JAMA Oncology* 1 (1) 50-58
42. Stiggelbout, A. M., Pieterse, A. H., & De Haes, C. J. M. (2015). Shared decision making: Concepts, evidence and practice. *Patient Education and Counseling* 98 (10) 1172–1179
43. Cushing, A. M. (2015). Learning patient-centred communication: The journey and the territory. *Patient Education and Counseling* 98, 1236–1242
44. Martin, E. B., Mazzola, N. M., Brandano, J., Luff, D., Zurakowski, D., & Meyer, E. C. (2015). Clinicians' recognition and management of emotions during difficult healthcare conversations. *Patient Education and Counseling* 98, 1248–1254
45. Dubov, A. (2015). Ethical persuasion: the rhetoric of communication in critical care. *Journal of Evaluation in Clinical Practice* 21, 496–502
46. Mahr, G. (2015). Narrative medicine and decision-making capacity. *Journal of Evaluation in Clinical Practice* 21, 503-507
47. Weyer, P., & da Silva, S. A. (2015). ‘One mission accomplished, more important ones remain’: commentary on Every-Palmer, S., Howick, J. (2014) How evidence-based medicine is failing due to biased trials and selective publication. *Journal of Evaluation in Clinical Practice* 21, 518-528
48. Qidwai, W., Kazmib, Z., & Nanji, K. (2015). Patients' attitudes and perceptions regarding person-centered care: results of a survey from an urban city of Pakistan. *European Journal for Person Centered Healthcare* 3 (1) 65-70
49. Miles, A. (2015). Ongoing problems with the E of EBM and on the need for person-centered healthcare. A commentary on Steurer et al. (2014). “Are clinically heterogeneous studies synthesized in systematic reviews?” *European Journal for Person Centered Healthcare* 3 (1) 134-137
50. Shields, L. (2015). What is “family-centered care”? *European Journal for Person Centered Healthcare* 3 (2) 139-144
51. Kuppermann, M., & Sawaya, G. F. (2015). Shared Decision-Making: Easy to Evoke, Challenging to Implement. *JAMA Internal Medicine* 175 (2) 167-168
52. Engebretsen, E., Vollestad, N. K., Wahl, A. K., Robinson, H. S., & Heggen, K. (2015). Unpacking the process of interpretation in evidence-based decision making. *Journal of Evaluation in Clinical Practice* 21, 529–531.
53. Muela, R. A. (2015). A homage to Edmund Pellegrino. *European Journal for Person Centered Healthcare* 3 (2) 233-237
54. Davies, E. A. (2015). Tales from a medical apprenticeship: reflections on supporting empathy. *European Journal for Person Centered Healthcare* 3 (2) 245-248
55. Gilewski, T. (2015). The Complexities of Compassion in Patient Care. *JAMA Oncology* 1 (2) 183-184
56. Rousseau, P. (2015). Bedside Encounter. *JAMA Internal Medicine* 175 (4) 487-488
57. Kirkpatrick, J. N. (2015). Goals of Care Discussion: How Hard It Can Be. *JAMA Internal Medicine* 175 (4) 557-558
58. Shin, D. W., Roter, D. L., Roh, Y. K., Hahn, S. K., Cho, B., & Park, H-K. (2015). Physician gender and patient centered communication: The moderating effect of psychosocial and biomedical case characteristics. *Patient Education and Counseling* 98, 55-60

59. Aper, L., Veldhuijzen, W., Dornan, T., van de Ridder, M., Koole, S., Derese, A., & Reniers, J. (2015). "Should I prioritize medical problem solving or attentive listening?": The dilemmas and challenges that medical students experience when learning to conduct consultations. *Patient Education and Counseling* 98, 77–84
60. Rachel R. Hardeman, R. R., Burgess, D., Phelan, S., Yeazel, M., Nelson, D., & van Ryn, M. (2015). Medical student socio-demographic characteristics and attitudes toward patient centered care: Do race, socioeconomic status and gender matter? A report from the Medical Student CHANGES study. *Patient Education and Counseling* 98, 350–355
61. Paul-Savoie, E., Bourgault, P., Gosselin, E., Potvin, S., & Lafrenaye, S. (2015). Assessing patient-centered care: Validation of the French Version of the Patient-Practitioner Orientation Scale (PPOS). *European Journal for Person Centered Healthcare* 3 (3) 295-302
62. Hoare, S.D. J., Broomhead, E., Stockdale, D., & Kennedy, V. (2015). Equity and person-centeredness in the provision of tinnitus services in UK National Health Service audiology departments. *European Journal for Person Centered Healthcare* 3 (3) 318-326
63. Nemes, S., Greene, M. E., Bulow, E., & Rolfson, O. (2015). Summary statistics for Patient-reported Outcome Measures: the improvement ratio. *European Journal for Person Centered Healthcare* 3 (3) 334-342
64. Quesada, M., Madrigal, M., Luna, A., & Perez-Carceles, M. D. (2015). Caring for the caregiver: factors associated with the quality of life of family caregivers to palliative care patients. *European Journal for Person Centered Healthcare* 3 (3) 352-361
65. Greysen, S. R., & Detsky, A. S. (2015). Understanding the Value of Continuity in the 21st Century. *JAMA Internal Medicine* 175 (7) 1154-1156
66. Tulsky, J. A. (2015). Decision Aids in Serious Illness: Moving What Works Into Practice. *JAMA Internal Medicine* 175 (7) 1221-1222
67. Ziegelstein, R. C. (2015). Personomics. *JAMA Internal Medicine* 175 (6) 888-889
68. Van Bommel, H. (2015). Results, not intentions: why assisted suicide has no place in person-centered healthcare and where it does belong. *European Journal for Person Centered Healthcare* 3 (3) 392-406
69. Trifiletti, D. M. (2015). Patient Trust—Keeping It in the Family. *JAMA Oncology* 1 (3) 279-280
70. Salmon, P. (2015). Argumentation and persuasion in patient-centred communication. *Patient Education and Counseling* 98, 543–544
71. Keen, M., Cawse-Lucas, J., Carline, J., & Mauksch, L. (2015). Using the patient centered observation form: Evaluation of an online training program. *Patient Education and Counseling* 98, 753–761
72. Couët, N., Desroches, S., Robitaille, H., Vaillancourt, H., Leblanc, A., Turcotte, S., Elwyn, G., & Légaré, F. (2015). Assessments of the extent to which health-care providers involve patients in decision making: a systematic review of studies using the OPTION instrument. *Health Expectations* 18, 542–561
73. Kreindler, S. A. (2015). The politics of patient-centred care. *Health Expectations* 18, 1139–1150
74. Kelleys, M., James, C., Alessi Kraft, S., Korngiebel, D., Wijangco, I., Rosenthal, E., Joffe, S., Cho, M. K., Wilfonde, B., & Soo-Jin Lee, S. (2015). Patient Perspectives on the Learning Health System: The Importance of Trust and Shared Decision Making. *American Journal of Bioethics* 15 (9) 4-17
75. Vikströma, S., Sandman, P. O., Stenwall, E., Boström, A., Saarnio, L., Kindblom, K., Edvardsson, D., & Borell, L. (2015). A model for implementing guidelines for person-centered care in a nursing home setting. *International Psychogeriatrics* 27 (1) 49-59
76. Livingstone, S. G., Smith, M. J., Silva, D. S., & Upshur, R. E. G. (2015). Much ado about omics: welcome to 'the permutome'. *Journal of Evaluation in Clinical Practice* 21 (6) DOI: 10.1111/jep.12406
77. Ziegelstein, R. C. (2015). Who will deliver personalized medicine? *Journal of Evaluation in Clinical Practice* 21 (6). DOI: 10.1111/jep.12440
78. Sacristán, J. A. (2015). Where is the person in precision medicine? *Journal of Evaluation in Clinical Practice* 21 (6) DOI: 10.1111/jep.12456
79. Sacristán, J. A., & Dilla, T. (2015). No big data without small data: learning healthcare systems begin and end with the individual patient. *Journal of Evaluation in Clinical Practice* 21 (6) DOI: 10.1111/jep.12350
80. Weaver, R. R. (2015). Reconciling Evidence-based Medicine and Patient-Centered Care: Evidence-based inputs to inform Patient-centered Decisions. *Journal of Evaluation in Clinical Practice* 21 (6) DOI: 10.1111/jep.12465
81. Wieten, S. E. (2015). What the patient wants: an investigation of the different methods of ascertaining patient values in Evidence-Based Medicine and Values-Based Practice. *Journal of Evaluation in Clinical Practice* 21 (6) DOI: 10.1111/jep.12471
82. Laba, T-L., Essue, B., Kimman, M., Jan, S. (2015). Understanding Patient Preferences in Medication Nonadherence: A Review of Stated Preference Data. *The Patient* 8, 385-395
83. Eaton, S., Roberts, S., & Turner, B. (2015). Delivering person centred care in long term conditions. *British Medical Journal* 350 doi: <http://dx.doi.org/10.1136/bmj.h181> *British Medical Journal* MJ 2015;350:h181
84. Brandes, K., Linn, A. J., Smit, E. G., & van Weert, J. C. M. (2015). Patients' reports of barriers to expressing concerns during cancer consultations *Patient Education and Counseling* 98, 317–322
85. Rissi, J. J., Gelmon, S., Saulino, E., Merrithew, N., Baker, R., & Hatcher, P. (2015). Building the Foundation for Health System Transformation: Oregon's Patient-Centered Primary Care Home Program. *Journal of Public Health Management & Practice* 21 (1) 34–41
86. Lossnitzer, N., Herzog, W., Schultz, J. H., Taeger, T., Frankenstein, L., & Wild, B. (2015). A patient-centered perspective of treating depressive symptoms in chronic heart failure: What do patients prefer? *Patient Education and Counseling* 98, 783–787
87. Winn, K., Ozanne, E., & Sepucha, K. (2015). Measuring patient-centered care: An updated systematic review of how studies define and report concordance between patients' preferences and medical treatments. *Patient Education and Counseling* 98, 811–821
88. Stephens, J. (2015). A participatory learning model and person centred healthcare: moving away from 'one hand clapping'. *European Journal for Person Centered Healthcare* 3 (3) 279-287
89. Finset, A. (2015). Living with chronic heart failure: The importance of tailoring self-care and treatment to individual values, goals and preferences. *Patient Education and Counseling* 98, 925–926
90. Lown, B. A., Muncer, S. J., & Chadwick, R. (2015). Can compassionate healthcare be measured? The Schwartz Center Compassionate Care Scale™. *Patient Education and Counseling* 98, 1005–1010
91. van Dulmen, S. A., Lukersmith, S., Muxlow, J., Mina, E. S., Nijhuis-van der Sanden, M. W. G., & van der Wees, P. J. (2015). Supporting a person-centred approach in clinical guidelines. A position paper of the Allied Health Community – Guidelines International Network (G-I-N) *Health Expectations* 18, 1543–1558
92. Gullery, C., & Hamilton, G. (2015). Towards integrated person-centred healthcare – the Canterbury journey. *Future Hospital Journal* 2 (2) 111–116
93. Pollard, S., Bansback, N., & Bryan, S. (2015). Physician attitudes toward shared decision making: A systematic review. *Patient Education and Counseling* 98, 1046–1057
94. Cameron, R. A., Mazer, B. L., DeLuca, J. M., Mohile, S. G., & Epstein, R. M. (2015). In search of compassion: a new taxonomy of compassionate physician behaviours. *Health Expectations* 18, 1672–1685
95. Rathert, C., Williams, E. S., McCaughey, D., & Ishqaidif, G. (2015). Patient perceptions of patient-centred care: empirical test of a theoretical model. *Health Expectations* 18, 199–209
96. Liu, Z., Speed, S., & Beaver, K. (2015). Perceptions and attitudes towards exercise among Chinese elders – the implications of culturally based self-management strategies for effective health-related help seeking and person-centred care. *Health Expectations* 18, 262 - 272
97. Elf, M., Fröst, P., Lindahl, G., & Wijk, H. (2015). Shared decision making in designing new healthcare environments—time to begin improving quality. *BMC Health Services Research* 15:114 doi:10.1186/s12913-015-0782-7
98. Gustafsson, S., Lood, Q., Wilhelmson, K., Häggblom-Kronlöf, G., Landahl, S., & Dahlin-Ivanoff, S. (2015). A person-centred approach to health promotion for persons 70+ who have migrated to Sweden: promoting aging migrants' capabilities implementation and RCT study protocol. *BMC Geriatrics* 15:10 doi:10.1186/s12877-015-0005-4
99. Lawn, S. (2015). Integrating service user participation in mental health care: what will it take? *International Journal of Integrated Care* 15: e004
100. Ross, H., Tod, A. M., & Clarke, A. (2015). Understanding and achieving person-centred care: the nurse perspective. *Journal of Clinical Nursing* 24, 1223–1233
101. Hwang, J. I. (2015). Development and testing of a patient-centred care competency scale for hospital nurses. *International Journal of Nursing Practice* 21 (1) 43–51
102. Delaney, K. R., Johnson, M. E., & Fogg, L. (2015). Development and Testing of the Combined Assessment of Psychiatric Environments. A Patient-Centered Quality Measure for Inpatient Psychiatric Treatment. *Journal of the American Psychiatric Nurses Association* 21 (2) 134-147
103. Luxford, K. (2015). New South Wales mounts "patient based care" challenge. *British Medical Journal* 2015; 350 doi: <http://dx.doi.org/10.1136/bmj.g7582>
104. Richards, T., Coulter, A., & Wicks, P. (2015). Time to deliver patient centred care. *British Medical Journal* 2015; 350 doi: <http://dx.doi.org/10.1136/bmj.h530>
105. Bennett, A. H., Hassinger, J. A., Martin, L. A., Harris, L. H., & Gold, M. (2015). Developing patient-centered teams: The role of sharing stories about patients and patient care. *Families, Systems, & Health* 33 (3) 203-212
106. Frazier, M., Schnell, K., Baillie, S., & Stuber, M. L. (2015). Chaplain Rounds: A Chance for Medical Students to Reflect on Spirituality in Patient-Centered Care. *Academic Psychiatry* 39 (3) 320-323
107. Concannon, T. W. (2015). Can patient centered outcomes research improve healthcare? *British Medical Journal* 2015; 351 doi: <http://dx.doi.org/10.1136/bmj.h3859>
108. Elvey, R., Hassell, K., Lewis, P., Schafheutle, E., Willis, S., & Harrison, S. (2015). Patient-centred professionalism in pharmacy: values and behaviours. *Journal of Health Organization and Management* 29 (3) 413 - 430
109. Freeman, J. S. (2015). Providing whole-person care: integrating behavioral health into primary care. *North Carolina Medical Journal* 76 (1) 24-5, 27-8.
110. Lines, L. M., Lepore, M., & Wiener, J. M. (2015). Patient-centered, Person-centered, and Person-directed Care: They are Not the Same. *Medical Care* 53 (7) 561–563
111. Slater, P., McCance, T., & McCormack, B. (2015). Exploring person-centred practice within acute hospital settings. *International Practice Development Journal* 5 (Suppl) [09] <http://www.fons.org/library/journal.aspx>
112. Price, A. I., Djulbegovic, B., Biswas, R., & Chatterjee, P. (2015). Evidence-based medicine meets person centred care: a collaborative perspective on the relationship. *Journal of Evaluation in Clinical Practice* DOI: 10.1111/jep.12434
113. van Lieshout, F., & Cardiff, S. (2015). Reflections on being and becoming a person-centred facilitator. *International Practice Development Journal* 5 (Suppl) [Http://www.fons.org/library/journal.aspx](http://www.fons.org/library/journal.aspx)
114. Joseph-Williams, N., Davies, F., Wood, F., & Edwards, A. (2015). Will Patients Vote With Their Feet (and Wallets) for Person-Centered Care? *Medical Decision Making* doi: 10.1177/0272989X15583267
115. Berghout, M., van Exel, J., Leensvaart, L., & Cramm, J. M. (2015). Healthcare professionals' views on patient-centered care in hospitals. *BMC Health Services Research* Sep 16;15(1):385. doi: 10.1186/s12913-015-1049-z.



IPDC PRACTICE DEVELOPMENT SCHOOL@ QMU

PRACTICE DEVELOPMENT FOR PERSON-CENTRE CULTURES

MSc PERSON-CENTRED PRACTICE

To give you the opportunity to acquire the knowledge and skill to be person-centred practice developers, with the aim of embedding person-centred cultures within teams and organisations. You will have the opportunity to critically and creatively explore your values and beliefs about practice development and workplace cultures and to experientially appraise contemporary approaches and methods of practice development. You will also be able to learn more about participatory approaches to evaluation in practice development as well as reflecting on how critical reflection and facilitation are core to practice development and moving towards person-centred and more effective cultures. In addition, you will be offered facilitated active learning where you can consider your own practical knowledge, skills and underpinning assumptions of practice development and person-centredness.

Where is it delivered?

At Queen Margaret University, Edinburgh

Overview

This module is part of the MSc Person-centred Practice framework and is delivered as an International Practice Development Collaborative [IPDC] Foundation School. This means students can opt to undertake 15 credits at SCQF Level 11 (postgraduate level) but this is not a requirement.

What types of learning activities should I expect?

You will have an opportunity to:

- Clarify the concept of practice development: the values and evidence base underpinning its processes and outcomes
- Experience the use of practice development approaches
- Experience the mechanisms necessary to establish effective active learning groups/supervision groups and meetings
- Engage in the process of active learning as an approach for focussing on professional effectiveness as a practice developer and develop further skills
- Reflect on your own learning in an environment of high support and high challenge
- Explore and critique the concepts of facilitation, context, culture, evidence and effectiveness
- Develop insight and skills in cultural change and leadership
- Experience the use of creativity in learning
- Learn about evaluation as a method for learning in the workplace
- Network with others involved in practice development
- Explore how practice development brings added value and benefits to patient care and the organisation.

What is the optional assessment?

The assessment will give you the opportunity to lead practice development within your own setting. You will be required to evaluate the culture and context of your own practice area and consider its influence with the organisational culture and the broader culture within practice. Format is a 3000 word reflective evaluation of the learning experience.

Can I do some pre-school preparation?

You will join the Queen Margaret University's virtual learning environment, HUB@QMU to introduce yourself, access all your course materials and other information. Once matriculated, you will be able to access HUB@QMU via the QMU website – quick links on main page.

What is the focus of the school?

- Values clarification, visioning and shared values
- Facilitation, reflection and active learning
- Workplace culture
- Evidence, effectiveness and evaluation
- Group learning in relation to concepts of practice development

How is the school designed?

The school is not a conventional didactic or research methods course but is based around interactive and creative means of utilising participants own experiences of work and practice development. The school encourages active engagement through interactive workshops and an introduction to active learning as a process to enable the development of personal and professional effectiveness. All sessions are built on a small amount of pre-course work which needs to be undertaken prior to commencement of the course. Participants are helped to take questions and action plans back to their workplace for auctioning with others.

What is the International Practice Development Collaborative (IPDC)?

The IPDC is a community of practice (practice developers and researchers) committed to working together to develop healthcare practice. The IPDC believes that the aim of PD is to work with people to develop person-centred cultures that are dignified, compassionate and safer for all. The course and resources are agreed by the members of the IPDC. IPDC collaborators are:

- Queen Margaret University, Edinburgh (UK)
- Canterbury Christ Church University (UK)
- Ulster University, Northern Ireland (UK)
- Foundation of Nursing Studies (UK)
- Fontys University of Applied Sciences (The Netherlands)
- Monash University (Australia)
- University of Technology & Sydney Children's Hospital Network (Australia)
- University of Wollongong (Australia)
- University of Tasmania (Australia)
- Bern University Hospital (Switzerland)
- University Hospital Zurich (Switzerland)
- University Hospital of Basel (Switzerland)

How do I apply?

[<CLICK HERE>](#)

Apply now and click on associate student 2016.

Closing date 4th January 2016.

Places restricted to 30.

Address

School of Health Sciences, Queen Margaret University
Musselburgh, East Lothian EH21 6UU

Telephone

(+44) (0) 131 474 0000

Contact Information

Please feel free to email any of the team for more information about the module/PD School. If you need information about the application process please contact Dr. Caroline Dickson: cdickson@qmu.ac.uk

Meet the team:



Professor Brendan McCormack
bmccormack@qmu.ac.uk



Professor Jan Dewing
jdewing@qmu.ac.uk



Dr Caroline Dickson,
cdickson@qmu.ac.uk



Dr Deborah Baldie
dbaldie@qmu.ac.uk



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE

Membership Application

The President, Senior VP and Officers of the Society cordially invite interested colleagues to membership of the Society. Interested colleagues should consult the Notes for Guidance and then complete the Membership Application Form:

Notes for Guidance

A. Membership of the Society is open to all healthcare workers (including retired), healthcare managers, health academics, healthcare policymakers and government advisers, patients, patient advocacy groups (as corporate members) and members of the pharmaceutical and healthcare technology industries. The costs of membership are as detail below and the benefits of membership are set out below (see 'D'). Applications received will be considered by the Society's Membership Committee. Membership fees become payable on election and are annually renewable.

B. All applications should be accompanied by full and up-to-date Curriculum Vitae and a covering letter outlining the applicant's achievements (and/or plans) in the field of person-centered care. The covering letter should document the achievement with reference to the membership criteria set out below (see 'C') and should indicate which Special Interest Group (SIG) or SIGs the applicant would like to join (no limit) The Application Form with the covering letter and CV should be sent to Professor Andrew Miles using the 'SEND' function at the end of the Application Form below. If preferred, the Application Form and supporting materials can be sent by post to: European Society for Person Centered Healthcare, c/o 77 Victoria Street, Westminster, London SW1H 0HW, UK.

C. The Society has various categories of membership and these are as follows:

(a) **Distinguished Fellow** (Clinical Professional and/or Academic)

[Criterion and fee: outstanding contribution to the field of person-centered clinical practice: €150]

(b) **Fellow** (Clinical Professional and/or Academic)

[Criterion and fee: major contribution to the field of person-centered clinical practice: €100]

(c) **Member** (Clinical Professional and/or Academic)

[Criterion and fee: significant contribution to the field of person-centered clinical practice. Membership fee: €75]

(d) **Member** (Patient)

[Criterion and fee: currently a patient or a patient's carer: €75]

(e) **Member** (Industry)

[Criterion and fee: an active member of the healthcare industry: €250]

(f) **Associate** (Clinical Professional and/or Academic)

[Criterion and fee: a promising ongoing contribution to the field of person-centered clinical practice: €50]

(g) **Student** (Clinical or health-related studies)

[Criteria: detectable commitment to the principles of person-centered clinical practice: €25]

D. There are 10 principal benefits to membership of the Society. These are as follows:

(1) Free on-line access to the European Journal of Person Centered Healthcare (Priced for non-members at €270, for print and online and €195, for online only and for non-member institutions €345, for print and online and €250, for online only).

(2) Bi-monthly Bulletin of the ESPCH by e-mail direct from the President, detailing new bibliography of relevance to the field, forthcoming European and other conferences and all details relating to the Society's activities, including updates on the work of the Special Interest Groups.

(3) A Directory of Members documenting their areas of interest, current research activities and contact details, to enable cross-institutional collaboration and networking.

(4) Eligibility for consideration of award of the Society's Platinum, Gold, Silver and Bronze Medal and Book and Essay Prize in recognition of individual contribution to the development of excellence in person-centered clinical care

(5) 25% discount of the Annual Conference and Awards Ceremony delegate fee and a 25% discount on the delegate fees for other events within the European Conference Series on Person Centered Healthcare.

(6) 20% discount on the published price of the Society's publications. (e.g., the price of €60, versus €75, for the forthcoming major textbook: Person-Centered Healthcare. How to Practise and Teach PCM. The same 20% discount applies to the forthcoming textbook Person-centered Healthcare Education: A Vision for the 21st Century. Similar preferential prices are also available to Society members for each publication within the Society's forthcoming 'Clinical Practitioner Handbooks on Person Centered Healthcare' Series, which will generate diagnoses-specific guides for immediate use within routine clinical practice in the management of a wide range of chronic illnesses and to assist study of a wide variety of non-clinical areas of relevance to PCH.

(7) Eligibility for invitation to lecturing positions on the intensive educational courses to be organised by the Society (Fellows and Members only) in various European countries and also within the USA.

(8) Eligibility to apply to the Society for research grants and Higher Degree Studentship fee grants.

(9) Automatic 10% discount on registration for the Society's 7-day residential intensive study courses on person-centered healthcare, whether at practitioner-learner level or practitioner-teacher/mentor/leader level.

(10) A 15% discount on the subscription costs to any of the Society's clinical condition-specific quarterly journals and an automatic invitation to apply for membership of their Editorial Boards, Peer Review Colleague Directories.

E. Corporate Membership and also Corporate Sponsorship of the Society (Platinum, Gold, Silver, Bronze) is invited and available at a negotiable cost based on the size of the organisation and the World Bank status of its geographical location. The benefits of Corporate Membership and Corporate Sponsorship are highly substantial and include:

(1) High visibility of the Institution's Logo and Statement of Commitment to Person-Centered Healthcare

(2) Free advertising opportunities in the Society's Monthly Bulletin

(3) A gratis Advertising/Marketing Stall at the Society's Annual Conference & Annual Academic Awards Ceremony

(4) Personal Introductions to Distinguished Clinicians of the Society by the President/Senior VP

(5) Generous reductions on block purchases of delegate places at the Society's Annual Conference and Academic Awards Ceremony

(6) Preferred Sponsor Status of the Society's publications and also of its Intensive Training Courses for practising clinicians wishing to:

(a) become PCH trained practitioners

(b) those practitioners who seek to become PCH Mentors and Leaders in their field of practice

Further information

• Please fill all the required fields in the membership application form found at the following page, and then save it as a PDF file only from the pages 118-120 of this e-Bulletin, and name the file as "ESPCH Membership Application Form (your name)". Send the application with your CV and any supporting documents to Professor Andrew Miles at: andrew.miles@pchealthcare.org.uk.

• The Application to Society Membership is also available online at <http://pchealthcare.org.uk/conferences/joining-european-society-person-centered-healthcare>

• For further information, teleconference or face-to-face meetings and indicative cost estimates, please contact in the first instance: Professor Andrew Miles at: andrew.miles@pchealthcare.org.uk



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE
Membership Application Form



EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE
2016 ESPCH Awards Nomination Form

I would like to be considered for membership of the Society at the following level (tick as appropriate):

- a. Distinguished Fellow (Clinical Professional and/or Academic)
- b. Fellow (Clinical Professional and/or Academic)
- c. Member (Clinical Professional and/or Academic)
- d. Member (Patient)
- e. Member (Industry)
- f. Associate (Clinical Professional and/or Academic)
- g. Student
- h. Chairmanship/Deputy of an SIG

*Name of SIG:

*ESPCH SIG Network: <http://pchealthcare.org.uk/about-espch/special-interest-group-network-of-the-society>

I would like my Institution to become a Corporate Member or Corporate Sponsor (select below) of the Society and request relevant details and fees.

- Corporate Member
- Corporate Sponsor

Name of Institution:

Address of Institution:

Address 1:

Address 2:

Town:

County:

Postal Code:

Country:

Contact e-mail:

Your details

Title (Prof/Dr/Mr/Ms, etc.):

Name:

Occupation:

Address 1:

Address 2:

Town:

County:

Postal Code:

Country:

Contact e-mail:

Dear Colleague

EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE – ANNUAL AWARDS 2016

You are cordially invited to nominate a clinician or scientist working in the field of person-centered care/humanistic medicine for one of the Society's annual awards.

The Society's awards are intended to recognise various degrees of excellence and achievement in the promotion and implementation of person-centered approaches to healthcare design and delivery and also scholarship and teaching.

Individual members and non-members of the Society are eligible for consideration of the awards with the exception of the President and Senior Vice President. Awards can also be made to institutions, e.g., hospitals and universities, where progress has been achieved by a team.

Please complete the nomination form. If you have only one nomination for one prize we are grateful. If you can nominate more than one individual for the other awards, then we are most grateful.

The successful candidates will be awarded their medals and prizes by the President at the Annual Awards Ceremony which will take place September 2016, London, UK, following the conclusion of Day 1 of the Society's Third Annual Conference

We look forward to receiving your advice latest by the 31st August 2016, and in the interim send kind collegial regards.

Further information

- Please fill all the required fields onwards, and then save it as a PDF file only from the pages 121-127 of this e-Bulletin, and name the file as "ESPCH 2016 Awards Nomination Form (your name)". Send the Nomination Form with any supporting documents to Professor Andrew Miles at: andrew.miles@pchealthcare.org.uk.
- For further information, teleconference or face-to-face meetings and indicative cost estimates, please contact in the first instance: Professor Andrew Miles at: andrew.miles@pchealthcare.org.uk

Declaration of Conflict of Interest

I have read the criteria for the awards and confirm that I have no conflicts of interest in making my nominations.

Name

Title

Position

Email Address

Institution

Date dd/mm/yyyy

Signature (electronic if possible)



Dear President and Senior VP

My nominations

I would like to nominate the following individuals or institutions for the Society's awards:

For the Platinum Medal

Criterion: Unequivocal excellence in the promotion and development of PCH

Name Title

Position Email Address

Institution

Statement in support of the Nomination (circa 300 – 600 words. Please identify as many key achievements of the nominee as possible, including seminal publications in peer reviewed journals and any other awards received).



For the Gold Medal

Criterion: A very high level of achievement in the promotion and development of PCH

Name Title

Position Email Address

Institution

Statement in support of the Nomination (circa 300 – 600 words. Please identify as many key achievements of the nominee as possible, including seminal publications in peer reviewed journals and any other awards received).



For the Silver Medal

Criterion: A high level of achievement in the promotion and development of PCH

Name	Title
Position	Email Address
Institution	

Statement in support of the Nomination (circa 300 – 600 words. Please identify as many key achievements of the nominee as possible, including seminal publications in peer reviewed journals and any other awards received).



For the Bronze Medal

Criterion: A significant level of achievement in the promotion and development of PCH

Name	Title
Position	Email Address
Institution	

Statement in support of the Nomination (circa 300 – 600 words. Please identify as many key achievements of the nominee as possible, including seminal publications in peer reviewed journals and any other awards received).



For the Book Prize

Name _____ Title _____

Position _____ Email Address _____

Institution _____

Statement in support of the Nomination (circa 300 – 600 words. Please identify the book, including the title, author/authors or editor/ editors, the publisher and an evaluation of how the book contributes to the advancement of person-centered healthcare).



For the Essay Prize

Name _____ Title _____

Position _____ Email Address _____

Institution _____

Statement in support of the Nomination (circa 300 – 600 words. Please identify the Essay itself, including the title, author/authors, the place of publication and an evaluation of how the Essay contributes to the understanding and advancement of person-centered healthcare).





EUROPEAN SOCIETY FOR PERSON CENTERED HEALTHCARE
Madrid, June 2016

For online registration to conferences: <http://pchealthcare.org.uk/conferences>

ESPCH Online Presence:



ESPCH website: www.pchealthcare.org.uk



YouTube: espchealthcare@gmail.com



Twitter: [@ESPCHHealthcare](https://twitter.com/ESPCHHealthcare)



Facebook: <https://www.facebook.com/espchealthcare>

Enquiries:

Dr. Vivian Mounir: vivian.mounir@pchealthcare.org.uk