





SDM-I SHARED DECISION-MAKING

Person-Centred Care & The Values Agenda

CONFERENCE BROCHURE



University of West London
Ealing Site, The Weston Hall
London W5 5RF, UK
25-26 March 2019







SDM-I

SHARED DECISION-MAKING

Person-Centred Care & The Values Agenda

A 2-Day Conference jointly organised by the European Society for Person Centered Healthcare (ESPCH), London, UK, the Collaborating Centre for Values-based Practice in Health and Social Care (VBP) at St. Catherine's College, Oxford, UK, and the European Institute for Person Centered Health and Social Care (EIPCHSC), University of West London, UK.

Conference Brochure

Table of Contents

4-5 **SDM-I Welcome Address**

SDM-I Conference Programme

- 6-7 First Day Agenda 25-03-2019
- 8-9 Second Day Agenda 26-03-2019

SDM-I Conference Abstracts

- 10-14 First Day Presentations 25-03-2019
- 15-20 Second Day Presentations 26-03-2019

21-34 Biographies of SDM-I Session ChairPersons & Speakers

Image Credits:

- Cover vector image was reproduced from © Gibsonff Dreamstime.com
- Infographic vector "Social-network-connection" (p.20) by © Alvaro Cabrera Freepick.com

SDM-I Welcome

WELCOME

We are delighted to welcome you to this two-day Conference on shared clinical decision-making, a joint initiative of the European Society for Person Centered Healthcare (ESPCH), the European Institute for Person Centred Health and Social Care of the University of West London (EIPCHSC), and the Collaborating Centre for Values-based Practice (VBP) at St. Catherine's College, University of Oxford.

The SDM-I Conference, the very first of its type to examine the inter-relationship between decision sharing, person-centred care and the values agenda, brings together a stellar line-up of speakers and chairpersons from across the globe, including the United States of America, Germany, Spain, Italy, Australia, Denmark and Norway. From the UK, we are delighted to welcome senior colleagues from the National Institute for Health and Care Excellence (NICE), the Academy of Medical Royal Colleges, the Universities of Oxford and Cambridge, the London School of Hygiene and Tropical Medicine, University College London, the University of West London, St. Mary's University London, City University London, University of Warwick, Kingston University and St. George's London, Canterbury Christ Church University, Manchester Metropolitan University, Swansea University, the University of South Wales and the General Osteopathic Council, UK.

Patients, when becoming ill and asking for help, present not as subjects, objects or complex biological machines, but rather as persons. They possess a narrative of illness, values, preferences, psychological and emotional needs, existential and spiritual complexities, worries, anxieties, fears, goals, psychosocial and psychosexual/relational dysfunctions, work and economic stressors — and a great deal more. It stands to reason that any approach to care that can be considered adequate, let alone optimal, must surely take all such factors into full and proper account, avoiding a concentration simply (and reductively) on the biological body alone. Rather, clinicians and carers, within the modern health and social care systems in which they operate, must strive to attend to the person of the patient as an integral whole. It is in this context

that the value and necessity of shared decision-making becomes, we assert, immediately clear. At its simplest, shared clinical decision-making (SDM) is a process through which both patient and clinician (or patient and family and clinicians) share the decision-making process in the face of multiple investigative and treatment options. The concept is not new, with the term 'shared decision-making', as an ethical imperative, having been first employed by Veatch in 1972. Since that time, the evolution of SDM has progressed slowly but surely, accelerating, over the last 10 years or so, as a function of the influence of major SDM work programmes, such as those of the Dartmouth Institute for Health Policy and Clinical Practice, USA, and elsewhere. At the time of writing, SDM is now well recognised as a central ethical and methodological component of the person-centered approach to health and social care, with increasing interest in how the basic tools of SDM, such as patient education, option grids and decision aids (etc), can be shifted, against barriers, from experimental clinical settings, into routine, operational clinical care.

As co-organisers of the Conference, we are indebted to our colleague speakers for their agreement to participate, many travelling considerable distances in order to contribute. Their collective expertise is formidable indeed, and we extend our further gratitude to these colleagues for working with us in the compilation of a special issue of the *Journal of Evaluation in Clinical Practice* on the subject of the Conference, to be co-ordinated by Professor Michael Loughlin in his role as Assistant Editor of the *JECP*. Further contributions of this nature will be invited for publication in the *European Journal for Person Centered Healthcare*, the official journal of the European Society for Person Centered Healthcare, to be co-ordinated by Professor Andrew Miles as Editor-in-Chief of *EJPCH*. Later this year we will announce the dates of a further conference on shared decision-making, SDM-II, to take place in 2020, with a definitive focus on methodological development and the implementation of SDM, as a central component of person-centered care, within modern health and social care systems.

We wish you a good Conference!



Professor Andrew Miles,
BMedSci, MSc, MPhil, PhD, DSc (hc),
Senior Vice President and Secretary
General, European Society for Person
Centered Healthcare & Co-Director,
European Institute for Person Centred
Health and Social Care, University of
West London, UK



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

5



Professor Bill (KWM) Fulford, MA, DPhil, PhD, FRCP, FRCPsych, Emeritus Professor of Philosophy and Mental Health, University of Warwick & Director of The Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford, UK

ドナナナナナナナナナナナナ

FIRST DAY AGENDA 25-03-2019

	TIKST DAT AGENDA 25-05-201		
08:00	REGISTRATION AND REFRESHMENTS	10:10	Values-based practice in surgical practice as a
09:00	Welcome to the University of West London Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc), Senior Vice President and Secretary General, European Society for Person Centered Healthcare & Editor-in-Chief, European Journal for Person Centered		model for shared decision-making Mr. Ashok Handa, Director of Surgical Education & Consultant Vascular Surgeon, Nuffield Department of Surgical Sciences, Division of Medical Sciences, University of Oxford, UK
	Healthcare; Co-Director, European Institute for Person	10:35	Panel discussion with delegate participation
	Centred Health and Social Care, University of West London, UK	11:00	MORNING BREAK WITH REFRESHMENTS
09:05	Presidential Address Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc), President and Chairman of Council, European Society for Person Centered Healthcare		Late Morning Session FOCUS ON SHARED CLINICAL DECISION- MAKING AND THE NEED FOR ADDITIONAL CONCEPTUAL CLARIFICATION
ľ	Early Morning Session FOCUS ON THE POLICY AND WORK OF THE NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE), PERSON- CENTRED CARE, AND THE VALUES AGENDA		Late Morning ChairPerson Professor Michael Loughlin, Professor of Applied Philosophy/Co-Director, European Institute for Person Centred Health and Social Care, University of West London & Associate Editor, Journal of Evaluation in Clinical Practice
09:10	Early Morning ChairPerson Professor Sir Jonathan Elliott Asbridge, Chief Clinical Officer, Healthcare at Home & Deputy Chairman, Oxford Health NHS Foundation Trust, Oxford, UK KEYNOTE 1 NICE and shared decision-making	11:30	New conceptual resources for developing the values agenda in shared decision-making Dr. Anna Bergqvist, Associate Professor in Philosophy, Department of History, Politics & Philosophy, Manchester Metropolitan University, UK & Theory Network Convener, Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford, UK
09:40	Sir Andrew Dillon, Chief Executive, National Institute for Health and Care Excellence (NICE), London, UK KEYNOTE 2 Shared decision-making with the empowered person not the dependent patient: the ethical and legal implications for guidelines Professor Jack Dowie, Professor Emeritus of Health Impact Analysis, London School of Hygiene and Tropical Medicine; Honorary Professor, University of Sydney School of Public Health & Adjunct Professor, University of Southern Denmark	11:55 12:20	The place of values in shared decision-making: a proposal Dr. Marco Annoni, Research Fellow, Institute of Biomedical Technologies, National Research Council, Rome, Italy Shared decision-making in fusion with other sciences Professor Ed Peile, Professor Emeritus (Medical Education), Institute of Digital Healthcare, University of Warwick, UK, and Professor Bill Fulford, Director, Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford & Professor Emeritus of Philosophy and Mental Health, University

12.45		
12:45	Panel discussion with delegate participation	
13:00	LUNCHEON	
	Early Afternoon Session FOCUS ON THE PATIENT'S VOICE AND INCREASED PUBLIC INVOLVEMENT IN SHARED DECISION-MAKING PRACTICES	
	Early Afternoon ChairPerson Dr. Amy Price, Senior Research Analyst, MedicineX, School of Medicine, Stanford University, United States of America; Patient Editor for Research and Evaluation at the British Medical Journal and Researcher, Department of Continuing Education, University of Oxford, UK	15:5
13:50	From populations to individuals - how evidence-based guidance can support patients' decisions Ms. Laura Norburn, Senior Manager, Public Involvement Programme, National Institute for Health and Care Excellence (NICE), Manchester, UK	16:2
14:15	Will the National Standards for Public Involvement in Research have a role to play in improving shared decision-making? Dr. Paula Wray, Senior Public Involvement Manager — INVOLVE, INVOLVE Coordinating Centre, National Institute for Health Research, University of Southampton Science Park, Southampton, UK	16:5 17:1
14:40	The power of language: the importance of shaping language as a constructive tool in health care Ms. Veryan Richards, Individual Partner, Collaborating Centre for Values-Based Practice (VBP), St. Catherine's College, Oxford & Patient Representative, Royal College of Psychiatrists, London, UK	17:3 17:3
15:10	Panel discussion with delegate participation	

AFTERNOON BREAK WITH REFRESHMENTS

Late Afternoon Session FOCUS ON PATIENTS, PRACTITIONERS AND REGULATORS, AND SHARED DECISION-MAKING IN END-OF-LIFE CARE Late Afternoon ChairPerson Professor Andrew Miles, Professor of Person Centred Health and Social Care & Co-Director, European Institute for Person Centred Health and Social Care; Editor-in-Chief, European Journal for Person Centered Healthcare, University of West London, UK Connecting patients, practitioners and regulators in supporting positive experiences and processes of shared decision-making Ms. Fiona Browne, Director of Education, Standards and Development, General Osteopathic Council, London, UK Some problems and dilemmas in shared decision-making in end of life care Professor Michael Kelly, Senior Visiting Fellow, Primary Care Unit, Institute of Public Health, University of Cambridge, UK So you think you need a new knee? Mr. Richard Wyatt-Haines, Founder and Director of Health and Care Videos, a partnership with Torbay and South Devon NHS Foundation Trust, UK Panel discussion with delegate participation **Closing Remarks** Professor Joëlle Fanghanel PhD TransDip MèsL LèsL NTF FHEA, Pro Vice-Chancellor, University of West London, UK Close of Day I **Networking Cocktail Reception** Served with Canapes & Wines

17:45 - 20:00
(Limited to reception subscribers only)

7

of Warwick; Founding Editor and Chair of the Advisory Board *Philosophy, Psychiatry and Psychology*

SECOND DAY AGENDA 26-03-2019

REGISTRATION AND REFRESHMENTS 09:00 Welcome to Day Two of the Conference Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc), Senior Vice President and Secretary General, European Society for Person Centered Healthcare & Editor-in-Chief, European Journal for Person Centered Healthcare; Co-Director, European Institute for Person Centred Health and Social Care, University of West London, UK Early Morning Session FOCUS ON SHARED CLINICAL DECISION-MAKING IN MENTAL HEALTHCARE: POSSIBILITIES AND LIMITS Early Morning ChairPerson Professor Bill (KWM) Fulford, Director, Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford & Professor Emeritus of Philosophy and Mental Health, University of Warwick; Founding Editor and Chair of the Advisory Board Philosophy, Psychiatry and Psychology 09:10 **KEYNOTE 1** Choosing wisely for mental health Professor Dame Sue Bailey, Past President of The Royal College of Psychiatrists and of the Academy of Medical Royal Colleges, London, UK 09:40 **KEYNOTE 2**

> Values in action: micro-analysing verbal and non-verbal communication during real time healthcare decision-making

Professor Rose McCabe, Professor of Clinical Communication, School of Health Sciences, City University of London, UK

Service User Involvement in Mental Health Care: an approach towards Shared Decision **Making and Person-Centred Care**

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

A Patient-Practitioner Orientation Scale: shared decision-making in mental healthcare

> Ms. Karin Drivenes, Clinical Pharmacist, Division of Mental Health, Sørlandet Hospital HF, Kristiansand, Norway

11:00 Panel discussion with delegate participation

11:15 MORNING BREAK WITH REFRESHMENTS

> Late Morning Session FOCUS ON WORKPLACE TRANSFORMATION AND HEALTHCARE LAW

Late Morning ChairPerson

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

11:45 The Venus Model for Person-Centered Sustainable Transformation - I. Facilitation and Leadership

> Professor Kim Manley, Professor of Practice Development, Research & Innovation & Co-Director England Centre for Practice Development, Canterbury Christ Church University, UK & Joint Clinical Chair, and Associate Director Transformational Research and Practice Development, East Kent Hospitals University Foundation NHS Trust, UK

12:05 Making Montgomery work for patients not **lawyers**

> Professor Sir Jonathan Montgomery, Professor of Health Care Law, Faculty of Laws, University College London, London, UK & Chair, Health Research Authority, UK

12:30 The Venus Model for Person-Centered Sustainable Transformation - II. Practice **Development, Improvement and Culture** Change

> Professor Kim Manley, Professor of Practice Development, Research & Innovation & Co-Director England Centre for Practice Development, Canterbury Christ Church University, UK &

Joint Clinical Chair, and Associate Director, Transformational Research and Practice Development, East Kent Hospitals University Foundation NHS Trust,

12:50 Panel discussion with delegate participation

13:10 LUNCHEON

> Early Afternoon Session FOCUS ON BARRIERS TO IMPLEMENTING AND MAINTAINING SHARED DECISION-MAKING

Early Afternoon ChairPerson

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

14:00 Patient and public involvement/engagement in healthcare - a positive step forward. But what are the negatives?

> Dr. Amy Price, Senior Research Analyst, MedicineX, School of Medicine, Stanford University, United States of America; Patient Editor for Research and Evaluation at the British Medical Journal and Researcher, Department of Continuing Education, CAMS Oxford, UK

14:25 What barriers are there to establishing decision-making as the norm in obstetrics?

> Professor Stella Villarmea Requejo, Professor of Philosophy, Faculty of Philosophy and Arts, University of Alcalá, Madrid, Spain & ERC Marie S. Curie Fellow, University of Oxford, UK, and Dr. Brenda Kelly, Consultant Obstetrician, John Radcliffe Hospital, Oxford, UK & Honorary Senior Clinical Fellow, Nuffield Department of Obstetrics & Gynaecology, University of Oxford, UK

The limits to shared decision-making. How do we tackle low health literacy and education to help patients understand risk and make informed decisions?

Dr. Paul Batchelor, Hon. Senior Lecturer, Dental Public Health Group, University College London, UK

15:15 Epistemic injustice and care-related decisionmaking

> Dr. Gideon Calder, Senior Lecturer & Director, Social Care Policy Programme, Department of Public Health, Policy and Social Sciences, University of Swansea, Wales, UK, and Ms. Nicola Blunden, Senior Lecturer, Therapeutic Studies, Faculty of Life Sciences and Education, University of South Wales, UK

Panel discussion with delegate participation

15:55 **President's Closing Remarks**

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

16:00 **Close of Conference**

15:40

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

14:50

FIRST DAY PRESENTATIONS

25-03-2019

09:10 KEYNOTE 1

NICE and shared decision-making

Sir Andrew Dillon, Chief Executive, National Institute for Health and Care Excellence (NICE), London, UK

It seems odd to talk about shared decision-making in healthcare as a novel idea. Surely, it must be something that happens automatically, almost without either the patient or the health professional thinking about it. It does, of course, but not as much as it could. More can be done to involve people more closely in decisions about their care and in doing so, help to address a range of challenges facing the NHS, including rising costs, an ageing population and increasingly complex treatment options.

NICE has always recognised the importance of a conversation between people providing and people receiving care, before decisions are made, to inform choice and to give consent to treatment. Each guidance publication contains advice to professionals to consider the individual needs and preferences of their patients and service users, and since our involvement with the Collaborating Centre for Values-based Practice, their values too. We make it clear that our recommendations do not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

In 2012, we published guidance and a quality standard on optimising the experience of adult patients in secondary care. We have begun to develop shared decision-making aids to accompany our guidance and we train our staff and our advisory committee members in recognising the importance of and the opportunity for supporting shared decision-making. In 2015, we set up the NICE shared decision-making collaborative with more than 40 partner organisations, all committed to thinking collectively about the role of shared decision-making in UK health systems, drawing on international experience. And in 2021, we will publish a guideline on practical approaches to building it into practice.

09:40 KEYNOTE 2

Shared decision-making with the empowered person not the dependent patient: the ethical and legal implications for guidelines

Professor Jack Dowie, Professor Emeritus of Health Impact Analysis, London School of Hygiene and Tropical Medicine; Honorary Professor, University of Sydney School of Public Health & Adjunct Professor, University of Southern Denmark

As with many constructs in healthcare (e.g. "evidence-based medicine", "health-related quality of life", "decision aid") shared decision making is "formative" not "reflective", i.e. "it" has no prior existence prior to its definition and measurement. Any particular formative construct is preference-sensitive, based on the preferences of those who form it by their indicator selection and weighting. These preferences often reflect interests of various sorts, many not financial. So cave litteras maiusculas sdm not SDM. Since "shared" is a qualifier of "decision making", two fundamental preferences relevant to decision making are relevant in any construction of sdm: (i) for provider-controlled, direct-to-patient intermediation or provider-independent, directto-person, apomediation, and (ii) for verbal deliberative reasoning (vdr) or numerical analytical calculation (nac). From their crosstabulation we can see that, within both practice and research - and legal standards and ethical guidelines for both - sdm is currently being constructed exclusively within the intermediative verbal deliberative reasoning ("inter-vdr") frame. The three other possibilities are "inter-nac", "apo-vdr", and "apo-nac". We explore and illustrate the four frames through the type of decision support they involve and suggest alternatives to the "inter-vdr" model would better meet the preferences of some in heterogenous populations. While the current number may be small, apomediative constructions, where the sharing is exclusively, or initially, with provider-independent organisations of the "Which" product comparison type, will be increasingly demanded as the digital revolution impacts on the self-production and co-creation of health through wearables and cyber connectivity. We stress that there is no objection to the preference-based dominance of inter-vdr sdm practice and guidelines, unless it is used, either overtly or covertly, to deny those with other preferences access to the alternative constructs of sdm, and to the decision support

tools that would be appropriate to them. In a publicly-resourced service the only arguments for denying these alternative forms to those who would prefer them are economic. There is therefore a strong case for the rigorous, fair and comprehensive evaluation of implementations of all the main constructs of sdm - evaluation in which particular interests and preferences do not bias the measures of costs and effectiveness in such a way as to guarantee the overall result is in their favour.

A video "Constructing shared decision making" (9mins 35secs) is available at http://bit.ly/sdmspowtoon

10:10

Values-based practice in surgical practice as a model for shared decision-making

Mr. Ashok Handa, Director of Surgical Education & Consultant Vascular Surgeon, Nuffield Department of Surgical Sciences, Division of Medical Sciences, University of Oxford, UK

"Values" are the beliefs we have about what is right and wrong and what is most important in life. When making a clinical decision, many people's values may be involved: the patient's, their relatives', the clinician's, society's or the Trust's. However, how often do clinicians ask patients, "What's important to you?"? We assume we know what our patients want but it isn't always as simple as we think.

This presentation will describe the setting up and delivery of a series of seminars, open to consultants, trainees, multidisciplinary staff and patients to introduce the concept of values-based practice (VBP). Through exercises to demonstrate VBP, participants will be shown that values are deeply personal and vary to a surprising degree. Applying this to case studies will show the importance of recognising the VBP concept in clinical practice. These siminars have been positively received, and demonstrate a methodology for introducing the concepts of shared decision making in the post Montgomery Judgement era.

11:30

New conceptual resources for developing the values agenda in shared decision-making

Dr. Anna Bergqvist, Associate Professor in Philosophy,
Department of History, Politics & Philosophy, Manchester
Metropolitan University, UK & Theory Network Convener,
Collaborating Centre for Values-based Practice, St Catherine's
College, University of Oxford, UK

Objectives

The deployment of recent philosophical and empirical work on hope and perceptual ethics in healing relational crises, intrapsychic conflicts and identity disturbance, and to explain why hope in narrative self-creation is central to the recovery process through shared decision making (SDM) in relational psychiatry.

Background and Aims

The overall aim is to make a conceptual correction to the psychological literature on selfhood in adults diagnosed with personality difficulties by showing that lacking control over one's own actions (and intrusions) and failing to see oneself as the *subjective mental agent* of the thoughts and feelings one undergoes in dissociation cases are two different situations.

Materials and Methods

Using the distinction between propositional hope and non-intentional orientation or existential feeling in moral perception and shared decision making, Dr. Anna Bergqvist argues that it is possible to lose one's sense of agentic control (and experience severe despair from it) and yet retain another kind of access to the content of one's mental agency in dissonance cases.

Results

Two broad kinds of predicament that are easily confused in understanding agency in shared decision making: propositional hope as an intentional state (hoping that) and pre-intentional "loss of hope" in the subject's emotional orientation or existential feeling.

The narrative agency that remains is something like a transcendental condition for experience by which other kinds of intentional state, including intentional hope, are intelligible in relational psychiatry.

Conclusions

Dr. Bergqvist concludes by showing how the phenomena of resting in the hoping gaze of others shows an essentially relational dimension to subjectivity in these under-theorized, non-standard cases that is helpfully understood in terms of professional virtue. Herein lies also the moral and clinical significance of reappraising hope as virtue in shared decision making in working with emotional personality difficulties in times of despair.

11:55

The place of values in shared decision-making: a proposal

Dr. Marco Annoni, Research Fellow, Institute of Biomedical Technologies, National Research Council, Rome, Italy

In the last decades "shared decision-making" has been hailed as the new paradigm for the doctor-patient relationship by institutions, policy-makers and scholars alike. However, the meaning and practical implications of such a new paradigm remain unclear; a variety of different models of clinical decision-making appear to be compatible with the core tenets of "shared decision-making". Dr. Annoni argues that a panoply of different models arises because of clinical practice is too variegated and complex to be reduced to a single overarching theoretical ideal, i.e, different decision-making models may be appropriate depending on the circumstances.

Delving into these themes, Dr. Marco Annoni's presentation is organized into three sections. First, he will present an exemplar clinical case. Second, he will distinguish five possible models of clinical decision-making: (i) the "instrumental"; (ii) the "paternalistic"; (iii) the "informative"; (iv) the "interpretative"; and (v) the "persuasive" models. For each model he will present its fundamental assumptions as well as the role that patients and doctors are expected to play with respect to value-laden dilemmas. Finally, he will argue that, with the exception of the instrumental model, each of the other four models may be appropriate depending on the circumstances. Finally, he will conclude by highlighting the importance of structuring clinical care around actual persons rather than around abstract frameworks.

12:20

Shared decision-making in fusion with other sciences

Professor Ed Peile, Professor Emeritus in Medical Education, Institute of Digital Healthcare, University of Warwick, UK, and Professor Bill (KWM) Fulford, Director, Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford & Professor Emeritus of Philosophy and Mental Health, University of Warwick, UK, Founding Editor and Chair of the Advisory Board Philosophy, Psychiatry and Psychology

This presentation focuses on the implications for shared decision making of the recent (2015) UK Supreme Court *Montgomery* judgment. It argues that the judgment puts values alongside evidence at the heart of shared decision making as the basis of person-centred care.

The Montgomery judgment marks a decisive shift in the legal test of duty of care in the context of consent to treatment from the perspective of the clinician (as represented by Bolam rules) to that of the patient. A majority of commentators on Montgomery have focused on the implications of the judgment for disclosure of risk. This presentation will set the risk disclosure requirements of Montgomery in context with three further elements of the judgment: benefits, options, and dialogue. Taken together these elements reflect recent developments on shared decision-making between clinician and patient widely regarded (by the General Medical Council and others) as representing best practice on consent in contemporary clinical care. Integral to this best practice approach are the skills for balancing the values of (what is important from the perspective of) the particular patient against the values of a reasonable person in the patient's position.

Alongside the lessons of the Montgomery case, another contemporary theme in the improvement of person-centred care has been the recent emphasis on utilising digital healthcare to augment the support offered to individual patients. Contrary to common perceptions that digital advances supplant personcentred approaches, the speakers seek to demonstrate how "fusion sciences" enhance the support that can be offered to individuals seeking to improve their health and wellbeing. Valuesbased practice and evidence-based practice are central to the science of clinical decision-making which is one of the four science strands in the "fusion sciences". These are at the heart of the first UK degree programmes for Digital Healthcare Science Practitioners. The other strands are the behavioural sciences; clinical physiology; and digital healthcare science. Professors Peile and Fulford will show how these come together in education with a strong emphasis on personal and professional development.

13:50

From populations to individuals - how evidencebased guidance can support patients' decisions

Ms. Laura Norburn, Senior Manager, Public Involvement Programme, National Institute for Health and Care Excellence (NICE), Manchester, UK

On the surface there is an inherent tension between the provision of evidence-based recommendations and shared decision making. Particularly for an organisation like NICE, charged with delivering the greatest utility to the UK health service, the relationship between population level recommendations and individual choices seems problematic. This presentation will explore these problems and tensions and discuss how NICE considers the importance for

individuals to make evidence-informed decisions, and how our guidance and other tools can support people to do so, whilst still providing a broad framework of recommendations aimed at achieving "the greatest good for the greatest number".

14:15

Will the National Standards for Public Involvement in Research have a role to play in improving shared decision-making?

Dr. Paula Wray, Senior Public Involvement Manager – INVOLVE, INVOLVE Coordinating Centre, National Institute for Health Research, University of Southampton Science Park, Southampton, UK

The UK Standards for Public Involvement in Research have developed in partnership with the devolved nations and will be formally launched in the autumn. The development of the standards in itself is an example of shared decision making. The partners include public contributors, researchers, policy leads and public involvement practitioners all working towards a common goal, to improve the quality and consistency of public involvement in research. Although the standards were developed with research in mind they are values based and therefore could be applicable in many contexts. The potential role for the standards supporting effective shared decision making will be shared along with the links to how improving research outputs will also contribute to this agenda.

The six standards are; inclusive opportunities, working together, communication, support and learning, impact and governance. They are designed to be a reflective quality improvement tool and one area in research practice were this is needed is around communication. More effective communication of research outputs and what these mean to patients and healthcare professionals is an area that is rapidly developing with work on Plain Language Summaries. So much research evidence does not reach those who would potentially benefit from it. We see this through our James Lind Alliance Priority Setting Partnerships. The aim is not only to make the content and methodology of research accessible to the informed patient but to support wider dissemination to populations who need support for shared decision making to be possible.

14:40

The power of language: the importance of shaping language as a constructive tool in health care

Ms. Veryan Richards, Individual Partner, Collaborating Centre for Values-Based Practice (VBP), St. Catherine's College, Oxford & Patient Representative, Royal College of Psychiatrists, London, UK

The language used in clinical practice is a key enabler to the success of treatment. Without good communication which is underpinned by values, therapeutic engagement and treatment outcomes will not be as successful. Ms. Veryan Richards will discuss language as the substrate of relationships in person-centred care and shared decision-making. She will introduce "Guidelines on the use of language – RCPsych in Wales" which aims to provide a helpful lens through which to shape the language used in training and in clinical practice.

It would enhance the quality of care if everyone engaged in healthcare were to commit to shaping and influencing a culture and standard of communication which diminishes stigma and promotes language which is appropriate, respectful and empowering.

15:50

Connecting patients, practitioners and regulators in supporting positive experiences and processes of shared decision-making

Ms. Fiona Browne, Director of Education, Standards and Development, General Osteopathic Council, London, UK

This session will explore how regulators, working with patients and practitioners, may contribute to supporting person-centered care and processes of shared decision making in implementing professional standards. It will demonstrate pilot resources for patients and practitioners.

Health professional regulation has mostly been known for its role in fitness to practise which usually involves removing or restricting the right to practice of individuals and ensuring public protection.

Today, regulators are increasingly working towards "upstream" activity, embedding standards in a variety of ways to reduce harm. This approach tends to focus on providing resources, guidance, advice and dialogue, mostly for practitioners, to support the implementation of standards. However, less attention is given by

regulators to how standards are interpreted by a practitioner working in a particular context and to what health means to a patient and how patients interact within their environment. And yet, it is in precisely this dialogue between patient and practitioner that regulatory standards are manifested.

This presentation will discuss the shared process of development involving collaborative work between regulators (the General Osteopathic Council and the General Dental Council), the Collaborating Centre for Values Based Practice, patients and practitioners. This project is developing ways of supporting patients and practitioners to make explicit what is important to them in a consultation, thereby enhancing the possibility of a positive dialogue, a shared decision making process and an informed patient decision.

16:20

Some problems and dilemmas in shared decisionmaking in end of life care

Professor Mike (Michael) P. Kelly, Senior Visiting Fellow, Primary Care Unit, Institute of Public Health, University of Cambridge, UK; Dr. Sarah Hoare, The Healthcare Improvement Studies (THIS) Institute, University of Cambridge, UK; Dr Stephen Barclay, Primary Care Unit, Department of Public Health and Primary Care, Cambridge Institute of Public Health, University of Cambridge

One of the arenas in the UK Health Service where the idea of shared decision making is very strong, is end of life care. There are several elements to this. The rhetoric of policy is that patients should be able to choose, in consultation with their medical and nursing advisors and their families, where they want to die. The rhetoric of policy, however, presupposes that it knows the answer to patient preferences. Policy is driven by the idea that home is the best place for deaths to occur and that this is what the majority of people want. The evidence in support of this is far from supportive of the policy rhetoric. It is the case that people's preferences are highly situationally dependent. This begs the question of in what sense is decision making really shared? It also raises the question of the extent to which the dominant ideology actually constrains choice in decision making? Overlaid on this is another argument which policy makers frequently invoke, which is that when deaths occur in hospital, they are in some sense inappropriate. Shared decision-making is an aspiration within end-of-life care, but is difficult to deliver in practice because of the inherent (and unrecognised) complexity of end-of-life care provision. An excellent example of this is the focus attributed to end-of-life

care conversations/advance care planning. Both are predicated on the now disputed presumption that place is an important priority to patients, and further that home is a desirable and feasible place of care/death. The empirical investigation of the processes involved reveals a complex picture in which joint planning, even where a discussion is possible and a patient has been able to specify their wishes, the reality of end of life experiences at home are highly constrained by a number of factors. These are: the resources available for care in the community, the unpredictable nature of the biological process of dying, the physical needs of the patient, family and lay carers' abilities and resources to cope with the needs of their dying relative, and the knowledge about patients which is available to out of hours staff and ambulance crews, during out of hours. The complex web of factors belies any easy policy solutions and demands instead confronting the complexity of end of life care in its social, psychological, economic as well as medical dimensions.

16:50

So you think you need a new knee?

Mr. Richard Wyatt-Haines, Founder and Director of Health and Care Videos, a partnership with Torbay and South Devon NHS Foundation Trust. UK

Hip and knee replacement procedures are one of the most common operations in the health service, but are they always needed? There is evidence that it is an intervention that is utilised too frequently and at the wrong time. So what is the cause and how do we change the current situation? Is it an inappropriate patient expectation or does fault lie with the surgeon? Or perhaps it is somewhere else in the system?

This presentation explores a new approach being adopted and tested in Torbay and South Devon towards shared decision making throughout the pathway of care so that expectations for clinicians and patients alike are more effectively managed and the options for treatment better understood.

The approach deploys marketing and communication skills alongside a mix of media, both online and off-line, taking lessons from retail marketing, social media and video.

The early results are really encouraging, but will it make a long-term impact? Can the same approach be deployed across multiple disease types?

SECOND DAY PRESENTATIONS

26-03-2019

09:10 KEYNOTE 1

Choosing wisely for mental health

Professor Dame Sue Bailey, Past President of The Royal College of Psychiatrists and of the Academy of Medical Royal Colleges, London, UK

Dame Professor Sue Bailey explores the intertwined themes of Choosing Wisely, parity for mental health and how they link to a future healthy and health creating society.

The core aim of Choosing Wisely UK is to promote good conversations between patients and clinical teams and to understand a patient's values. Every patient should be enabled to ask and expect an evidence-based answer to the following questions about their treatment: what are the benefits? What are the risks? What are the alternatives here? What will happen if I do nothing?

How can Choosing Wisely help to reverse the lack of parity for mental health? The shameful facts are: people with a severe mental illness face 15-20 years shorter life expectancy, 3 times higher risk of premature mortality, higher risks of developing diabetes, heart problems and cancer and live with multiple physical health problems. This should be everybody's business across communities, health, education, research and the voluntary sector. The Centre for Mental Health is promoting Equally Well, a collaborative aimed to spur collective action to end these physical health inequalities. It is rights-based and coproduced with those with lived experience of mental illness

How do we together look to the future, helping policy makers to develop sound policy for health? How do we secure a future for the citizens of 2035 where they can achieve mental health for themselves, their families and communities? This requires a rights values-based approach. It requires social justice for children where they are afforded fairness, protection and developmental autonomy.

Shared decision making is a truly social identity approach to the health of all and their communities. It is Choosing Wisely for our future.

09:40 KEYNOTE 1

Values in action: micro-analysing verbal and nonverbal communication during real time healthcare decision-making

Professor Rose McCabe, Professor of Clinical Communication, School of Health Sciences, City University of London, UK

Most research on shared decision making uses scales which offer a global picture of patient involvement, such as whether doctors ask patient preferences or list options. However, analysis of how, rather than whether, doctors discuss medication with patients is vital for a more nuanced understanding of decision making. Nonverbal communication is central, in particular whether the doctor is looking at the patient as patients become disengaged when doctors are writing or attending to (electronic) medical notes.

How doctors recommend treatment indicates whether the patient is identified as the primary decision maker or a passive party to the decision. Recently, a novel approach examining how doctors format treatment recommendations in more or less authoritative ways has been developed by Stivers, McCabe et al I. There are clear differences between "I'm going to start you on X", "We can give you X to try" and "Would you like me to give you X". As these different formats are more or less authoritative, they afford patients different degrees of autonomy to decide whether or not to accept or resist treatment recommendations. This presentation will use data from video-recorded healthcare encounters across different treatment settings in primary and secondary care to illustrate subtly different ways of involving patients in decisions, whether patients accept or resist the recommendations and whether the treatment is ultimately prescribed in accordance with the patient's preference. It will also draw on interviews with doctors about the contextual factors impacting on decisions to illustrate how they shape decision making in action.

Reference

 Stivers T, Heritage J, Barnes RK, McCabe R, Thompson L, Toerien M.Treatment Recommendations as Actions. Health Communication. 2017;33(11):1335-1344. doi: 10.1080/10410236.2017.1350913.

SDM-I Abstracts

10:10

Service User Involvement in Mental Health Care: an approach towards Shared Decision Making and Person-Centred Care

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

There is widespread recognition of the importance of patient and public involvement (PPI) at all levels of health care from policy development to the provision of individual care and treatment. Mental health care in the form of service user involvement (SUI) has been leading the way since the 1970s assisted by the introduction of the recovery approach. This approach focuses on the principles of partnership working and shared decisionmaking between service users and professionals in all aspects of care and social support. However, whilst the implementation of the recovery approach is accepted as good-practice it is not straightforward and signifies a "quantum leap" from the traditional, paternalistic methods of mental health care to more social, democratic endeavours. A major confounding factor in this transition is the stigma and discrimination that remains towards metal illness, which sets it apart from other forms of illness. Given this societal positon, it is remarkable that the service user voice has advanced as far as it has, which is due in large part to the service users themselves.

This presentation, through practical case study examples, will address key elements of SUI and consider some of the challenges from the perspectives of both professionals and service users.

10:35

A Patient-Practitioner Orientation Scale: shared decision-making in mental healthcare

Ms. Karin Drivenes, Clinical Pharmacist, Division of Mental Health, Sørlandet Hospital HF, Kristiansand, Norway

Ms. Drivenes' team has performed a cross sectional study at Sørlandet Hospital, Division of Mental Health, where more than 900 patients and 300 professionals were included. Patient reported outcome measures (PROMs) were used for data collection. The Patient-Practitioner Orientation Scale (PPOS) was used to explore professionals' attitudes and CollaboRate was used for shared decision-making evaluation. Data from this study were analyzed in a mixed-effects regression using Stata SE, and the

results showed that the professional's higher scores of the sharing dimension of PPOS increased the probability for the patient to have experienced shared decision-making.

The presentation aims to give an insight in how professionals' attitudes influence the performance of treatment decisions. The study had focused on the PPOS instrument, which assesses the sharing and caring dimensions of professional attitude regarding the clinical encounter. These, however, are only fragments of a complex and diverse inclination, which form and set the direction of the patient-professional interaction.

The presentation will discuss the importance of the individual therapist's attitudes versus the organizational structure's influence on the achievement of fully integrated SDM in mental health care.

11:45

The Venus Model for Person-Centered Sustainable Transformation – I. Facilitation and Leadership

Professor Kim Manley, Professor of Practice Development,
Research & Innovation & Co-Director England Centre for
Practice Development, Canterbury Christ Church University, UK
& Joint Clinical Chair, and Associate Director Transformational
Research and Practice Development, East Kent Hospitals
University Foundation NHS Trust, UK

This, the first of two papers, presents a synthesis of the theoretical and practical insights relevant to all those engaged in the transformation of health and social care based on person centred values and relationships. This synthesis is presented as a theoretical framework – the Venus Model for sustainable person centred transformation, derived from three practice-based research studies that focused on using the workplace as the main resource for learning, developing and improving;

- A realist evaluation of how to embed safety cultures in frontline teams¹.
- A Delphi study developing international standards for supporting an integrated approach to facilitation using the workplace as the main resource for inter-professional learning, development, improvement, inquiry, knowledge translation and innovation -a key factor in transforming the workforce²
- A realist evaluation of how continuous professional development from an inter-professional perspective can be more focused on providing care that is person-centred, safe and effective.^{3,4}

These studies were combined with outputs from an interprofessional workshop for an international network of fellows.

The Venus model describes the 5 key elements and linked concepts (and relationships) required to support front line teams (micro-systems) to transform practice through inter-professional learning, development, improvement and innovation, and the essential organisational and systems factors required to enable this. Two elements of the model will be covered in this first part of the presentation on the Venus Model for PC Sustainable Transformation, namely:

- Supporting development of facilitation skills across a continuum of complex purposes in the workplace^{2,5}
- 2. Leadership development at clinical to systems levels^{6,7}

The remaining three elements is the focus of the second presentation, together with general implications for transformation towards person centred practices and relationships.

References

- Manley K, Jackson C, Mckenzie C, Martin A, Wright T. Safety Culture, Quality Improvement, Realist Evaluation (SCQIRE): Evaluating the impact of the Patient Safety Collaborative initiative developed by Kent Surrey and Sussex Academic Health Science Network (KSSAHSN) on safety culture, leadership, and quality improvement capability. ISBN 978-1-909067-79-0. Website. http://create.canterbury.ac.uk/17011/ Published November 2017. Updated January 29, 2019. Accessed March 13, 2019.
- Martin A, Manley K. Developing standards for an integrated approach to workplace facilitation for interprofessional teams in health and social care contexts: a Delphi study. *Journal of Interprofessional Care*. 2018;32(1):41-51. doi: 10.1080/13561820.2017.1373080.
- Jackson C, Manley K, Martin A, Wright T, Martin A.
 Continuing Professional Development for Quality Care:
 Context, Mechanisms, Outcomes and Impact. Final Report.
 England Centre for Practice Development (ECPD),
 Canterbury Christ Church University. ISBN 978-1-909067-39-4. Website. http://create.canterbury.ac.uk/14359/
 Published January 2015. Updated March 31, 2016. Accessed March 13, 2019.
- Manley K, Martin A, Jackson A, Wright T.A realist synthesis of effective continuing professional development (CPD):A case study of healthcare practitioners' CPD. Nurse Education Today. 2018;69:134-14. doi:10.1016/j.nedt.2018.07.010.
- Manley K, Titchen A. Facilitation Skills: The Catalyst for Increased Effectiveness in Consultant Practice and Clinical Systems Leadership. Educational Action Research.

- 2017;25(2):256-279. doi: 10.1080/09650792.2016.1158118
- Akhtar M, Casha JN, Ronder J, Sakel M, Wight C, Manley K. Leading the health service into the future: transforming the NHS through transforming ourselves. *International Practice* Development Journal. 2016;6(2):Article 5. doi: 10.19043/ ipdj.62.005
- 7. Manley K, Martin A, Jackson C, Wright T. Using Systems
 Thinking to identify workforce enablers for a whole systems
 approach to urgent and emergency care delivery: A multiple
 case study. BMC Health Services Research. 2016;16(a):368. doi: 10.1186/s12913-016-1616-y.

12:05

Making Montgomery work for patients not lawyers

Professor Sir Jonathan Montgomery, Professor of Health Care Law, Faculty of Laws, University College London, London, UK & Chair, Health Research Authority, UK

The Montgomery decision on informing patients is seen by some as merely codifying the expectations of good clinical practice, by others as imposing unrealistic burdens on clinicians, and by yet others as forcing the provision of inappropriate care. The reasons for this variation of interpretation will be explored and it will be suggested that the intention of the Supreme Court was to ensure that patients were fully involved in decisions and not manipulated by clinicians. This intention need not undermine evidence-based practice but there is a risk that it might do so. It need not place clinicians under threat of litigation, but a flurry of cases is a necessary part of reaching a settled interpretation of what is required by law, by ethics, but above all by patients. Clinicians, health providers and patients need to work together to ensure that implementing the Montgomery decision promotes person-centred care not legalistic and defensive practices.

12:30

The Venus Model for Person-Centered Sustainable Transformation – II. Practice Development, Improvement and Culture Change

Professor Kim Manley, Professor of Practice Development,
Research & Innovation & Co-Director England Centre for
Practice Development, Canterbury Christ Church University, UK
& Joint Clinical Chair, and Associate Director Transformational
Research and Practice Development, East Kent Hospitals
University Foundation NHS Trust, UK

SDM-I Abstracts

The origins and overview of the Venus model were presented in first part of the presentation on the Venus Model for PC Sustainable Transformation (p. 16, 11:45), and it included two of the model's five key elements; facilitation and leadership. This second part of the presentation covers the remaining three elements as well as general considerations about how the model for transforming person centred health and well-being can be used to support values based shared decision-making.

The remaining three arms of the Venus model that will be covered include:

- Practice development a complex methodology that focuses on collaborative, inclusive and participative approaches with stakeholders, to develop person-centred, safe and effective cultures^{1,2}
- 4. Using quality improvement skills and tools³
- 5. The culture change skills at the front line of practice4

Bottom up, as opposed to top down models for supporting complex change in organisations, are crucial to understand how to transform systems, services and cultures of care within and across organisations to deliver new models for 21st century health, and values based approaches to support inter-professional learning for shared decision-making, person centred, compassionate, safe and effective care.

This presentation will conclude by sharing implications of sustainable person centred transformation of health care practice based on person centred values and authentic relationships, informed by the enablers at micro, meso and macro systems levels. This will include consideration of how inter-professional learning, practice and leadership as well as continuous professional development are all pivotal to the delivery and evaluation of sustainable transformation across the health economy to impact on future new models of care with a foundation in person centred values, relationships and shared decision-making.

References

- Manley K, McCormack B, Wilson V (2008) International Practice Development in Nursing and Healthcare. Blackwell Publishing, Oxford
- McCormack B, Manley K, Titchen A, eds. (2013) Practice development in Nursing & Health Care. 2nd ed. (2nd edition). Oxford, UK:Wiley-Blackwell; 2013.
- Manley K, Büscher A, Jackson C, O'Connor SJ, Stehling H. Overcoming synecdoche: why practice development and quality improvement approaches should be better integrated. *International Practice Development Journal*. 2017; 7(1):Article 12. doi: 10.19043/ipdj.71.012. [Commentary

- Response to: Lavery G. Quality improvement rival or ally of practice development? *International Practice Development Journal*. 2016; 6 (1): Article 15. doi: 10.19043/ipdj.61.015].
- Manley K, Sanders K, Cardiff S, Webster J. Effective Workplace Culture: The Attributes, Enabling Factors and Consequences of a New Concept. International Practice Development Journal. 2011; 1(2): Article 1. Website: https://www.fons.org/library/journal/volume1-issue2/article1

14:00

Patient and public involvement/engagement in healthcare – a positive step forward. But what are the negatives?

Dr. Amy Price, Senior Research Analyst, MedicineX, School of Medicine, Stanford University, United States of America; Patient Editor for Research and Evaluation at the *British Medical Journal* and Researcher, Department of Continuing Education, CAMS Oxford, UK

Background

As partnering with the public and patients in medical research, grows in prevalence, we may become curious about how to implement successful co-production partnerships in our own work. Co-production in healthcare research is the activation of public and patient involvement in which patients and members of the public work with clinicians and researchers to create, redesign and build medical research. Involvement and co-production can also be initiated by the public as they seek researchers and clinicians to partner with in research. In contrast with traditional public and patient involvement, citizens are not only consulted, but they are part of the conception, design, steering, implementation, and management of the research.

Objective

This presentation seeks to unravel some fine print and to discuss research process, methods and reporting gaps in Co-production Public and Patient Involvement (CPPI)

Key Challenges to Co-Production

There are multiple challenges to be unpacked when undertaking PPI co-production, including unpacking of disparity and equality concerns, dealing with assumptions and uncertainty, understanding role confusion, and managing expectations while investing in meaningful PPI that obtains adequate consent as well as understanding of competing interests and funding policies. These points are addressed along with recommendations for better reporting of PPI co-production and the introduction of an "Everyone included" framework.

Take Home Mission

Your mission if you choose to accept it will be to openly consider how to move beyond the challenges together and improve Public and Patient Co-production in practice.

14:25

What barriers are there to establishing decisionmaking as the norm in obstetrics?

Professor Stella Villarmea Requejo, Professor of Philosophy,
Faculty of Philosophy and Arts, University of Alcalá, Madrid, Spain
& ERC Marie S. Curie Fellow, University of Oxford, UK, and Dr.
Brenda Kelly, Consultant Obstetrician, John Radcliffe Hospital,
Oxford, UK & Honorary Senior Clinical Fellow, Nuffield
Department of Obstetrics & Gynaecology, University of Oxford,
UK

How difficult can it be to establish shared decision-making (SDM) as the norm when caring for a woman in labour? The benefits for SDM in delivery of high-quality, personalised care are undisputed. But what is it about the dynamics of the delivery room that lead some to doubt that true SDM is possible?

In this jointly presented session, Professor Stella Villarmea Requejo and Dr. Brenda Kelly examine a theory of female rationality and its application to women in labour, and juxtapose this with the view from the frontline of care delivery. Is a woman in labour able to fully engage in a SDM process? The answer to this question will uncover some associations in the discourses and practices around women's full capacity during labour that frequently act as barriers to establishing SDM as the norm in obstetrics and midwifery.

14:50

The limits to shared decision-making. How do we tackle low health literacy and education to help patients understand risk and make informed decisions?

Dr. Paul Batchelor, Hon. Senior Lecturer, Dental Public Health Group, University College London, UK

Shared decision making in health care requires an understanding of the risks and benefits of interventions to be understood by both patients and clinicians if it is to help improve outcomes. While the goal of such arrangements may be laudable, it presupposes that the understanding of risks and benefits can be

made by both parties and not least their numeracy and literacy skills have allowed interpretation to be made. This presentation will examine the extent to which numeracy and literacy levels can play a part in decision making and as a consequence, impact on addressing the problems that shared decision making attempts to overcome. Indeed, in combination with the creation of a market style approach adopted by politicians in health care, while seen as a solution to many of the problems which shared decision making attempts to address, may well be a considerable hindrance as it contributes to a climate in which trust between patients and clinicians may be weakened. The presentation will argue that there is a need to strengthen the relationship between the population and the care professionals and politicians held to greater account if outcomes are to improve.

15:15

Epistemic injustice and care-related decision- making

Dr. Gideon Calder, Senior Lecturer & Director, Social Care Policy Programme, Department of Public Health, Policy and Social Sciences, University of Swansea, Wales, UK, and Ms. Nicola Blunden, Senior Lecturer, Therapeutic Studies, Faculty of Life Sciences and Education, University of South Wales, UK

Decision-making about care involves complex, nuanced practical reasoning. Such reasoning will partly reflect professional expertise: knowledge of relevant bodies of evidence, and fluency in ways of speaking, judging, and practising. It will (or should) also be shaped significantly by the dynamics of the relationship between practitioner and service-user, or care-giver and care-receiver. Those dynamics are importantly constitutive of what care is, and of the way it plays out in any particular situation.

This presentation offers a conceptual analysis of some of the issues which arise in this context. It is framed around two themes. One is the centrality of knowledge in the care relationship. So the ways in which people know things, and how they talk about them, and the relative status accorded to different ways of knowing and speaking, are all materially at stake in every care-based encounter. The second is the concept of economic injustice, as developed by Miranda Fricker (2007) and since taken up and applied in a variety of social settings. Economic injustice concerns wrongs which may be done to someone specifically as the kind of 'knower' they are. It may happen where a speaker is not taken seriously, or has not been given the resources to make sense of their experiences, or the situation they find themselves in. Putting these two themes together, Dr. Calder and Ms. Blunden suggest, illuminates a series

of significant features about processes of care-related decision-making, and the ways in which they may empower, inhibit or deny the perspective of the care-receiver. Such concerns have been at the heart of person-centred care. As they seek to show, the notion of epistemic injustice is a helpful way of unpacking why questions of knowledge sit at the heart of any such project, and attention to them is an important part of making good on its promise.



20

CONFERENCE PARTICIPANTS

Who's Who

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

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



Professor Joëlle Fanghanel PhD, TransDip, MèsL, LèsL, NTF, FHEA Professor of Higher Education & Pro Vice-Chancellor, University of West London, UK

Professor Fanghanel has been leading academic development centres for over 10 years, including at the University of Leicester and at City University London. Her research is focused on academic identities and disciplinary cultures, academic work and education for a globalised world. She has held leading positions in national and international organisations, including as Convenor of the London Scholarship of Teaching and Learning International Conference and Chair of the Editorial Board for the London Scholarship of Teaching and Learning International Conference. Professor Fanghanel is a Panel Member of the Social Sciences Subject Panel in the Teaching Excellence Framework Year 3. She is a former vice-president (Europe) of the International Society for the Scholarship of Teaching and Learning (ISSOTL), and a current re-elected member and trustee of the Society for Research into Higher Education governing council, a member of the publications committee, and co-convenor of the Academic Practice Network. She was selected as a national teaching fellow in 2011. Professor Fanghanel is an active reviewer for Studies in Higher Education, Higher Education Quarterly, Teaching in Higher Education and Perspectives in Education, and coeditor of the London Scholarship of Teaching and Learning International Conference Proceedings. Her book, Being an Academic, examines the impact of higher education policies on academic practices (Routledge, 2012).



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



Professor Sir Jonathan Elliott Asbridge DSc (hc) DHSc (hc), has a long and distinguished record of achievement within healthcare system organisation, accreditation, re-configuration and regulation. Gaining appointment to the positions of Chief Nurse of the Oxford University and Cambridge University Teaching Hospitals early in his career, he moved to Bart's and the London NHS Foundation Trust as Chief Nurse and Executive Director of Quality, subsequently becoming Chief Executive. He was the Inaugural President of the UK Nursing and Midwifery Council, and a previous Deputy Chairman of the UK Council for Healthcare Regulatory Excellence. Sir Jonathan has acted as a Government 'Tsar' for Patient Experience in Emergency Care and also for Patient and Public Involvement in Healthcare, has been involved in the development of several major NHS policies, and has conducted several formal Inquiries both in the UK and overseas. He was appointed Foundation Professor of Nursing at the University of Buckingham UK in 2010 and was a Founding Board Member of the European Federation of Nursing Regulators and a Member of the International Council of Nurses Global Observatory on Licensure and Registration. Sir Jonathan was awarded the Degree of Doctor of Science honoris causa for services to healthcare by the City of London University in 2004 and was made Knight Bachelor by HM Queen Elizabeth Il for services to healthcare in 2006. In 2016, Sir Jonathan was awarded a second honorary doctorate by Anglia Ruskin University, Cambridge, in recognition of his leadership in personcentered healthcare. Sir Jonathan is currently Chief Clinical Officer of Healthcare at Home, and Deputy Chairman, Oxford Health NHS Foundation Trust, Oxford, UK.

Professor Michael Loughlin PhD

Professor of Applied Philosophy & Co-Director, European Institute for Person Centred Health and Social Care, University of West London, UK & Associate Editor, *Journal of Evaluation in Clinical Practice*

22



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

Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc)

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

Professor Andrew Miles BMedSci MSc MPhil PhD DSc (hc) is Professor of Person Centered Health and Social Care and Co-Director of the European Institute for Person Centered Health and Social Care within the Office of the Vice Chancellor of the University of West London, UK. He is Senior Vice President and Secretary General of the European Society for Person Centered Healthcare (ESPCH), a major institution he co-founded with Professor Sir Jonathan Asbridge DSc (hc) DHSc (hc) in late 2013. Professor Miles is Editor-in-Chief of the European Journal for Person Centered Healthcare, and Founding Editor-in-Chief of the Journal of Evaluation in Clinical Practice (1994-2019). Professor Miles trained at the University of Wales and its Medical School in Cardiff. Gaining his first Chair in London at the age of 30, Professor Miles was latterly Professor of Clinical Epidemiology and Social Medicine & Deputy Vice Chancellor of the University of Buckingham UK, holding previous professorial appointments at Guy's, King's College and St. Thomas Hospitals Medical School London, and at St. Bartholomew's and The Royal London Hospitals School of Medicine, London. He is an Honorary Professor of Person Centered Care within the loint Faculty of Health, Social Care and Education at St. George's University Teaching Hospital London, and a Visiting Professor of Person Centered Care within the Faculty of Medicine of the Medical University of Plovdiv, Bulgaria, and the Faculty of Theology, National University of Bulgaria at Sofia. He has been a Visiting Professor at the State University of Milan and at the Catholic University of Francisco de Vitoria, Madrid. He is a former World Health Organisation Senior Fellow, Faculty of Medicine, Imperial College London, UK. He is a Distinguished Academician of the National Academy of Sciences and Arts of Bulgaria, a Fellow of the New York Academy of Medicine USA, a Fellow of the Royal Society of Medicine UK, and a Fellow of the Royal Society of Public Health UK. Professor Miles is also a Fellow of the Catholic Medical Association of the United States of America, and a Fellow of the Society of Catholic Scientists. Professor Miles has published extensively within the peer reviewed medical and biomedical press. He is co-editor of some 47 medical textbooks published in direct association with an extensive number of UK medical Royal Colleges and medical and clinical societies in the UK, and has organised and presided over more than 130 clinical conferences and masterclasses in London and elsewhere as part of a major and long term contribution to British national postgraduate medical education. He has lectured, and lectures, widely in person-centered care across Europe and elsewhere, and is a sought after speaker. Professor Miles is accredited with having changed the direction of the global EBM debate away from scientistic reductionism based on population-derived aggregate biostatistical data and rigid foundationalism, towards the embrace of the complex and the personal within international medicine and health policymaking. He has a profound interest in the modern person-centered management of the long term, multi-morbid and socially complex illnesses, and the methods through which medicine's traditional humanism can be re-integrated with continuing scientific and technological advance.



Professor Bill (KWM) Fulford MA DPhil PhD FRCP FRCPsych

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



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

Sir Andrew Dillon CBE FMedSci

Chief Executive, National Institute for Health and Care Excellence (NICE), London, UK



Sir Andrew Dillon graduated from the University of Manchester in 1975. He has held a number of senior management positions in the UK National Health Service, including General Manager of the Royal Free Hospital and Chief Executive of St George's Healthcare NHS Trust in London. He joined NICE as its founding Chief Executive in 1999.

Dr. Anna Bergqvist PhD FRSA MA BA FilKand

Associate Professor in Philosophy, Department of History, Politics & Philosophy, Manchester Metropolitan University, UK & Theory Network Convener, Collaborating Centre for Values-based Practice, St Catherine's College, University of Oxford, UK

24



Dr Anna Bergqvist is Associate Professor of Philosophy at Manchester Metropolitan University and Director of the Values-based Practice Theory Network at St Catherine's College University of Oxford. Her principal research interests are metaethics and aesthetics, moral perception and philosophy of psychology and psychiatry. She is editor of *Evaluative Perception* (Oxford University Press, 2018) and *Philosophy and Museums* (Cambridge University Press, 2016). She has also published on aesthetic and moral particularism, narrative, thick evaluative concepts and selected issues in philosophy of language and mind. Dr. Anna Bergqvist is interested in the intersection between value philosophy and analytic psychology, currently preparing a volume on relationality and moral perception in mental health.

Professor Jack Dowie MA (NZ) PhD (ANU)

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

Professor Jack Dowie took up the newly-created chair in Health Impact Analysis at the London School of Hygiene and Tropical Medicine in 2000, leaving the Open University where he had been a member of the Faculty of Social Sciences since 1976. While at the OU, he designed and ran the multi-media courses on RISK (from the late seventies) and PROFESSIONAL JUDGMENT AND DECISION MAKING (from the late eighties). His early qualifications were in history and economics at the University of Canterbury, New Zealand and he went on to merge these disciplines in doctoral work (at the Australian National University) and subsequent lecturing in economic development and economic history (at ANU, Kent and Durham). What had been side interests in accidents, gambling and health, it eventually took over and led to full time involvement with risk and judgment in health decision making and to involvement with both clinical decision analysis and cost-effectiveness analysis in healthcare. Professor Jack Dowie was a founder member of the Health Economists Study Group and the Society for the Study of Gambling. He recently completed ten years of service as a member of the Appraisals Committee of the then National Institute for Clinical Excellence (NICE). Professor Dowie had formally retired in 2003, but remains active in the School, and also as an Adjunct Professor in the Department of Public Health, University of Southern Denmark, and he is a Honorary Professor in the University of Sydney School of Public Health. His research is mainly in connection with the software implementation of Multi-Criteria Decision Analysis, called Annalisa, which he developed. Annalisa is designed to facilitate more equal balancing of intuition and analysis in health decision making, whether it be in the person-centred settings of screening or clinical consultation, or the citizen-centred setting of health and non-health sector policies, programmes and projects. The decision support tools built in Annalisa provide personalised decision support based on individual preferences as well as evidence and expertise. Professor lack Dowie was recently honoured to receive the Gold Medal of the European Society for Person Centered Healthcare for his work in this area.



Mr. Ashok Handa MBBS FRCS MA

Director of Surgical Education & Consultant Vascular Surgeon, Nuffield Department of Surgical Sciences, Division of Medical Sciences, University of Oxford, UK

Mr. Ashok Handa is Associate Professor of Surgery at Oxford University and Consultant Vascular Surgeon at the John Radcliffe Hospital in Oxford. He is the Director for Surgical Education for Oxford University and responsible for the Undergraduate curriculum in surgery. Until recently, he was also Associate Director of Clinical Studies with responsibility for assessment. He is Co-Director of the Collaborating Centre for Values Based Practice in Health and Social Care based at St Catherine's College, Oxford. He is responsible for education and research for the centre. He is Fellow in Clinical Medicine and Tutor for Graduates at St Catherine's College, the largest in Oxford. Mr. Ashok Handa is the Principle Investigator for the OxAAA study, investigating the cause and growth of abdominal aortic aneurysms. His research interests include carotid imaging and patient safety. He is recognised nationally as a surgical educator and is the Training Programme Director for Vascular Surgery for Wessex and Oxford, a member of the Specialist Advisory Committee for Vascular training and the national lead for selection in vascular surgery.



SDM-I Biographies

Dr. Marco Annoni PhD Research Fellow, Institute of Biomedical Technologies, National Research Council, Rome, Italy



Dr. Marco Annoni graduated in Philosophy and holds two PhD degrees; one in Philosophy of Science, and the other in Foundations and Ethics of the Life Sciences. Since 2015, he is a Post-Doctoral Research Fellow of Bioethics at the Institute of Biomedical Technologies, Rome, Italy. His research interests are focussed on the ethics of doctor-patient communication and the ethics of using placebos in clinical and research settings. Dr. Annoni is part of the Scientific Secretariat of the Research Ethics and Bioethics Advisory Committee of the National Research Council (CNR), Rome, Italy, and he is the Secretary of the Ethics Committee of the Fondazione Umberto Veronesi, Milano, Italy, for which he also operates in the public engagement of science and ethics. Dr. Marco Annoni is the Editor-in-Chief of the peer-reviewed and open-access scientific journal The Future of Science and Ethics, and the author of over 50 scientific publications.

Professor Ed Peile EdD FRCP FRCPCH FRCGP FHEA FAcadMEd HonFAcadMed Professor Emeritus in Medical Education, Institute of Digital Healthcare, University of Warwick, UK

26



A Fellow of three Royal Medical Colleges, Professor Ed Peile holds the President's Medal of the Academy of Medical Educators for lifetime achievement in Medical Education. In 2017, he was also awarded Honorary Fellowship, the Academy's highest honour. With leadership experience of undergraduate and postgraduate clinical education at Universities of Oxford, Warwick, and Exeter, he has held visiting professorships in Ireland and Malaysia. He has undertaken strategic reviews of curriculum and research at several leading UK and international medical schools and universities. He was formerly the clinical lead for Health and Social Care for Children at the NHS West Midlands Strategic Health Authority. Since he retired from clinical practice, Professor Peile has mentored senior clinicians and he chaired the Education, Training, and Professional Standards Committee for the Academy of Healthcare Scientists. He has also researched and published on Values-Based Practice (V-BP) through the Collaborating Centre at St Catherine's College, Oxford, UK. Most recently Professor Ed Peile has been developing new degrees in Digital Healthcare Science at the University of Warwick. He coined the term "fusion sciences" to describe the holistic preparation of scientists in the new specialism supporting individual's Health and Well-being.

Dr. Amy Price PhD

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

Dr. Amy Price has worked as a Neurocognitive Rehabilitation consultant and in International Missions before sustaining serious injury and years of rehabilitation. She emerged with a goal to build a bridge between research methods, research involvement and public engagement where the public are empowered and trained as leaders to take their places as co-production partners in health research. She is a Doctoral Candidate at the University of Oxford and has worked in multi-faceted areas of research and development. Dr. Price's research and experience has shown her that shared knowledge, interdisciplinary collaboration, and evidence-based research will shape and develop the future. She is a *BMJ* Editor and a Stanford Senior Research Advisor for Stanford Medicine X. She serves on multiple boards and charities.



Ms. Laura Norburn BA (Hons) MA

Senior Manager, Public Involvement Programme, National Institute for Health and Care Excellence (NICE), Manchester, UK

Ms. Laura Norburn is a Senior Manager in the Public Involvement Programme (PIP) at NICE. Graduating with a BA (Hons) in Psychology and Philosophy in 2006 and joining NICE in 2007, she has focussed on supporting patient and public involvement in the development of NICE medical technologies guidance, diagnostics assessment guidance and technology appraisals. Completion of an MA in Healthcare Ethics and Law in 2012 has led the way to her more recent work focussing on shared decision making, by supporting and coordinating the work of the NICE Shared Decision Making Collaborative. Ms. Laura Norburn also facilitates cross-organisation SDM activities at NICE and has worked with colleagues to develop processes and methods for producing NICE patient decision aids.



Dr. Paula Wray BSc PhD

Senior Public Involvement Manager – INVOLVE, INVOLVE Coordinating Centre, National Institute for Health Research, University of Southampton Science Park, Southampton, UK

Everyone has an experience to share and Dr. Paula Wray's wish is to support people to recognise the value of these experiences and not only communicate them but also to value the knowledge of those around them. Dr. Paula Wray works with members of the public, researchers and staff to provide confidence and guidance in enabling multiple perspectives shape a project, team, activity or organisation. She is currently a Senior Public Involvement Manager at INVOLVE, leading on Diversity and Inclusion and the development of the UK Standards for Public Involvement in research. Dr. Wray has a neuroscience PhD and has previously held public involvement leadership roles in the voluntary sector and with the National Institute of Health Research Collaboration in Applied Health Research and Care and Research Design Service in the East Midlands. She has built comprehensive networks both nationally and internationally and utilises her own experiences as a researcher, patient and carer to provide leadership, appropriate resources and support for others.



Ms. Veryan Richards BSc (Hons)

Individual Partner, Collaborating Centre for Values-Based Practice (VBP), St. Catherine's College, Oxford & Patient Representative, Royal College of Psychiatrists, London, UK



Ms. Veryan Richards contributes as a lay participant towards shaping the policy narrative in several areas of mental healthcare. She is particularly interested in the balance of evidence-based practice and values-based practice in person-centred healthcare and is an Individual Partner in the Collaborating Centre for Values-based Practice in Health and Social Care, St Catherine's College, Oxford. Ms. Richards co-authored the Royal College of Psychiatrists College Report 204 "Core Values for Psychiatrists" (2017) and is a member of the Working Group for the CR 215 "Person-centred care: implications for training in psychiatry" (2018). She is co-ordinating the RCPsych in Wales Language Guidelines Working Group which recently developed "Guidelines on the use of language — RCPsych in Wales".

Professor Mike Kelly PhD FRCP Hon FRCPE FFPH

Senior Visiting Fellow, Primary Care Unit, Institute of Public Health, University of Cambridge, UK



Professor Mike Kelly is Senior Visiting Fellow in the Department of Public Health and Primary Care at the Institute of Public Health and a member of St John's College at the University of Cambridge. Between 2005 and 2014, when he retired, he was the Director of the Centre for Public Health at the National Institute of Health and Care Excellence (NICE). From 2005 to 2007 he directed the methodology work stream for the World Health Organisation's (WHO) Commission on the Social Determinants of Health. His research interests include the prevention of non-communicable disease, living with chronic illness, health inequalities, health related behaviour change, end of life care, dental public health, the relationship between evidence and policy and the methods and philosophy of evidence based medicine.

Professor Dame Sue Bailey DBE FRCPsych

Past President of The Royal College of Psychiatrists and of the Academy of Medical Royal Colleges, London, UK

28

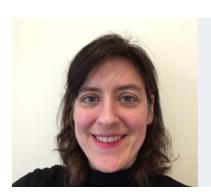


Professor Dame Sue Bailey's clinical background is that of a child and adolescent psychiatrist. Her research centres on a social identity approach to health, social care, education and justice. Formerly president of the Royal College of Psychiatrists and Chair of the Academy of Medical Royal Colleges, she is currently Chair of the Academy Choosing Wisely UK group, Chair of the Children and Young People's Mental Health Coalition and Chair of the Centre for Mental Health. All her work is directed at achieving Parity for Mental Health and social justice for children, young people and families.

Ms. Fiona Browne MRes LL.B (Hons)

Director of Education, Standards and Development, General Osteopathic Council, London, UK

Ms. Fiona Browne is Director of Education, Standards and Development at the General Osteopathic Council, one of the nine statutory health professional regulators in the UK. She is particularly interested in themes of engagement, support and community to support practitioners to work in partnership to meet standards. Ms. Browne has led various initiatives to contribute these goals including, most recently, a new continuing professional development scheme with these themes at its heart along with a comprehensive longitudinal evaluation and impact programme. Ms. Fiona Browne is a trustee at the Patient's Association, a charity dedicated to supporting the rights and interests of all patients and their families. She is passionate about clinicians working collaboratively in partnership empowering patients to live their life in the way they want to. Ms. Browne sees different health professionals on a regular basis, and so has a "user" perspective which she hopes brings a broad perspective to decision making. Ms. Bowne and colleagues work to promote health and social care to be delivered in a way that meets every person's health and social care needs, to give effect to the patient voice, to improve patient experience and to support people to engage fully in their own care. Ms. Fina Browne also holds a role on a local government standards committee. She has previously chaired the UK Interprofessional Continuing Professional Development Forum and held roles in health professional regulation and medical education including the General Medical Council, the London Deanery and the Law Society.



Mr. Richard Wyatt-Haines

Founder and Director of Health and Care Videos, a partnership with Torbay and South Devon NHS Foundation Trust, UK

Mr. Richard Wyatt-Haines is the Founder and Director of the largest provider of health information videos in the UK. Health & Care Videos, is a partnership with Torbay & South Devon NHS Foundation Trust, and plays a key part in developing new technological solutions for the NHS. Mr. Wyatt-Haines's past experience includes working as the sales and marketing director of an insurance company, founding a consultancy firm and becoming a leadership fellow at the University of Exeter. He is the author of *Align IT: Business Impact Through IT* (John Wiley & Sons Ltd, 2007), an insightful book that helps readers recognise the potential of IT and take steps to achieve their goals. Throughout this book, he incorporates his knowledge gained from years as a facilitator and insightful speaker.





Professor Rose McCabe BA PhD

Professor of Clinical Communication, School of Health Sciences, City University of London, UK



Professor Rose McCabe is Professor of Clinical Communication at City University of London. Her research focuses on how meaning and shared understanding is negotiated between healthcare professionals and the people they treat. She records professional-patient encounters and micro-analyses verbal and nonverbal communication using conversation analysis. She also works on translating these findings into novel interventions to improve communication and patient outcomes in healthcare. Professor McCabe is currently working on decision making in healthcare encounters with different patient groups (e.g. depression, dementia, psychosis) across different treatment settings. Based on detailed insights from micro-analysis of healthcare consultations, she was recently involved in developing a new coding scheme for analysing how doctors make recommendations for medications and how these recommendations are responded to in primary and secondary care in the U.K. and the U.S: Stivers T, Heritage J, Barnes RK, McCabe R, Thompson L, Toerien M (2017) Treatment Recommendations as Actions. *Health Communication*. 2018; 33(11):1335-1344. doi:10.1080/10410236.2017.1350913.

Recent projects include:

- What is a therapeutic conversation about self-harm in the accident and emergency department?
- How a diagnosis of dementia is shared with people with dementia and their families and involvement of people with dementia in decisions to start anti-dementia medication (http://medicine.exeter.ac.uk/research/healthresearch/mentalhealth/projects/shared/)
- How General Practitioners communicate with people with common mental health problems in primary care (http://destressproject.org.uk)
- A novel training programme to improve communication between patients with psychosis and psychiatrists, focusing on understanding the patient's experience, empowering patients in the consultation and increasing involvement in decision making (http://medicine.exeter.ac.uk/media/universityofexeter/medicalschool/profiles/TEMPO_full_manual.pdf). The training has been evaluated in a randomised controlled trail in routine care and shown to improve communication and the therapeutic relationship.

Professor Mary Chambers Dip.N (Lond) RCNT RNT PhD BEd(Hons) PgCert RMN RGN Professor of Mental Health Nursing; Director, Centre for Public Engagement & Associate Editor, Health Expectations, Joint Faculty of Health, Social Care and Education, St. George's University Hospital Campus, St. George's University of London, UK

30



Professor Mary Chambers is Professor of Mental Health Nursing and Director of the Centre for Public Engagement, Faculty of Health, Social Care and Education, Kingston University and St George's, University of London. Throughout her career, she has held a number of clinical, managerial and academic positions including coordinator of the Northern Ireland Centre for Health Informatics. She is involved in a number of research projects locally and internationally. Professor Cahmbers is a fellow of both the Royal Society of Medicine and the European Academy of Nurse Scientists, and an expert panel member of HORATIO, the European Association for Psychiatric Nurses, and a member of the Institute of Leadership and Management. Mary is also Associate Editor to Health Expectations. Outcomes of her work with respect to PPI in both these areas have had impact nationally and internationally. Integral to this work has been the coproduction and delivery of education programmes, as well as PPI at all stages of the research process.

Ms. Karin Drivenes MPharm (Clinical) PhD-student

Clinical Pharmacist, Division of Mental Health, Sørlandet Hospital HF, Kristiansand, Norway

Ms. Karin Drivenes graduated from School of Pharmacy, University of Oslo in 1997. She has 10 years' experience from community pharmacy, education, and public health efforts before entering hospital pharmacy. From 2006 she is engaged within the Kristiansand hospital pharmacy and Division of mental health at Sørlandet Hospital. In this period, she also completed a master degree in clinical pharmacy at the University of Oslo, School of pharmacy. From 2016 she has led the local initiative in the multi-center study Implementation of National Guidelines for Treatment of Psychoses. Currently, Ms. Drivenes pursues a PhD at the University of Oslo, Faculty of medicine. Her project aims to explore the perception of treatment within mental health care. Her interest lies in implementing modern health care initiatives into the service, hereby to identify characteristics of the service, which facilitate or impede shared decision making.



Professor Kim Manley BA, RN, MN, DipN (Lon), RCNT, PGCEA, RNT, PhD, CBE Professor, Practice Development, Research & Innovation & Co-Director England Centre for Practice Development, Canterbury Christ Church University, UK & Joint Clinical Chair, and Associate Director Transformational Research and Practice Development, East Kent Hospitals University Foundation NHS Trust, UK & Visiting Professor Wollongong University, New South Wales, Australia

Professor Kim Manley integrates research and scholarly inquiry, practice development, workplace learning and leadership development to develop and sustain effective workplace cultures that are person centred, safe, effective and good places to work. She is committed to whole systems integrated working, is passionate about helping staff to develop their potential and flourish, and for patients and service users to experience excellence. In 2000, Professor Manley was awarded the CBE for quality patient services, in 2015 identified as one of the Nursing Times top 50 leaders and in 2018 as part of the National Health Service (NHS) 70 year celebrations, recognised as one of seventy nurses having most impact on the NHS since its inception.



Professor Sir Jonathan Montgomery BA, LLM, HonFRCPCH

Professor of Health Care Law, Faculty of Laws, University College London, London, UK & Chair, Health Research Authority, UK

Sir Jonathan Montgomery is Professor of Health Care Law at University College London and Chair of the Health Research Authority. Prior to moving to UCL in 2013 he was professor at the University of Southampton. He chaired NHS bodies in the Hampshire and Isle of Wight health system 1998-2013 and will become Chair of Oxford University Hospitals NHSFT in March 2019. He was Chair of the Human Generics Commission 2009-12 and the Nuffield Council on Bioethics 2012-17. He chaired the Advisory Committee on Clinical Excellence Awards 2005-14. He was knighted for services to bioethics and healthcare law in the 2019 New Years Honours.



SDM-I Biographies

Dr. Thomas Fröhlich MD PhD

Vice President (Western Europe), European Society for Person Centered Healthcare, Heidelberg, Germany



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

Dr. Paul Batchelor BDS DDPH(RCS) MCHD MPH PhD FFGGDP FDS FFPH Hononrary Senior Lecturer, Dental Public Health Group, University College London, UK



Dr. Paul Batchelor qualified from Liverpool working in a number of primary dental care posts prior to taking up the post of lecturer at the London Hospital. He then moved to King's College and onto University College London. He currently holds an honorary Chair in the Faculty of Medicine at UCLan, and honorary Senior Lecturer post at UCL and is the Dental lead for the National Association for Primary Care. Dr. Batchelor holds the post of Chief Assessor for Fellowship of the FGDP(UK) as well as examiner for the Overseas Registration Examination of the General Dental Council. He is a past President of the British Association for the Study of Community Dental Health and held the post of Vice Dean of the Faculty of General Dental Practice twice. In addition to acting as an advisor to the British Dental Association, he is currently working with the Department of Health in Ireland on their oral health policy, has sat on a number of NICE Committees and acted as Advisor to the House of Commons Health Committee on their last dental inquiry. He has worked for a number of other international and national agencies as well as being a member of the European Health Policy Group. He is also a co-author of the undergraduate textbook Essential Dental Public Health and sits on a number of editorial boards.

32

Professor Stella Villarmea Requejo PhD

Professor of Philosophy, Faculty of Philosophy and Arts, University of Alcalá, Madrid, Spain & ERC Marie S. Curie Fellow, University of Oxford, UK

Professor Stella Villarmea Requejo is a Professor of Philosophy at the University of Alcalá, Madrid, Spain, where she teaches "Theory of Knowledge", "Philosophy, Gender, and Emancipation" and "Contemporary Thinkers". Also, she is currently a Marie S. Curie Fellow at the University of Oxford, where she is conducting the research project "Controversies in Childbirth: from Epistemology to Practices" (VOICEs), which is funded by the European Research Council (ERC), at the Faculty of Philosophy and The Collaborative Centre for Values-based Practice, St. Catherine's College. She is also the Principal Investigator of "Philosophy of Birth: rethinking the Origin from Medical Humanities" (PHILBIRTH, https://phil-birth.org/), which is funded by the Ministry of Economy of Spain. She has been Adjunct Professor at the University of Saint Louis and Visiting Professor at the following Universities: Humboldt and Paderborn (Germany), Lund (Sweden), Marie Curie (Poland), Kent and Oxford (United Kingdom). Also, she has been the Head Coordinator of the Degree of Humanities, and its Coordinator of International Programs, at the University of Alcalá. Professor Stella Villarmea Requejo is a board member of The International Federation of Philosophical Associations (FISP), The Spanish Network of Philosophy (REF), and The International Birth Research and Action Association (IBRAA). Professor Villarmea Requejo is interested in the moral and political justification of our beliefs, and in the relationship between knowledge and emancipatory action. She is currently doing research on the Philosophy of Birth and how our concepts of pregnancy and childbirth reflect our view of the world and of the human being. She has previously published on epistemology (Wittgenstein and skepticism) and ethics (Kant and Levinas), with and/or without a gender approach.



Dr. Brenda Kelly PhD FRCOG

Consultant Obstetrician, John Radcliffe Hospital, Oxford, UK & Honorary Senior Clinical Fellow, Nuffield Department of Obstetrics & Gynaecology, University of Oxford, UK

Dr Brenda Kelly is a full-time NHS Consultant Obstetrician and Fetal Medicine subspecialist at the John Radcliffe Hospital in Oxford. She is also founder and director of the Oxford Rose Clinic - a multidisciplinary service for women and girls with FGM, and one of the co-founders of the Oxford Refugee Health Initiative. Her academic interests include prenatal screening, patient experience of clinical care, and perinatal palliative care.



Dr. Gideon Calder BA (Hons) MA PhD

Senior Lecturer & Director, Social Care Policy Programme, Department of Public Health, Policy and Social Sciences, University of Swansea, Wales, UK



Dr. Gideon Calder is Senior Lecturer in Social Sciences and Social Policy at Swansea University, where he directs the Social Policy programme. His main research interests lie in the application of moral and social philosophy to matters of current social concern. In this vein he has written on issues ranging from sexual consent to disability, and healthcare ethics to children's wellbeing. His main current interests lie in two areas: social justice for children, and the ethics and practice of co-production as a means of delivering public and social services. Dr. Calder chairs the Newport Fairness Commission, an independent body set up by Newport City Council to provide analysis of the fairness of its decisions as a local authority, and advises Swansea Council on its equality-related initiatives. He is also currently leading on the 'co-production' component of the Welsh Government-funded evaluation of the Social Services and Well-Being (Wales) Act 2014. A former president of the Association for Social and Political Philosophy, Dr. Gideon Calder is author or editor of ten books, most recently The Routledge Handbook of the Philosophy of Childhood and Children (2018), and co-edits the Routledge journal Ethics and Social Welfare.

Ms. Nicola Blunden MA PGDip PGCE BACP (Accred) FHEA

Senior Lecturer, Therapeutic Studies, Faculty of Life Sciences and Education, University of South Wales, UK



Ms. Nicola Blunden is a Senior Lecturer in Psychotherapy and Consultative Supervision at the University of South Wales, where she leads the Masters Programme for qualified practitioners. As an accredited psychotherapist and supervisor, she has two decades of experience working with clients in health and private settings, and of supervising teams in health and the voluntary sectors. She specialises in working with clients facing life-limiting illness, and with those who have experienced childhood abuse and family violence. She is interested in questions of professional ethics, in the context of helping people with their suffering, in particular interrogating the tensions between normative and dialogical ways of framing help. Ms. Blunden is currently conducting research into the co-production of an ethical framework for supervision, and is co-convenor of Holi: Co-production Inquiry Wales.



Developed by the European Institute for Person Centered Health and Social Care at the University of West London, in association with the European Society for Person Centered Healthcare.

The last decade has brought with it an increasing recognition that chronically ill patients need more comprehensive forms of assistance, mandating a need to move away from current approaches to the management of these conditions and towards newer models of care that are personalised, integrated and contextualised.

This course is for graduates and practitioners who wish to develop their careers in health and social care. This course was designed to respond to the new challenges created by the need to integrate health and social aspects of care, across a wide range of professional areas and disciplines. Duration

Two years (part-time)

Location

West London Campus

Modules

In the first year the students study the following

- Theory and Practice of Person-Centred Health and Social Care
- Health and Wellbeing
- · Research Methods
- Implementation and Change: Leadership and Shared Decision-Making

Plus one option from:

- Person-Centred Mental Health Care
- Primary Care: Approaches to Person Centredness
- Secondary Health and Social Care: Approaches to Person-Centredness

In the **second year** students complete a 12,000 word dissertation for the award of the degree.



For further information, please contact:

Professor Michael Loughlin, Course Director 😫 michael.loughlin@uwl.ac.uk Professor Andrew Miles, Associate Course Director **★ andrew.miles@uwl.ac.uk**

Find out more uwl.ac.uk/ PersonCentred



CARDIOLOGY



Putting knowledge in patients' hands to:

- · Improve work flow
- · Reduce pressure on staff
- Reduce appointment time
- Remove the need for appointments

..........

Overview

A collection of cardiology information videos were produced to aide patient understanding by providing angiogram preoperative assessment information.

Videos were also created to support staff and patients in the implantation and monitoring of a cardiac device (LINQ™), to facilitate the consent process.

They have been added to a comprehensive online video library used by Torbay and South Devon NHS Foundation Trust.

These specific videos are designed to help educate patients, relieve anxiety and prepare patients and their carers for cardiac procedures.

Impact

22%

Case study

Reduction in outpatient appointments each week

85%

Reduction in nurse time spent each week





Problem

- 1. Historically, pre-admission angiogram appointments were carried out by a Band 5 Nurse over two clinics and 10 one-to-one consultations each week, equating to over 6 hours of staff to patient contact time. This caused a huge drain on staff resources and led to patients having to wait longer for their procedures.
- 2. Torbay and South Devon NHS Foundation Trust wanted to investigate the possibility of performing procedures more simply and at a lower cost, so worked on a service redesign for the implantation of the LINQ™ Device to change the standard clinical procedure.

..........

Solution

 A video entitled 'Having an Angiogram' was produced.

Patients are contacted by phone and sent a video link via email. They are given the choice to watch the video at home, or to attend a group session where it is played on a large TV screen with a Q&A at the end and telephone support offered.

2. Health and Care Videos worked with Torbay and South Devon NHS Foundation Trust to produce two LINQ™ patient information videos. One being a pre-procedure video to inform patients of what the device is, its benefits and what to expect on the day of their procedure and also a post-procedure video that describes the use and set-up of the LINQ™ activator and the MyCarelink remote communicator.



www.healthandcarevideos.com

Key Results

There has been a 22% reduction in outpatient appointments with more angiogram patients opting to watch the video at home, or attend a video led group session. This has reduced nurse time by 85% as patients are seen in small groups of 10, with the appointment lasting only 20 minutes.

In LINQ™ implantation, they have successfully removed the need for ALL pre-assessment appointments

Other results include:

· Better patient experience and satisfaction

•••••

- · Reduced level of staff training
- An improved work flow
- · Reduced overall costs

"It's what our patients want.

I could see this video content being used across the country."

Jack Greenhalgh, Cardiac Charge Nurse







European Society for Person Centered Healthcare

March 2019

www.pchealthcare.org.uk