Where’s the Patient’s Voice in Health Professional Education?

Program & Abstracts

International Conference

November 3, 4 & 5, 2005
Coast Plaza Hotel & Suites
Vancouver, BC, Canada

Conference Organizers:

Division of Health Care Communication
informed and shared decision making
Dear Participant,

On behalf of the University of British Columbia I have great pleasure in welcoming you to *Where's the Patient's Voice in Health Professional Education?*, an international conference being held at the Coast Plaza Hotel & Suites in Vancouver, British Columbia. In order to deliver the best care, health professionals are constantly searching for the best ways to incorporate collaborative health and human service activities, along with meaningful patient involvement, into educational programs. UBC feels privileged to be associated with the presenters, participants, and organizers of this conference who are doing so much to advance knowledge in this area.

For many Conference participants this may be your first time in this part of Canada. During your stay here I hope you will find time to visit the Point Grey campus of UBC Vancouver, which sits in a spectacular setting overlooking Howe Sound and the North Shore mountains. UBC is the largest university in the province, with more than 45,000 full-time students and 2,300 faculty members. Over the past three years international rankings have consistently ranked it among the top 50 research-intensive universities in the world.

The UBC Museum of Anthropology, close to the Chan Centre for the Performing Arts, houses one of the finest collections of First Nations art in the world. Nearby you will find the Nitobe Memorial Garden, an authentic Japanese garden that blends flowers, trees, and water in perfect harmony. A second campus, UBC Okanagan, has recently opened in the city of Kelowna in the heart of BC’s scenic wine-producing district, itself well worth a special excursion.

You have a complex and exciting program in front of you. I hope that you find your visit to British Columbia rewarding and enjoyable on both personal and professional levels.

Sincerely,

[Signature]

Martha C. Piper
The members of the Conference Steering Committee and Task Force welcome you to the first international conference “Where’s the Patient’s Voice in Health Professional Education?” The conference aims to explore practice, innovation and theory that embeds the patient’s voice in health professional education – to empower patients and enrich and enlighten practice.

(“We use “patient” as the single most widely understood term, and is meant to encompass consumers, users, clients, etc.)

We have identified the following outcomes for the conference:
1. Establish a network of people interested in promoting and supporting meaningful patient involvement in health professional education.
2. Publish a review of good practice that can serve as examples of how patients can be involved in health professional education and outcomes of participation.
3. Identify gaps in our understanding of the barriers and drivers to bringing the patient’s voice into health professional education.
4. Publish recommendations for repositioning the role of patients in health professional education.
5. Publish a mandate for the inclusion of the patient’s voice in the development of socially responsible, patient-centred health professional curricula.

We are excited about the conference and its potential for bringing together people who have not met each other before. We look forward to your participation and hope you leave with renewed ideas and enthusiasm.

Conference Steering Committee and Task Force members:
Angela Towle (Task Force Chair, Co-Director, Division of Health Care Communication, UBC)
Lesley Bainbridge (Associate Principal, College of Health Disciplines, UBC)
Cathy Kline (Research Coordinator, Division of Health Care Communication, UBC)
Christine Farrell (Lay Member of Health Professions Council, UK)
Bill Godolphin (Co-Director, Division of Health Care Communication, UBC)
Meg Gaines (Director, Center for Patient Partnerships, University of Wisconsin, USA)
Beth Lown (Harvard Medical School & Past President American Academy on Physician and Patient, USA)
Penny Morris (Medical Education Unit, University of Leeds, UK)
Samantha Van Staalduinen (Student Coordinator, Division of Health Care Communication, UBC)
Wayne Weston (Dept of Family Practice, University of Western Ontario, Canada)
Patients as teachers have a long tradition in health professions education but usually in a passive role (patients as “clinical material” or “audiovisual aid”). A number of recent publications show that the value of patients taking a more active role as teachers has been recognized (Wykurz & Kelly, 2002; Warnes & McAndrew, 2005; Livingston & Cooper, 2004). A recent article by O’Keefe and Britten states that “lay participation in curriculum development is clearly on the horizon for medical schools”. However, current educational initiatives are varied, isolated and often ephemeral. For the first time this conference will provide a forum to share good practice, and articulate a coherent framework for the involvement of patients in health professional education, analogous to the rationale for involvement of patients / lay people in health services or research.

The conference is timely because of the following current important trends related to patient / community involvement in health care, research and in health professions education.

1. Patient involvement in health care has been identified as an important component of patient safety and governments have promoted user involvement in health service delivery.
2. Patient involvement in research. The value of actively involving patients and the community in research has recently been identified. They take part in advisory panels on ethical issues and review research proposals, and there are a number of guidelines on involving consumers in research either from the perspective of the researchers or the consumers.
3. In academic programs, social accountability and community engagement are manifestations of the recognition of the importance of partnerships between academic institutions and the communities they serve. Social accountability, as defined by the World Health Organization has been adopted as a unifying vision for academic medicine in Canada. Central to this vision is the concept of partnership with key stakeholder groups: policy makers, health managers, health professions, communities and academic institutions.
4. Interprofessional education is becoming an essential learning experience for health professionals of the future. However, amid the emerging literature and funding in support of interprofessional education and collaborative practice there is little that describes the role of the patient or client in these learning experiences.

**FURTHER READING**

**CONFERENCE SCOPE AND PROGRAM**

The conference is interdisciplinary and international in scope. It brings together the academy and the community. Participants represent community groups, individual patients, researchers, health professions educators, students, practitioners and policy makers. Those attending come from a variety of professions including medicine, nursing, midwifery, rehabilitation sciences, law, psychology, social work, etc. The conference will address education across the continuum: undergraduate / basic training; postgraduate / specialty; continuing professional development and in-service learning.
The program consists of the following activities:

1. **Task Force meetings.** Conference outcomes and reports will be developed by an interdisciplinary Task Force who meet regularly before, during and after the conference. A member of the Task Force will attend each session and act as either chair or rapporteur. Summaries from the different sessions will be reviewed by the Task Force at the end of each day and a report compiled to present back to conference participants at the start of the following day. Information gathered through the conference will be used to inform the final conference documents.

2. **Plenary presentations.** The first plenary session will be a panel presentation by students from different health professions who will describe their experiences of patient involvement in their programs. Parallel plenary sessions on Thursday and Friday will provide participants with examples of the range of educational initiatives that involve patients and the community that are being implemented in different health professional programs.

3. **Parallel podium presentations and workshops organized into themes.** Conference themes include: models of patient and public involvement; student and patient / carer / giver experiences; patients as teachers; learning for service improvement; patient narratives; outcomes of patient involvement; innovations with standardized patients.

4. **Poster presentations,** with dedicated time for poster viewing and discussion.

5. **Facilitated networking** to help participants find like-minded souls from across the world to discuss topics of their choice.

6. **Working group sessions** on Saturday morning to allow participants to discuss topics of interest, participate in the development of action plans and recommendations, and review draft statements for inclusion in the final reports.

### DISSEMINATION

We are planning to produce at least three documents as a result of the conference. These documents will be produced by the Task Force based on information collected throughout the conference and by the working groups which will meet on Saturday morning.

**Conference statement** comprising a coherent definition of what is meant by the patients' voice in health professional education and the rationale; categories and examples; and research questions. This statement will be published in a health professions education journal.

Proposed framework for the conference statement

1. What are the roles that patients / clients currently play in health professions education?
2. What are the expected / actual outcomes?
3. Why are patients serving in these roles?
4. What factors facilitate these roles?
5. What factors impede?
6. What challenges / issues for patients / education providers (individual or institutional) face?
7. How can patients / education providers that are already engaged be supported?
8. How can patients / education providers not already engaged be encouraged?
9. What are exemplary models of……?
10. What lessons can be learned from these models that can be translated and applied?
11. What are the important research questions?

**Conference report** in the form of a “how to” manual containing examples and lessons from the conference presentations and discussions. The report will be mailed to conference participants and will be available on the Division of Health Care Communication website and links made from other relevant websites that have advertised the conference.

**Summary conference statement:** a short policy statement summarizing what ought to happen in education and research. This will be mailed out to key stakeholder groups in health professions education in North America, the UK and Australia, including the educational leadership in professional schools, accrediting bodies, professional organizations, as well as relevant patient and community groups.
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Program at a Glance

Wednesday, November 2, 2005

Convention Foyer 16:00 Registration
Convention Foyer 18:00 Welcome Reception
19:30 Registration Closed

Thursday, November 3, 2005

Convention Foyer 7:30 Registration and light refreshments
Ballroom 8:15 Conference Welcome
Setting the Stage
Ballroom 9:00 Student Panel Presentation
Convention Foyer 10:30 Coffee Break and Exhibits Open
11:00 Parallel Plenary Sessions 1.1
(Please see detailed program, page 9)
12:00 Luncheon (Participants on their own)
13:30 Concurrent Sessions 1.2 and Workshops 1.2
(Please see detailed program, page 10)
Convention Foyer 15:30 Coffee Break and Exhibits Open
16:00 Concurrent Sessions 1.3 and Workshops 1.3
(Please see detailed program, page 11)
Convention Foyer 18:00 Conference Reception

Friday, November 4, 2005

Convention Foyer 7:30 Registration and light refreshments
Ballroom 8:15 Summary of Thursday’s Conference Proceedings
9:00 Parallel Plenary Sessions 2.1
(Please see detailed program, page 12)
Convention Foyer 10:30 Coffee Break and Exhibits Open
Barclay/Gilford 11:00 Poster Sessions
12:00 Luncheon (Participants on their own)
13:00 Concurrent Sessions 2.2 and Workshops 2.2
(Please see detailed program, page 13)
Convention Foyer 15:00 Coffee Break and Exhibits Open
15:30 Concurrent Sessions 2.3 and Workshops 2.3
(Please see detailed program, page 14)

Saturday, November 5, 2005

Convention Foyer 7:30 Registration and light refreshments
Ballroom 8:15 Summary of Friday’s Conference Proceedings
9:00 Facilitated working groups to develop conference reports
Ballroom 11:30 Report back from groups
12:30 Closing Presentations
13:30 Task Force meeting to work on conference documents (closed)
**Task Force Members**

**Lesley Bainbridge**, Associate Principal, College of Health Disciplines, University of British Columbia, lesleyb@interchange.ubc.ca

Lesley worked in the public hospital system for several years as a clinician (physical therapy) and administrator before entering the academic environment at UBC in 1994 as interim head of the physical therapy academic program, becoming the permanent head in 1998. She obtained tenure at UBC in 2003 and served as interim Director of the School of Rehabilitation Sciences from 2002 until 2005. She currently holds two new part-time positions at UBC as Associate Principal Interprofessional Programs (College of Health Disciplines) and Director Interprofessional Health Education (Faculty of Medicine).

Lesley also chairs the Accreditation Council for Canadian Physical Therapy Academic Programs and sits on the Canadian Working Group for HIV/AIDS and Rehabilitation (CWGHR) and the first assessment panel for the Canadian Academy of Health Sciences. She chairs the Evaluation Working Group for the BC Interprofessional Education for Collaborative Patient Centred Practice (IECPCP), is a member of the Project Team and sits on the Steering Committee, the Curriculum Working Group and the Communications Working group. She also sits on several committees and task forces at UBC and in the wider community in relation to IPE, collaborative practice and research initiatives.

**Christine Farrell**, Health Professions Council of UK, cfarrell@stander.demon.co.uk

Christine Farrell is currently a lay member of the Health Profession’s Council, the UK Regulatory Body for 13 Health Professions. This body is responsible for approving all UK courses for the training of relevant health professionals. She has worked in Higher Education as a teacher and researcher and was also a policy adviser to the English Minister of Higher Education during the 1980-90s. Her most recent publication was for the Department of Health (England): Patient and Public Involvement: the evidence for policy implementation, 2004.

**Martha E. (Meg) Gaines**, Professor of Law, University of Wisconsin, Director, Centre for Patient Partnerships, mgaines@wisc.edu

Meg received her BA from Vassar College in 1977 and her JD and LLM from the University of Wisconsin Law School in 1983 and 1993. On the faculty at the University of Wisconsin Law School since 1987, she directs the Center for Patient Partnerships which she co-founded with several colleagues in 2000. The Center, committed to empowering patients as equal partners with health care practitioners, brings together students and faculty from various disciplines including Medicine, Nursing, Law, Social Work, Business, Counseling Psychology, Public Policy, Pharmacy and Industrial Engineering to serve as advocates for patients with life threatening and serious chronic illnesses.

**Bill Godolphin**, Co-Director, Division of Health Care Communication, College of Health Disciplines, UBC, wgod@interchange.ubc.ca

Bill Godolphin is a professor of Pathology & Laboratory Medicine at UBC and Co-Director of the Division of Health Care Communication. He has been a teacher and a researcher for many years, with projects and publications ranging across lipoproteins, breast cancer prognostic factors, clinical laboratory toxicology, automation & robotics, medical education and faculty development. For the past decade he and Angela Towle have collaborated in attempts to unloose the Gordian knot of informed and shared decision making.

**Cathy Kline**, Research Coordinator, Division of Health Care Communication, College of Health Disciplines, UBC, cckline@interchange.ubc.ca

Cathy is the Research Coordinator for the Division of Health Care Communication. Her interests are in qualitative health research and informed choice. Her work has involved qualitative analysis of audio-taped patient-doctor encounters to identify elements of informed and shared decision making. Cathy has also spent a number of years working in the area of adolescent mental health with youth at risk. She has a BA (psychology) from Simon Fraser University and an MA (health promotion) from Dalhousie University.
Task Force Members (Continued)

Beth Lown, Carl J. Shapiro Institute for Education and Research, Harvard Medical School, Past President, American Academy on Physician and Patient (AAPP), blown@caregroup.harvard.edu

Beth Lown is a primary care internist based in Cambridge, USA and a clinician-educator at Harvard Medical School and its affiliated hospitals. She is immediate Past-President of the American Academy on Physician and Patient, Director of Faculty Development at Mt. Auburn Hospital and Associate Director of Fellowships in Medical Education within the Harvard system. She has had an enduring interest and commitment to exploring, teaching and assessing healthcare relationships and communication.

Penny Morris, Senior Lecturer in Communication Skills, Medical Education Unit, University of Leeds, UK, p.a.morris@leeds.ac.uk

From a community development background, she begun work in the late 70s with the Department of General Practice at Manchester University on teaching the medical interview in primary care, using new methods with simulated patients as an active lay voice. She moved to Cambridge, UK in 1986 to undertake a controlled trial of the learning of communication skills, particularly in information-giving, across the undergraduate medical curriculum. She established and disseminated learning and assessment methodologies including video review and simulated patient feedback and founded a UK network for communication in healthcare. In 1990 she took up a Harkness Fellowship at Northwestern University, USA, exploring patient and community involvement in health with a coalition of community groups on Chicago’s Westside. She returned to Cambridge to develop methods and strategies for promoting student and faculty capacity to practise partnership with patients. She came to Leeds in 2000 to lead the new undergraduate theme of communication from the South Thames Postgraduate General Practice Deanery where her role had been to promote multiprofessional development in primary care, in particular the review of relationships with patients in the new NHS. Her current research and development work focuses on patient and public involvement in health professional learning and helping GPs and medical students in difficulty with communication.

Angela Towle, Task Force Chair, Co-Director, Division of Health Care Communication, College of Health Disciplines, UBC, atowle@interchange.ubc.ca

Angela Towle is Co-Director of the Division of Healthcare Communication in the College of Health Disciplines at UBC which has a research and development focus on patient/client involvement in health care decision-making. She has been Associate Dean for Undergraduate Medical Education in the Faculty of Medicine since August 2002 and has taken a lead in implementing a major expansion of the medical school which is being done in partnership with the University of Victoria, the University of Northern BC and the six provincial health authorities. The expansion is designed to address physician shortages in the province and difficulties in recruiting and retaining physicians in rural and remote areas. Angela has 16 years experience of medical education research, curriculum and faculty development, and curriculum management and change at UBC (formerly as Director of the MD Undergraduate Program) and at various medical schools in the UK. She was for five years based at the King’s Fund Centre for Health Service Development in London where her work focused on the interface between medical education and health care delivery.

Samantha Van Staalduinen, Student Coordinator, Division of Health Care Communication, College of Health Disciplines, UBC, savan@interchange.ubc.ca

Samantha is a project coordinator and researcher with the Division of Health Care Communication. She has a passion for health and well-being with a special interest in improving communication between patients/clients and their health care providers. Her work has involved coordination and expansion of a workshop-based communication skills training project for adolescents and development of a cross-cultural communication program for health professional students and instructors. She has a B.Sc in Integrated Science (Medical Genetics/Microbiology) from the University of British Columbia.
Task Force Members (Continued)

Wayne Weston, Professor Emeritus, Dept. of Family Medicine, Consultant to the Dean on Faculty Development, wweston@uwo.ca

W. Wayne Weston is a Professor Emeritus of Family Medicine in the Schulich School of Medicine and Dentistry at the University of Western Ontario, London, Ontario, Canada. After graduating from the University of Toronto in 1964, he practiced in Tavistock, Ontario, for 10 years before joining the faculty at Western. He has a special interest in patient-physician communication and faculty development and has been a leader in the development of two large educational projects involving the five Ontario medical schools – the EFPO (Educating Future Physicians for Ontario) Project and Project CREATE (Curriculum Renewal and Evaluation of Addiction Training and Education).

He is currently the Director of Undergraduate Education in the Department of Family Medicine at Western; Chair of the Task Force on Family Medicine Undergraduate Education; consultant to the Dean on faculty development; Co-director of GAMES (The Group for Advocacy and Advancement of Medical/Dental Education Scholarship) for the Schulich School of Medicine and Dentistry at Western.
Financial Contributors

We would like to thank the following contributors:
Exhibitors

BC Paraplegic Association
Dual Diagnosis Program of BC
AIDS and Disability Action Program of BC
ODIN Books
BC Medical Guide Program
Physiotherapy Association of British Columbia (PABC)
Canadian Diabetes Association, Greater Vancouver & District
Association for the Study of Medical Education – Edinburgh, Scotland
Centre for Health Sciences Interprofessional Education, University of Washington
Maps and Locations

Conference Level

Please Note: Mountain Suite and English Bay Suite are located on the 35th Floor.
Local Restaurant Guide

Banana Leaf Malaysian Restaurant
1096 Denman Street
(604) 683-3333
Price Range: $-$

The Boathouse Waterfront Restaurant
1785 Beach Avenue
(604) 669-2225
*Chicken, Pasta, Soup, Salad, Seafood, Steak. Licensed.*
Price Range: $$$

The Brasserie Bistro
1763 Comox Street
(inside the Coast Plaza Hotel & Suites)
(604) 688-7711
*Pasta, Salad, Soup, Sandwiches, Seafood, Stirfry. Licensed.*
Price Range: $

Bread Garden Bakery Cafe
1040 Denman Street
(604) 685-2996
*Bagels, Muffins, Pasta, Salads, Wraps and Desserts*
Price Range: $

Delilah’s
1789 Comox Street
(604) 687-3424
*Open for Dinner: Pasta, Soup, Salad, Seafood, etc. Licensed.*
Price Range: $$$

Milestone’s Restaurant
1210 Denman Street
(604) 662-3431
*Burgers, Chicken, Pasta, Salad, Seafood, Steak, Vegetarian dishes. Licensed.*
Price Range: $$

Raincity Grill
1193 Denman Street
(604) 685-7337
*Pasta, Soup, Salad, Seafood, Steak. Licensed.*
Price Range: $$$
Thursday, November 3, 2005

7:30  Registration and light refreshments  Conference Foyer

8:15  Conference Welcome  Ballroom
John Gilbert
Opening Remarks
Angela Towle, Task Force Chair
Setting the Stage
Beth Lown, Meg Gaines

9:00  Student Panel Presentation: Where is the Patient’s Voice in Health Professional Education: A Learner’s Perspective  Ballroom
Chair: Lesley Bainbridge
Nicole Fernandes, Pam Hirakata, Wesley Jang, Rita Lung, Lucinda McQuarrie, Carolyn Saunders & Teresa Wood

10:30  Coffee Break and Exhibits Open

11:00-12:00 Thursday, November 3, 2005
Parallel Plenary Presentations

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<td>1.1.2  An Action Research Approach to Developing User Involvement in a University Faculty of Health (the Comensus project)  Lidia Koloczeck, Lisa Shoja, David Liberato, Nat Solanki</td>
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<td>1.1.2.1  Whose Voice Is It Anyway? Embedding the Patient Voice in the Simulated and Standardised Patient  Penny Morris, Andrea Armitage, Julie Symons, Jackie Reed, Ernie Dalton</td>
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12:00  Luncheon  Participants on their own for lunch (see restaurant listing on page 8) and poster viewing
### 13:30 - 15:30 Thursday, November 3, 2005

#### Concurrent Sessions

**Room: Nelson** Chair: Angela Towle  
**Learning for Service Improvement (using patient feedback)**

1.2.1.1 Patients are Teachers (With a Little Help from their Friends)  
Laura Vercler

1.2.1.2 Use of Feedback from Patient Questionnaires to Develop and Assess Patient-centred Medical Professionalism  
Alison Chisholm

1.2.1.3 Informing the Profession with a Systematic Approach to Capturing and Applying Individual Patient Values  
Duane Steward

1.2.1.4 Beyond the Tick Box: Developing the Patient Voice in Learning for Service Improvement in the NHS in the UK  
Fiona O’Neill, Julie Symons, Andrea Armitage

**Room: Denman** Chair: Penny Morris  
**The Trained Patient**

1.2.2.1 Where is the Patient in the Standardized Patient?  
Nancy McNaughton

1.2.2.2 The Implementation of Patient Centered Care (PCC) Using Standardized Patients (SPs) in Continuing Education  
Silvi Groe

1.2.2.3 What Makes a Good Doctor? Who Knows? Who Decides?  
Kathryn Robertson

1.2.2.4 Intimate Encounters: Teaching Pelvic Exams  
Lenore Riddell

**Room: Comox** Chair: Cathy Kline  
**Student Experiences**

1.2.3.1 Creative/Artistic Education and Communication Techniques: A Path Towards Authentic Knowledge of Patients in Mental Health Facilities  
Gillian May

1.2.3.2 Being Treated for “Free” – Should I Expect Less?  
Minha Rajput

1.2.3.3 Understanding Lived Experience of Health and Illness: Student Perspectives from Innovative Clinical Placements  
Sheryl Reimer Kirkham, Lynn Van Hofwegen

1.2.3.4 Perception Versus Reality: Students’ Awareness of the Patient Experience  
Jennifer Vassie, David Fox

**Room: Beach** Chair: Christine Farrell  
**Models of Community Involvement**

1.2.4.1 Local Realities of National Requirements: Involving Service Users in UK Social Work Education  
Pat Taylor

1.2.4.2 Transforming Listening into Action  
Margaret Gallagher

1.2.4.3 Using Public Consultation to Develop Curriculum Learning Outcomes for Disability Equality Teaching in Healthcare  
Margaret Byron, Paul Bradley

1.2.4.4 Learning Lessons from Involving Patients in Research – The Folk.us Experience  
Rachel Purtell

### Concurrent Workshop Sessions

**Room: English Bay Suite (35th Floor)**

1.2.W1 Proactive and Powerful - Working to Maximize our Collective Potential  
Pamela West, Sandi Pniauskas

1.2.W4 Patient Narrative as a Tool to Developing Compassion  
Mary Kraft, Patricia Abreu

**Room: Bayside**

1.2.W2 A Council of Elders: Creating a Culture of Care  
Arlene Katz

1.2.W5 What We Have Learned Is What We Teach – Making The Connection  
Betty Sinclair

**Room: Parkside**

1.2.W3 Health Care from the Other Side: One Patient’s Perspective  
Susan Harris

**Room: Mountain (35th Floor)**

1.2.W3 Health Care from the Other Side: One Patient’s Perspective  
Susan Harris

**Room: Pacific**

1.2.W4 Patient Narrative as a Tool to Developing Compassion  
Mary Kraft, Patricia Abreu

1.2.W5 What We Have Learned Is What We Teach – Making The Connection  
Betty Sinclair
### Concurrent Sessions

#### Learning for Service Improvement

*Room: Nelson  Chair: Angela Towle*

1.3.1.1 The Implementation of a Bill of Client Rights  
Jane Paterson, Jennifer Chambers

1.3.1.2 Building in Patient’s Voice in Daily Practice: Springboard to Improving Practice Outcomes and Accountability in Nursing Staff  
Rosanna DiNunzio

1.3.1.3 An Interdisciplinary Approach to Improve Health Literacy in the Rural Elderly  
Jan Peeler, Serena Britt

1.3.1.4 Patient Empowerment Through e-Health Approaches - an Empirical Analysis of Barriers and Drivers  
Karl Stroetmann

#### Patient Empowerment

*Room: Denman  Chair: Meg Gaines*

1.3.2.1 Empowerment as Treatment and the Role of Health Professionals  
Penny Powers

1.3.2.2 Education for Empowerment of Breast Cancer Survivors: Ensuring a Voice  
Scott Secord

1.3.2.3 Preoperative Education: Maximizing the Learning Potential  
Nicola Spalding

1.3.2.4 Patient Education Prescriptions: Tailored Health Information, Cultural Translations, and Community Learning Networks  
Robert Luke, David Wiljer

#### Evaluation of Impact

*Room: Comox  Chair: Wayne Weston*

1.3.3.1 Patient Participation and the Use of Multiple Methods to Research and Teach Student Nurses: Results from an Exploratory Study  
Aled Jones

1.3.3.2 Teaching Partnerships: Using the Ages and Stages Questionnaire to Validate Parent’s Knowledge  
Pam Nicol

1.3.3.3 A Collaborative Approach to Learning Shared Decision-Making  
Beth Lown, Janice Hanson

1.3.3.4 Service User Involvement in Postgraduate Mental Health Education  
Richard Khoo, Andy McVicar

#### Discussion Topics

*Room: Beach  Chair: Bill Godolphin*

1.3.4.1 The Case of the Missing Letter in IECPCP  
Yhetta Gold, John Gilbert

1.3.4.2 Education for Partnership: How Can Doctors Learn to Engage Patients?  
Alison Chisholm

1.3.4.3 Enhancing Ethical Practice in Prenatal Screening: An Educational Imperative  
Eleanor Milligan

1.3.4.4 The Knowledge Economy and Health Care: A Usurping of the Patient’s Voice?  
Florence Myrick

### Concurrent Workshop Sessions

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</table>
| 1.3.W1 The Comensus Project: Community Engagement and Service User Support  
Lidia Koloczek, Lisa Shoja, David Liberato, Nat Solanki | 1.3.W2 Empowering Educators and End-Users: The Use of PAR (Participatory Action Research) to Foster Collaborative Health Education and Research with Six First Nations Communities  
Verle Harrop, Sharon Mah, Angela Nash | 1.3.W3 How Can I Help You Today? Learning from Expert Patient Teachers  
Andrea Armitage, Chris Essen, Julie Symons, Shelley Fielden, Fiona O’Neill, Sam Samociuk, Rob Lane, Penny Morris | 1.3.W4 Difficult Discussions in the Neonatal Intensive Care  
Dorotha Graham Cicchinelli, Mary Cohn | 1.3.W5 Optimising the Contribution that Patients Can Make as Teachers of Health Professionals  
Ruth Chambers, Sara Buckley |
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<tbody>
<tr>
<td>7:30</td>
<td>Registration and light refreshments</td>
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<tr>
<td>8:15</td>
<td>Summary of Thursday’s Conference Proceedings</td>
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<tr>
<td>9:00-10:30</td>
<td>Friday, November 4, 2005: Parallel Plenary Presentations</td>
</tr>
<tr>
<td>9:00-10:30</td>
<td>Room: Nelson, Chair: Wayne Weston</td>
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<td>Room: Comox, Chair: Lesley Bainbridge</td>
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<tr>
<td>10:30</td>
<td>Coffee Break and Exhibits Open</td>
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<tr>
<td>11:00-12:00</td>
<td>Poster Sessions</td>
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**Patients as Educators**

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<tbody>
<tr>
<td>2.1.1.1</td>
<td>People with HIV as Educators of Health Professionals</td>
<td>Patricia Solomon, Deborah Stinson</td>
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<tr>
<td>2.1.1.2</td>
<td>Talking Cancer: Involving Patients and Carers in a Pre-registration Nurse Education Programme</td>
<td>Alison C Clark</td>
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<tr>
<td>2.1.1.3</td>
<td>Joint Learning: Musculoskeletal Education</td>
<td>Annalie Lydiatt</td>
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<tr>
<td>2.1.2.1</td>
<td>Teaching with Parents and Patients in Medical School</td>
<td>Janice Hanson, Carolyn-Jordan-Alexander</td>
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<td>2.1.2.2</td>
<td>Patients and Families Assessing Medical Students’ Communication</td>
<td>Kathy Zopp, Beth Lown</td>
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<td>2.1.2.3</td>
<td>Students Experience of a Patient as the Teacher</td>
<td>Annabel Kier</td>
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<td>2.1.3.1</td>
<td>Every Voice Counts: A Model for Meeting Educational Needs through Patient Partners</td>
<td>Cheryl Descent, Deborah Docherty</td>
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<tr>
<td>2.1.3.2</td>
<td>Increasing the Patient’s Voice in Medical Education: The Development of a Patient Educator Programme in a UK Medical School</td>
<td>Elaine Gill</td>
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<tr>
<td>2.1.3.3</td>
<td>Exploring the Challenges and Benefits of Nurse Educator / Patient Educator Collaboration in Mental Health Nursing Education</td>
<td>Lorna Bennett</td>
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### Concurrent Sessions

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<th>Learning for Service Improvement</th>
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<tbody>
<tr>
<td><strong>2.2.1.1</strong></td>
<td>Service Users As Teachers of Health Professionals – A Conceptual Framework</td>
<td>Pennie Roberts</td>
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<td><strong>2.2.1.2</strong></td>
<td>Dylan’s Gift: Teaching a Hospital to Care</td>
<td>Beth Seyda</td>
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<td><strong>2.2.1.3</strong></td>
<td>Stories from the Heart: Using Life Review to Elicit Narratives of Illness and Recovery in Women Following Myocardial Infarction</td>
<td>Michele Bowers, Sally Haliday</td>
</tr>
<tr>
<td><strong>2.2.1.4</strong></td>
<td>Integrating the Voice of Patients / Survivors / Families in the Cancer System</td>
<td>Emmie Luther-Hiltz</td>
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<tr>
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<tr>
<td><strong>2.2.2.1</strong></td>
<td>Introducing the Voice of the Older Person into Health Professional Education</td>
<td>Catherine Monaghan</td>
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<tr>
<td><strong>2.2.2.2</strong></td>
<td>Enhancing Undergraduate Nursing Education: The Patient and the Family</td>
<td>Judy Secombe</td>
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<td><strong>2.2.2.3</strong></td>
<td>Project DOCC - Delivery of Chronic Care: Family as Faculty in Medical Education</td>
<td>Maggie Hoffman</td>
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<td><strong>2.2.2.4</strong></td>
<td>Counseling Practicum: Patient's Stories in Family Medicine</td>
<td>Kathy Zoppi</td>
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<tr>
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<tr>
<td><strong>2.2.3.1</strong></td>
<td>Incorporating Patient Narratives in an Interdisciplinary Course</td>
<td>Wendy Hall, Marion Clauson</td>
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<tr>
<td><strong>2.2.3.2</strong></td>
<td>One Patient’s Narrative: The Health Care Professional as Patient - a Different Perspective</td>
<td>Deborah Docherty</td>
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<td><strong>2.2.3.3</strong></td>
<td>Alzheimer’s Narratives: Voicing the Experience of Patients and Caregivers</td>
<td>David H. Flood, Rhonda L Soricelli</td>
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<td><strong>2.2.3.4</strong></td>
<td>Slow Motion Ethics: Viewing Professional-Patient/Family Encounters from the Patient/Family Perspective</td>
<td>Daryl Pullman</td>
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<th>Curriculum Development</th>
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<tr>
<td><strong>2.2.4.1</strong></td>
<td>Working Together - Educationalists and Service Users Translating Rhetoric into Reality</td>
<td>Anne Fothergill, Victoria Jones</td>
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<tr>
<td><strong>2.2.4.2</strong></td>
<td>Patient and Public Involvement in the Development and Delivery of Pre-Registration Occupational and Physiotherapy Education Programmes</td>
<td>Elizabeth Bond</td>
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<tr>
<td><strong>2.2.4.3</strong></td>
<td>Child and Parent Voices in Developing Future Nursing Curricula</td>
<td>Angela Chakrabarti, Brenda Roberts</td>
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<tr>
<td><strong>2.2.4.4</strong></td>
<td>Learning from our Patients and Families, Teaching to our Students</td>
<td>Helen Frederickson, Sandra Devlin-Cop</td>
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### Concurrent Workshop Sessions

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<th>Room: Parkside</th>
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<tbody>
<tr>
<td><strong>2.2.W1</strong></td>
<td>Assessment Techniques for Measuring Skills And Attitudes Towards Disabled People</td>
<td>Margaret Byron, Paul Bradley</td>
</tr>
<tr>
<td><strong>2.2.W2</strong></td>
<td>Working Together: Patient, Community and University Reflections on Personal and Professional Development</td>
<td>Andrea Armitage, Chris Essen, Julie Symons, Shelley Fielden, Fiona O'Neill, Sam Samociuk, Rob Lane, Penny Morris</td>
</tr>
<tr>
<td><strong>2.2.W3</strong></td>
<td>Building a Foundation for Community Engagement In the Faculty Of Medicine at the University of British Columbia</td>
<td>Vince Verlaan, Peter Granger, Patricia Boston, Evan Adams, Betty Calam, Andrew Morgan</td>
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<tbody>
<tr>
<td><strong>2.2.W4</strong></td>
<td>Learning from the Patient’s Voice; Involving Patients as Co-Researchers with Health Professionals</td>
<td>Elizabeth Boath, Ruth Chambers</td>
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<tr>
<td><strong>2.2.W5</strong></td>
<td>Bull’s Eye- The Patient’s Voice at Front and Center: Educating for Advocacy at Sarah Lawrence College</td>
<td>Rachel Grob, Marsha Hurst</td>
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### Concurrent Sessions

**Room: Nelson**  
Chair: Bill Godolphin  
**Educational Models**

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<tr>
<th>Session Number</th>
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<th>Presenter(s)</th>
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<tbody>
<tr>
<td>2.3.1.1</td>
<td>Empowering Patients with Information: Educating Students to Find Appropriate Information of High Quality and Share it with Patients</td>
<td>Jim Henderson</td>
</tr>
<tr>
<td>2.3.1.2</td>
<td>Virtual Reflections: Online Blogs and Self Help Groups Addressing Mental and Physical Disorders</td>
<td>Joanne Levine</td>
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<tr>
<td>2.3.1.3</td>
<td>e-Health Promotion Programs: Empowering Underserved Consumers to Make Decisions About Their Health</td>
<td>Kevin Lyons</td>
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<tr>
<td>2.3.1.4</td>
<td>Involving Patients in Online Learning</td>
<td>Kieran Walsh</td>
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**Room: Denman**  
Chair: Penny Morris  
**Educational Potential of the Expert Patient**

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<tr>
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<tbody>
<tr>
<td>2.3.2.1</td>
<td>Expert Patients and their Experience of Health Services</td>
<td>Claire Gately</td>
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<tr>
<td>2.3.2.2</td>
<td>The Chronic Disease Self-Management Program</td>
<td>Patrick McGowan</td>
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<tr>
<td>2.3.2.3</td>
<td>What Motivates Heart Disease Patients for Physical Activity and Training?</td>
<td>Liv Bjerknes</td>
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**Room: Comox**  
Chair: Susan Harris  
**Patient Experiences**

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<th>Session Number</th>
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<tr>
<td>2.3.3.1</td>
<td>Radiation Therapy from the Inside Out</td>
<td>Fiona Mitchell</td>
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<td>2.3.3.2</td>
<td>Listening to the Voices: A Parent's Perspective</td>
<td>Linda Sullivan</td>
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<td>2.3.3.3</td>
<td>The Question Was: Could I Find a Way to Live with AIDS?</td>
<td>Jacob Peters</td>
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<td>2.3.3.4</td>
<td>The Patient Voice Project: Teaching Creative Writing to the Chronically-Ill</td>
<td>Austin Bunn</td>
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**Room: Beach**

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<th>Presenter(s)</th>
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<tbody>
<tr>
<td>2.3.W1</td>
<td>Advocacy as Alchemy: Empowering Patient Experience for Teaching and Service</td>
<td>Martha Gaines</td>
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**Room: Cardero**

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<tr>
<td>2.3.W2</td>
<td>Lights, Camera, and Action – Strengthening the Consumer/Survivor Voice</td>
<td>Shawn Lauzon, Raymond Cheng</td>
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**Room: Bayside**

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<tr>
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<tbody>
<tr>
<td>2.3.W3</td>
<td>Action Replay: Enhancing the Patient's Voice in Health Professional Education</td>
<td>Diana Kelly, Geoff Wykurz</td>
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**Room: Parkside**

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<tr>
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<th>Title</th>
<th>Presenter(s)</th>
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<tbody>
<tr>
<td>2.3.W4</td>
<td>Narrative Analysis – A Qualitative Research Methodology</td>
<td>Gretchen Zunkel</td>
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**Room: Mountain (35th floor)**

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<tr>
<td>2.3.W5</td>
<td>Ending the Journey - Talking with the Elders</td>
<td>Randi Gage</td>
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**Room: Pacific**

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<tr>
<td>2.3.W6</td>
<td>The Silent Voice of Mr. George</td>
<td>Penny Cash, Donna Kurtz, Susan Van Den Tillaart, Fay Karp, Joan Bassett-Smith</td>
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<tr>
<td>7:45</td>
<td>Registration and light refreshments</td>
<td>Conference Foyer</td>
</tr>
<tr>
<td>8:15</td>
<td>Summary of Friday’s Conference Proceedings</td>
<td>Ballroom</td>
</tr>
<tr>
<td>9:00</td>
<td>Facilitated working groups to develop conference reports</td>
<td>Ballroom</td>
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<tr>
<td>11:30</td>
<td>Report back from groups</td>
<td>Ballroom</td>
</tr>
<tr>
<td>12:30</td>
<td>Closing Presentations: conference outcomes and future directions</td>
<td>Ballroom</td>
</tr>
<tr>
<td>1:30</td>
<td>Task Force meeting to work on conference documents (closed meeting)</td>
<td>Refreshments will be available between 10:30-11:30</td>
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Conference Welcome

Presenter: John Gilbert, College of Health Disciplines, University of British Columbia, Vancouver, Canada

John Gilbert is the Principal of the College of Health Disciplines at UBC. During 1996-97 he facilitated the Committee of Deans Strategic Planning Initiative. He is a member of the Operating Committee of the Council of University Teaching Hospitals and is Chair of the Health Sciences sub-committee. He is a member of the Health Human Resources Advisory committee of the Ministry of Health Planning, and serves on its Sub-committee - the Health Education Working Group. He is currently Chair of the committee of Deans and Directors of Health Sciences (BC). Dr. Gilbert also played an integral role in organizing the very successful Altogether Better Health conference in May 2004 and is co-editing the special supplement of the Interprofessional Journal of Care that will publish some of the research presented at that conference.

Opening Remarks

Presenter: Angela Towle, Task Force Chair

Setting the Stage

Presenters: Beth Lown; Meg Gaines, Task Force
Student Panel Presentation: Where is the Patient’s Voice in Health Professional Education: A Learner’s Perspective

Nicole Fernandes
Nicole is a trained and certified genetic counsellor who has worked in both the clinical and research arenas in the University of British Columbia’s Department of Medical Genetics at the Women’s and Children’s Health Centre of B.C. Her varied volunteer experiences and especially her work as a genetic counsellor have helped her understand that delivery of effective and high-quality health care is dependent in part on our ability to listen and respond to the concerns and experiences of patients. Nicole recently embarked on a new and exciting journey, having begun her first year of medical school in September 2005.

Pam Hirakata
Pam is a third-year doctoral student in Counselling Psychology currently conducting research on the topic of early childhood trauma and dissociation. Her study aims to explore the process of treatment for dissociation and establish a set of client-driven treatment guidelines for therapists by means of a forum in which clients offer insight into what aspects of treatment helped and hindered their therapeutic process. Pam works with women and children who have been sexually abused.

Wesley Jang
A third-year pharmacy student at the University of British Columbia, Wesley is dedicated to expanding the pharmacy profession by way of practicing pharmaceutical care. His experience has recently involved educating, counseling and interviewing patients through disease state management programs to determine their optimal drug therapy plan as well as addressing any unmet needs. He is a firm advocate of working with fellow colleagues in the healthcare system to achieve the best outcome for a patient through means of interdisciplinary teamwork.

Rita Lung
Rita has a B.Sc. (Pharm) and recently graduated from the BC Hospital Pharmacy Residency Program. She has served as a peer teacher in the UBC Faculty of Pharmaceutical Science’s Professional Practice laboratory, and has worked with the Community Health Initiative for University Students, a student-run clinic in Vancouver’s downtown eastside. Rita is currently a clinical pharmacist at St. Paul’s hospital, where she strives to deliver engaging care that respects the needs and dignity of her patients.

Lucinda McQuarrie
Lucinda is a third-year medical student at the University of British Columbia with plans to pursue a career in Family Practice. She spent the summer of 2004 on a research project entitled “Enabling Prenatal Clients to Overcome Barriers in Health Care Communication,” where she worked to determine the need and opportunity for a communication skills workshop in existing childbirth education classes. With interests in education and communication, Lucinda hopes to incorporate involvement in medical education into her career as a physician.

Carolyn Saunders
A third-year Midwifery student at the University of British Columbia, Carolyn is committed to empowering people to make their own health care decisions. She was recently involved in the development of a manual for community groups on “Talking with your Doctor” and initiated a research project examining health care communication in the prenatal period. She is currently doing a placement with the South Community Birth Program in Vancouver, a program which provides prenatal care in a group setting.

Teresa Wood
A fourth-year medical student, Teresa is also a philosopher, writer, patient advocate, counselor, community educator, listener, performer and healer. While pursuing her BA (Philosophy) in Chicago, Teresa created a team of female advocates to aid an underserved population of women in accessing safe, comfortable health care. She has also worked with community advisory committees on health policy development for the Vancouver / Richmond Health Board.
Clients as Partners in Curriculum Planning and Delivery

Presenter: Sandra Hobson, School of Occupational Therapy, University of Western Ontario, London, Canada

Additional Authors: Thelma Sumsion; Debbie Rea

In today’s multicultural and inclusive society, professionals must be open to each individual client's values, goals, and objectives. These must be incorporated into treatment plans in order to ensure a successful outcome. The School of Occupational Therapy at the University of Western Ontario has incorporated consumer expertise into its approach to curriculum design and delivery. Consumer representatives can share information of concern to the healthcare user and, because of their involvement with other consumers, may be able to identify community events of interest to faculty and students. For over 10 years, the committee responsible for the professional curriculum has had a consumer representative who participates as an equal member. Consumer input is a standing agenda item. As well, this individual has full voting rights on all curriculum decisions, from the content of individual courses to curriculum re-design. Other methods of drawing upon consumer expertise include inviting clients into individual classes as guest educators (with or without clinicians) and including client interviews among course assignments. One example of a client driven curriculum decision was an increased emphasis on the confidentiality of client information, which resulted in students signing confidentiality forms annually. The curriculum uses cases extensively, and a consumer representative was also involved in the development of the guidelines that govern case writing and use, including the fact that clinical (as opposed to professional issues) cases must be released by the client involved. This presentation will address issues of identifying suitable consumer educators, validating consumer input, and recognizing consumer contributions.
Parallel Plenary Session 1.1.1.2
Room: Nelson/ Denman

An Action Research Approach to Developing User Involvement in a University Faculty of Health (The Comensus Project)

Presenters: Lidia Koloczec, Comensus Project, University of Central Lancashire, Preston, UK; Lisa Shoja, Comensus Project, Faculty of Health, University of Central Lancashire, Preston, UK; David Liberato, Comensus Project, University of Central Lancashire, Preston, UK; Nat Solanki, Comensus Project, University of Central Lancashire, Preston, UK

Additional Authors: Mick McKeown; Soo Downe; The Comensus Team

The Comensus Project (community engagement and service user support) has been established in the Faculty of Health at the University of Central Lancashire, UK. The aims are to provide for systematic participation of health and social care service users in all aspects of the Faculty’s work: practitioner education and training; research; and strategic planning. A key element of the project is the development of a group of service users, networked into the wider community, who will provide a forum for information exchange, consultation, negotiation and influence within the university, such that service user views and perspectives are more thoroughly engaged with across the variety of activity in the Faculty. This forum has been named by the participants as the ‘Community Involvement Team’.

The initiative has been conceived as a modified participatory emancipatory action research project, using a spiral process of iterative cycles of planning-action-observation-reflection-planning. This presentation will present findings to date.

Taken as a whole, the project aims to deliver a number of reciprocal benefits between the university and the local community. The anticipated benefits for the university include a range of enhancements to course provision and research quality, and a shift away from previously piecemeal involvement of service users towards a more systematic and co-ordinated enterprise. The forms of user involvement which are developed should have the added value of being credible, organic and independent. The process of community engagement and involvement should ensure associated beneficial impact upon the university’s public image and standing within the local community. Potential community benefits involve employment opportunities, opening up access to university resources and, importantly, the opportunity to make a difference.
Whose Voice is it Anyway? Embedding the Patient Voice in the Simulated and Standardised Patient

Presenters: Penny A Morris, Medical Education Unit, University of Leeds, UK; Andrea M Armitage, Medical Education Unit, University of Leeds, UK; Julie E Symons, Medical Education Unit, University of Leeds, UK

Additional Authors: Jackie Reed; Delia Muir; Ernie Dalton; Sue Power; Sue Kilminster; Trudie Roberts

Given that the largest group of the public actively involved in the education of health professionals is probably those committed to simulated or standardised patient teaching and assessment, our presentation will demonstrate approaches, developed in various locations in the UK and Chicago, aimed to ensure that the patient and community perspective is voiced and heard in such work. We will outline how patient and community groups can be involved to validate roles and how authentic feedback can be achieved to connect to the lived experience of the learner. We will describe how the authority of the simulated and standardised patient as teacher and assessor can be established and destroyed. Finally, we will illustrate and explore key issues arising: dealing with diversity, the question of patient as victim versus demonstrating community capacity, the questionable validity of some educational strategies in the standardisation of patient portrayal, the acknowledgement, or lack of it, of the patient contribution in this work, resources for partnership working, the potential health outcome benefit of patient involvement in simulated and standardised patient work and the authenticity of such a patient voice.

Listening to Women’s Voices: Developing Cultural Competence in Perinatal Care

Presenters: Claire McDonald, St. Joseph’s Health Care, London, Canada; Lori Robson, Perinatal Program, London Health Sciences Centre, London, Canada

Additional Authors: Elaine Pollett, Nancy Watts

Cultural sensitivity was identified as an area for improvement by the perinatal staff in two institutions in the city of London, Ontario. A family-centred care committee, composed of nurses, leaders, educators and parents from both institutions identified a clinical question: How can perinatal health care providers find ways to actively listen and collaborate in planning care for culturally diverse women? The chosen objectives included: 1) to increase the awareness of the cultural dimension of Family-Centred Care in perinatal care 2) to integrate cultural awareness into the assessment of patients and families in perinatal care, and 3) to include a panel of culturally diverse women in the conference to ensure that their “voices” would be heard. Outcomes include conference attendance by multidisciplinary health care providers, development of a perinatal cultural admission question(s) and a desire by providers to learn more. Participants evaluated the women’s stories as the most profound learning and reflection has been influential in changing their practice. Other applications of this learning include orientation information, and increased translator use. Our presentation would include a review of this journey beginning with a needs assessment, an understanding of our community, implementation and evaluation of a plan and hopes for the future.
**Patients are Teachers (With a Little Help from their Friends)**

**Presenter:** Laura Vercler, Press Ganey Associates, Inc, South Bend, USA

Additional Authors: Robert J. Wolosin

The role of patients as teachers of health professionals extends beyond face-to-face encounters. Patient feedback, in the form of patient satisfaction data systematically collected and distributed throughout the institution, constitutes a dynamic syllabus for health professionals' continuing education. This presentation will give an overview of the use of patient satisfaction data for educational purposes. Actual satisfaction survey data, including comments, collected by a US consulting firm from inpatient, outpatient, and long term care settings, will be used to illustrate how patient experiences can be transformed into learnable skills for health professionals, and how they can form the basis for reward/recognition programs. After noting methodological advantages of mailed surveys, several techniques will be illustrated: (1) Discovering specific, actionable service issues by drilling down into quantitative and qualitative data by patient characteristics, service rendered, clinical condition, temporal parameters, and geographic distribution; (2) Using drill down to discover model units where high quality patient care is provided, so as to create educational opportunities using “local experts,” and to recognize them for their contributions; (3) Prioritizing service issues into those that offer the greatest gains for the effort; (4) Starting small by instituting a pilot project within one sector that, if successful, can be replicated elsewhere in the institution; (5) Identifying staff contributors to positive and negative patient experiences, so as to avoid discouraging current champions and provide re-learning opportunities for poor performers. As a result of this presentation, attendees will be able to state how patient satisfaction data can help teach health professionals.

**Use of Feedback from Patient Questionnaires to Develop and Assess Patient-centred Medical Professionalism**

**Presenter:** Alison Chisholm, Picker Institute Europe, Oxford, UK

The teaching and assessment of medical professionalism have assumed increasing prominence in recent years. Professionalism can be conceptualised as a complex set of attitudes and ethics which develop over time through subtle processes of reflection on psychosocial experiences. However, many aspects of patient-centred professionalism are manifest in practice such as good communication, shared decision-making, sharing information and demonstrating respect for patient autonomy.

Patients themselves are best placed to judge these aspects of patient-centred professionalism, and increasingly this capacity has been harnessed through the use of patient questionnaires in the appraisal processes of practising doctors. However, they are not routinely used to provide feedback for formative assessment purposes in medical education.

This paper first argues that the use of patient questionnaires in this capacity would confer several advantages. Patient questionnaires that are psychometrically advanced offer high levels of physician-level reliability and validity. They can be administered anonymously to patients immediately post-consultation, by post, by telephone or on-line, offering anonymity to the patients and thus encouraging frankness. They can relate closely to patient-centred standards of professionalism against which students will be assessed in the future as qualified doctors. Formative assessment using credible sources of feedback is a powerful stimulus to learning.

It then critically reviews eight such patient questionnaires, and compares them on the basis of the areas of patient-centred professionalism they cover, the degree of patient involvement in their development, and the value of the data they produce to inform the maturity of patient-centred professionalism in medical students.
Informing the Profession with a Systematic Approach to Capturing and Applying Individual Patient Values

Presenter: Duane Steward, Orlando, USA

Systematic application of patient values is sparse because systematic approaches to collection and digestion of patient input are few and usually unstructured. Unreliable representations of the patient voice undermine efforts to invoke and apply patient values within healthcare delivery. A systematic approach to the acquisition of patient values regarding health is reviewed. The approach employs dynamic modeling based on a personalized ontology supporting repeatability. The model is multidimensional and expressed in the patient's own words. The structure of the model is derived by systematic solicitation using a novel combination of established tools for preference and utility assessment with unique result.

The protocol can be applied with rigor consistently to members of the same or differing populations and disease states. The protocol supports the rigor of research, experimentation, critical evaluation and changes in patient values over time through reapplication. As such, it supports the acquisition of aggregated voice populations for descriptive purposes and perhaps prediction or derived prescription based on those population studies. Finally, the systematic nature enables programmatic execution of individualized values acquisition via software and Internet technologies that capitalize on patient desire to be heard and minimize additions to healthcare provider work flow.

The challenge in education regarding the patient voice is the same as that of health care delivery itself—i.e., to first understand what the patient is saying and secondarily to ensure that what is understood be incorporated into decision making effectively. This tool extends the capacity for reliable understanding and also provides mechanics for application.

Beyond the Tick Box: Developing the Patient Voice in Learning for Service Improvement in the NHS in the UK

Presenters: Fiona O'Neill, Centre for Development of Health Policy & Practice, School of Health, University of Leeds, UK; Julie Symons, Medical Education Unit, University of Leeds and Bradford Cancer Support Centre, UK; Andrea Armitage, Medical Education Unit, University of Leeds, UK

Additional Authors: Rob Lane; Sue Power; Ernie Dalton; Penny Morris

This paper will focus on the learning needs of health service managers and leaders in relation to involving patients in service improvement activities. Although patient and public participation has been a central component of policy and there is now a statutory requirement for NHS Trusts to involve patients in decision-making at all levels of the service, progress remains slow. Involvement can be seen as a problem area for health care managers, another target to be met within a very noisy and rapidly changing policy environment. The paper will explore how managers and leaders, many of whom do not have a clinical background, can be supported to learn more about engaging with the patient voice. The paper will draw on the findings of a project, supported by University knowledge transfer funds, to develop educational approaches that facilitate managers to engage with the patient voice in a learning environment. The results of pilot work carried out with a group of 60 service improvement leaders within the local health economy will be discussed and key learning points identified.
Where is the Patient in the Standardized Patient?

**Concurrent Session 1.2.2.1**  
Room: Denman

**Where's the Patients' Voice in Health Professional Education — Vancouver, Canada, November 3-5, 2005**

**Presenters:** Nancy McNaughton, Wilson Centre for Research in Education, University of Toronto and Research Fellow, Department of Psychiatry, University of Toronto, Toronto, Canada

**Additional Authors:** Brian Hodges

**Background:** Standardized patients (SPs) are increasingly engaged in teaching and evaluation of health professionals at all levels of training across the healthcare field. Traditionally, patient scenarios portrayed by SPs are written by healthcare practitioners. Cases based on clinical experience with real patients are adjusted to both protect the anonymity of the patient, and to meet educational objectives. Both the complexity of the writing task and the clinical perspective of the writer can result in representations missing crucial affective information and patient perspectives. Clinical representations reflect values and ideas about patients engendered within the health professions. Cases that do not include the patient voice have educational implications.

**Methodology:** Standardized Patients enacting roles undercover during a day long mock psychiatry exam remained in role for one-hour interviews and between all interviews. SP responses were collected using a focus group, reflective journals, and telephone interviews and were analyzed by two researchers in a constant comparative process, iteratively reading all transcripts and journals, and discussing emerging themes.

**Summary of Findings:** Two themes emerged with respect to missing patient perspectives: “role fit” and SPs “reflection” about their portrayal while in role. SPs made up missing patient information, often using their own history. Missing details affected their response decisions. SPs perception of the role “fit” also negatively affected the SPs and their portrayals.

**Conclusion:** Details about patient stories that are not included have implications for the SP’s response decisions and portrayal of cases, and more importantly reflect clinical values transmitted in educational settings.

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**Concurrent Session 1.2.2.2**  
Room: Denman

**The Implementation of Patient Centered Care (PCC) Using Standardized Patients (SPs) in Continuing Education**

**Presenters:** Silvi Groe, University Health Network, Toronto, Canada

**Additional Authors:** Jeanne Elgie-Watson; Brenda Ridley

In 2004 University Health Network (UHN) adopted the Picker Institute’s eight dimensions as a basis for patient centered care (PCC). PCC is a collaborative partnership between patients, their families, and health care providers. It entails exploring the needs and values of patients and families and tailoring our care to meet those expressed needs and values. This leads to an enhanced experience of care for patients and their families.

Within UHN’s Heart and Circulation nursing program, an innovative strategy for implementing PCC was the utilization of standardized patients (SPs). Traditionally, SPs have been used for medical students. Nursing literature on the use of SPs in providing continuing education to nurses in a hospital setting is non-existent. SPs allow for competence development in a safe learning environment through demonstration and practice of communication in a variety of patient scenarios.

SPs enabled nurses to practice use of communication techniques drawn from Bayer Institute’s Clinician-Patient Communication model, adopted organization wide as a major initiative in support of PCC. Significant numbers of nurses found our SP program valuable.

Implications for future practice applications include incorporating SPs into educational sessions for nurses and the use of SPs for other disciplines based on the success of our program. This presentation will outline the UHN PCC Practice model, the communication model used, program evaluation, and future implications.
As with other professions, medical training is implicitly practitioner centred. At both undergraduate and postgraduate levels, it is doctors who are primarily responsible for determining the knowledge, skills and attitudes required of members of the profession. By and large, it is doctors who determine what it takes to be a “good” doctor. This is done through the content and processes of education programs and assessment. It is embedded in a culture which is reflected in the priorities of the profession; the issues that are championed by the profession’s organizations and their representatives, and by the body of knowledge it produces through its conferences and literature. It is defined by the profession’s registration and governing bodies.

The inclusion of the patient’s perspective can provide invaluable insights and challenges to the role and impact of the doctor, and thus enrich the profession. This presentation will describe the common theme of two educational interventions at the University of Melbourne. Both the Simulated Patient Program, and the Clinical/Gynaecological Teaching Associate Program provide an opportunity for medical students and doctors to receive feedback from trained members of the community on the impact of their consulting and examination skills from the patient’s perspective. This can be a powerful individual learning experience. More generally, however, the input from these representatives of the broader patient population has contributed to an ever-evolving conceptual basis for doctor-patient interactions. After all, medical practice should be a collaboration between doctor and patient. So too should medical education.

Women face numerous unique health concerns across the life span. One of these, cervical cancer, is almost totally preventable with appropriate use of the cervical cancer (Pap) test. Data indicates women with invasive cervical cancer are those who have not had cervical screening within the previous five years.

Multiple reports have outlined the many barriers women face in accessing health care even when those services already exist in their communities. A significant number of women avoid pelvic exams because of past encounters where they have experienced discrimination, pain, felt unsafe or unwelcome. A history of sexual abuse can also limit access to intimate exams. In order to enhance access to reproductive health, BC Women’s has developed a reproductive health screening program for nurses, naturopaths, midwives and nurse practitioners. Pelvic and clinical breast exam skills are taught using Clinical Teaching Associates (CTAs). This presentation will focus on the role of the CTA in training health professionals how to do these exams in a safe, respectful, effective manner. Clinical teaching associates learn to work with an in depth understanding of the procedure and their own bodies. They also receive specific training in the areas of feedback and student evaluation but no set script is provided. CTAs serve as both patient and instructor while at the same time they undergo the most intimate exam: pelvic and breast examinations.

An overview of the CTA training program and student evaluation of their work will be presented.
Creative/ Artistic Education and Communication Techniques:
A Path Towards Authentic Knowledge of Patients in Mental Health Facilities

Presenter: Gillian May, Faculty of Nursing, University of Toronto, Toronto, ON, Canada

This presentation will discuss a project by a Masters in Nursing student, conducted during a clinical placement at the Centre for Addiction and Mental Health in Toronto. The outcomes of the project led to some key ideas and understandings of the value of creative/artistic educational techniques. The student found that these techniques provided a collaborative experience that benefited both the student and the patients. Furthermore, creative/artistic techniques have implications for understanding and empowering the patients voice in education, communication, interpersonal relations and recovery in mental illness.

The project consisted of:
• 4 focus groups on 4 different units in the Schizophrenia Program
• 3 questions were posed around patient experiences with nursing practice
• An art activity that involved informal discussions during the creation of a personal recovery card.

This presentation will discuss the following:

• The unexpected outcomes of the project that greatly enhanced the student’s learning, namely:
  • Patient responses and demeanor between participating in a focus group and the art activity.
  • The types of artwork and discussions during the activity that greatly enhanced understanding of the patient’s experience.
• The theoretical underpinnings for the effectiveness of using creative/artistic modes of communication especially with patients who have mental health issues.
• A discussion of future implications for the development of creative/artistic educational techniques with an emphasis on:
  • Patient/student/staff collaboration.
  • Enhanced therapeutic and interpersonal relationships between staff/students and patients.
  • The therapeutic implications of creative/artistic communication and education techniques for the recovery movement in mental health.
Being Treated for “Free” – Should I Expect Less?

Presenter: Minha Rajput, Ninewells Hospital and Medical School, Dundee, UK
Additional Authors: S. Ray; K. Garvie; A. Angus; B. Rajput

A hospital admission is highly comparable to a hotel check in. Both are away from the home, paperwork is required to get a stay into the building. One can choose to go in electively i.e. pre planned or otherwise as emergency.

Once in, one has to adjust to the new environment and is dependant on strangers who assist in ensuring a comfortable stay. The list of similarities continues, however, there are some differences; the state of health, that individuals experience whilst in this setting within the hospital admissions most certainly comprising of unwell individuals.

Another difference, especially relevant to a health economy such as UK is that unlike a hotel, the ‘customer’ does not pay at the point of delivery. Thus, care is perceived to be ‘free’. Increasingly, there is a long waiting list to get into hospital for elective procedures (especially orthopaedic joint replacement). Just like a hotel, provided one can pay for the service these operations can be done within a matter of days at a private facility. The question that arises is – do patient’s expectations change depending on their financial contribution towards healthcare?

The patient can be a powerful ‘CCTV’ camera who can be more actively involved in health professional education. Hotels gather customer feedback forms. In a similar way by harvesting patient’s views this questionnaire based study shows clear and not so clear expectations that patients have if they were paying for care at the point of delivery.

Understanding Lived Experience of Health and Illness: Student Perspectives from Innovative Clinical Placements

Presenters: Sheryl Reimer Kirkham, Trinity Western University, Langley, BC, Canada; Lynn Van Hofwegen, Trinity Western University, Langley, BC, Canada
Additional Authors: Catherine Hoe Harwood; Landa Terblanche; Rick Sawatzky

Health professional education programs are responding to the community and population-based foci of health care by seeking to integrate strong community components in their curricula. At the same time, recent health care restructuring and cuts to community health programs, along with increased enrolments, have made the allocation of clinical placements for health professions students extremely challenging. Yet, clinical learning experiences continue as the backbone of health professional education where students bring theory and practice together (i.e., praxis) in a transition to professional practice. In the search for suitable clinical placements needed to fulfill mandated number of clinical hours, educators are turning to various non-traditional settings in a shift that is both philosophically and practically motivated.

We will present findings from a recently completed study “Innovative Clinical Placements: A Descriptive Study” (2002 – 2004, Funding WRCASN) that examined student learning opportunities for population-focused nursing care in several innovative clinical sites used by one university nursing program: parish, rural, corrections, Aboriginal, and international health settings. Findings from this study demonstrate that although these placements may require more administrative time, rich student learning occurs. Students in these placements report a heightened awareness of patients’ lived reality of health and illness and the social contexts that shaped these patient experiences. Student narratives also highlight catalysts and challenges of using innovative clinical settings and perspectives on how to maximize learning in these settings. In particular, the value of strong relationships between the academy and practice sites is emphasized.
Perception Versus Reality: Students’ Awareness of the Patient Experience

Presenters: Jennifer Vassie, Radiation Therapy Services, Peter MacCallum Cancer Centre, Melbourne, Australia; David Fox, Radiation Therapy Services, Peter MacCallum Cancer Centre, Melbourne, Australia

Additional Authors: Glenn Trainor; Kate Wilkinson

At The Peter MacCallum Cancer Centre it is our aim to maintain a patient focussed approach to the education of radiotherapy students. A recent increase in the number of our students has meant they may not all necessarily achieve the desired level of patient awareness due to work placement and time constraints. This has presented us with a challenge in providing legitimate patient experiences in our training program.

The new program we are developing has two specific patient-focussed elements.

The first element is for students to participate in an allied health week. This will involve one week designed specifically to experience the multidisciplinary pathway of the cancer patient. The aim of this is to heighten the students’ awareness of the holistic nature of treatment.

The second element is to involve the students in a patient led workshop. The primary objective being to initiate discussion regarding the students’ perceived patient experiences versus the patient’s personal narrative.

The program will be evaluated via discussion sessions held with the students before and after its implementation. If feedback were positive we would propose involvement of current radiotherapy staff in similar programs.
Local Realities of National Requirements: Involving Service Users in UK Social Work Education

Presenter: Pat Taylor, Faculty of Health and Social Care, University of the West of England, Bristol, UK
Additional Authors: Jane Dalrymple

The requirement to include service users and carers in the new social work degree represents a significant achievement for the UK service user movement. Service users are expected to be involved in all aspects of the degree, which has been described as ‘the fullest expression so far’ (Beresford and Croft, 2004 p61) of the government’s requirements for ‘user involvement’.

This presentation explores the experiences of one university’s attempts to develop a model to involve service users and carers as equal colleagues in its social work degree programme. The model is underpinned by four key principles:

- The importance of working with ‘active’ service users and those with independent sources of support. We recognised that service users and carers entering a large institution such as a university would need support both to understand the context in which they were working and support in retaining their own perspectives.
- The importance of creating space for dialogue between academic staff, practice partners and service users and carers and offering a safe environment to share experiences and develop perspectives about social work education.
- Acknowledging the need to create a sense of identity and a profile for the service users who become involved including their need for training and accessing resources within the institution.
- The need to develop a structure for our service users and carers which would give them links into the decision making groups on the programme and in the faculty as a whole.

Some of the challenges faced in the process of implementing this strategy will be described and critically reflected on.
Transforming Listening into Action

Presenters: Margaret Gallagher, Brunel University, London, UK

Additional Authors: Elizabeth Bond, Christine Craik; Sandra Naylor

The UK Government requires Higher Education Institutes delivering health education programmes to consult with the public to:

- fulfil accountability
- facilitate confidence in health services
- ensure service developments are informed by the needs of service users.

The underlying purpose of this initiative is to contribute to structural change in the delivery of services and the practice of health professionals.

Structures already exist for the inclusion of the public in the design and delivery of health care services but processes for public consultation within health care education are evolving.

Brunel University has developed a consultation process to include the public’s views in the design and delivery of the pre-registration programmes in Occupational Therapy and Physiotherapy.

The University is located within a diverse multi-cultural community. Ethical approval was given from the University to consult with community networks. The challenges of establishing an inclusive dialogue have been considerable particularly when consulting vulnerable groups or individuals.

The process focused on developing a partnership model, reflecting the diversity of London’s population. During the consultation process unexpected barriers emerged. For example, practitioners were initially concerned that their practice was being scrutinised, and preparing the public to contribute effectively proved much more complex than anticipated.

Aims of paper:
1. Present the process developed to consult with the public.
2. Consider the outcome in relation to barriers and effective approaches to collaboration.
4. Discuss the evaluation of the process so far.
Using Public Consultation to Develop Curriculum Learning Outcomes for Disability Equality Teaching in Healthcare

**Presenters:** Margaret Byron, Partners in Practice Project, University of Bristol, UK; Paul Bradley, Peninsula Medical School, Plymouth, UK

**Additional Authors:** Shekar Bheenuck; Ms Caro Howell; Claire Wickham

Partners in Practice has involved disabled people in developing a curriculum framework for disability equality teaching in undergraduate healthcare education. The Delphi Consultation process was used which is an anonymous method of achieving consensus on a controversial issue involving a group of people with very diverse opinions. Each contribution has equal weighting and anonymity ensures that no one opinion overly influences another.

Disabled people’s ideas on what health professionals should learn were gathered. 12 general themes emerged falling into 3 overarching categories – attitudes, skills and knowledge. Each theme was then subdivided into 39 specific descriptors forming the basis of the consultation document.

Participants scored each descriptor from 0 – 9 (0 = unimportant issue in a healthcare training and 9 = essential), and ranked the 12 categories in order of importance. The document existed in different formats and workshops were held for learning disabled people and British Sign Language users. Two iterations were run and over 150 participants took part. Of those descriptors that scored an 8 or 9 with 75% or more of respondents, fifteen issues were revealed to be the most important for teaching disability equality to healthcare professionals.

The top three were:

- An understanding that Deaf and disabled people with long-term conditions are often experts on their medical problems and lifestyle issues
- A recognition that different Deaf and disabled people have different needs, identities and preferences
- A recognition that not all problems have a medical solution.

Learning Lessons from Involving Patients in Research - The Folk.us Experience

**Presenter:** Rachel Purtell, Folk.us- University of Exeter & Peninsula Medical School, England

**Additional Authors:** Katrina Wyatt

Seeking the voice of patients, service users and carers in the education of health professionals and the development of health services is becoming common practice, however it is often forgotten that research is also a major activity in the health professions. It is just as crucial that patients, service users and carers have a voice in research, particularly if the aim is for research and practice to have a closer relationship. Folk.us (Forum for Collaboration with Users in Research Programme) has been funded since 2000. The aim of Folk.us is ‘to create a research culture that is meaningfully influenced by service users, patients and carers’. The project has built up a network of people, including patients, service users, academics and health care practitioners who are interested in patient involvement and in many cases are working collaboratively with patients on research projects. With our support for patients and service users to be involved in research projects, patients have played a major role in many aspects of research including, setting the questions, developing the methods by which the research is carried out and influencing what the research outcomes should be. Though involving people in research is a specific area, there are some basic principles that can be easily adapted to suit different situations, however involvement is an organic process there is not one particular way to do it. This presentation will reflect the key lessons learnt from our experience by highlighting some of the barriers and the enablers to meaningful involvement.
Proactive and Powerful - Working to Maximize our Collective Potential!

Presenters: Pamela West, Oncology and Supportive Care, Rouge Valley Centenary Health System, Toronto, Canada; Sandi Pniauskas, Whitby, ON, Canada

Additional Authors: P.J. West

Cancer is the leading cause of death.

Only on a selective basis, do cancer care communities recognize the power of patients and the role they can play in collaborating with health care professionals. Health care systems, physicians and practitioners are not ready for this change; nor are they ready to accept the patient as an equal. Consumers who question the ‘system’ are often treated with antipathy and labeled as a ‘difficult patient.’ In fact, many perceive the proactive and powerful patient as a threat rather than a welcome member of the team. The literature confirms this and, in certain segments of society, patients will be leaving health care professionals behind. The attitude, intellectual capability and knowledge of patients has changed!

Will healthcare practitioners readily lay down the gauntlet and work with, and for, the patient as a person on a level playing field? This interactive and engaging workshop will look at patient and practitioner partnerships, their evolution and success factors. It will focus on strategies of inclusion from both the patients’ and professionals’ perspective. Barriers will be hurdled to optimize the patient’s decision-making ability and to enable active participation throughout the patient’s disease and beyond.

We are preparing for the future. The future is now. We need to work together to maximize the best possible treatment, care and outcomes for patients who have walked this path every step of the way. Patients like to believe that their healthcare providers are ‘people first.’ Trust, inclusion and transparency reflect a positive environment for all parties involved.
A Council of Elders: Creating a Culture of Care

Presenter: Arlene Katz, Dept. of Social Medicine, Harvard Medical School, Cambridge, USA

“… have the young doctors come to one of our meetings; … they could look us over, and they would see that we have something to say.”
— Council of Elders member, age 103

In this age of “medical care delivery systems,” there is an increasing need for the patient’s voice to be heard, invited, listened to, and taken seriously. This is particularly so in geriatrics, a domain of medicine in which educators and clinicians alike must struggle to overcome adverse attitudes towards the elderly that are commonly called “ageism”.

Today we shall introduce our “Council of Elders”—an innovation in which we invited community elders to function as our “Senior Faculty”, to whom medical residents present their most challenging and heartfelt dilemmas in caring for elder patients. In the conversations that ensue, the community elders come to function not merely as teachers, but collaborators in a process by which doctors, researchers, and elders together create a community of resources which makes visible ways to overcome difficulties which were not apparent to either group separately. We shall discuss the special nature of such meetings, and the special preparations that are required in order to build a dialogic relationship between participants from different worlds, different generations, and different cultures, e.g., the professional culture and the world of lived experience. Meetings with the Council create the opportunity for a special kind of “open dialog” in which moral dilemmas can be presented, discussed, and reflected upon. It is not so much that the elders give good advice - as they often do - as provide orientation: young medical residents gain a better sense of the elders’ lived experience, of what mattered most to them in their local moral world.

The Council of Elders project has been particularly effective in addressing the problem of ageism—a way to render visible stereotypes and adverse values held by the world of medicine—allowing decisions to be made with the patient, not for the patient. The creation of fora in which disparate groups are encouraged to meet for the purpose of sharing resources that are unique to their own particular worlds is by no means limited to Elders and their health care providers. All ill people are to some extent “experts” on living with their illnesses, and can draw upon resources from within their own lived experiences that are unavailable to others.
Workshop Session 1.2.W3

Health Care from the Other Side: One Patient’s Perspective

Presenter: Susan Harris, School of Rehabilitation Sciences, UBC, Vancouver, Canada

As a physiotherapist with 30 years experience in health care and an appointment in the Faculty of Medicine, navigating through the complex cancer care system (1998-99) was, in itself, a full-time job. The first hour of the workshop will describe the experiences of a seasoned, health care professional patient who had to serve as her own navigator during a year that was also filled with chemotherapy, radiation, and four sets of surgeries (involving four different health care agencies and more than 40 health care providers). The lack of interdisciplinary communication among the various health care providers and the resulting information that fell through the cracks will be highlighted. Strategies for improving upon the current system will also be presented.

During the second hour of the workshop, specific strategies for assisting the patient in navigating through the health care system will be provided. These strategies should be helpful to patients, their caregivers, and health care providers - both within and outside the cancer care system. Audience participation will encourage the contribution of additional strategies for enhancing patient navigation as well as suggestions for improving upon the current lack of interdisciplinarity within cancer care.

At the close of this workshop, participants will be able to: 1) describe the role of the patient navigator within health care; 2) list 10 strategies for enhancing patient navigation; and 3) suggest additional helpful strategies based on their own experiences, as patients, caregivers, or health care providers.
Patient Narrative as a Tool to Developing Compassion

Presenters: Mary Kraft, Massachusetts General Hospital, Boston, USA; Patricia Abreu, Boston, USA

Medical school physical diagnosis courses teach students to elicit histories and perform physical examinations to diagnose patients' physical ailments. Although students may be taught interviewing techniques and wish to do the best for their patients, they cannot truly understand all factors bearing on the patient's illness unless they simultaneously analyze the patient's narrative description of the ailment and the meaning this ailment has to the patient. Rita Charon has written prolifically on this topic and parallel charting, but that approach is targeted to the longitudinal development of the student.

It is also important to come to a more immediate understanding of the patient narrative and the meaning of the illness because it enhances the patient's perception of care and develops the physician's compassion and open-heartedness, traits essential for healing (in distinction to curing).

In this workshop we will explore the actual narrative of a real patient (who may be able to attend). As Mrs. A. tells her story, participants will be encouraged to ask questions and synthesize the meaning of her illness (second degree burns of the right hand and forearm). Participants will work towards putting her experiences of her medical care into the context of developing compassion and knowing “what to say.” Participants will also be asked to analyze what is the difference (in the mind of the patient) between “just doing a job” and effecting healing.
What we have learned is what we teach - so where, how and from whom we acquire our information has a direct bearing on learning outcomes. Within this framework, the experience of the person who requires help and support has something to say and to teach that is uniquely valuable.

Making the Connection is a new training program of the Alzheimer Society of B.C. aimed at professionals who work directly in support of people with dementia in either residential or day program settings. It reflects twenty-five years of working directly with individuals and families impacted by dementia. We recognize that the best teacher is the person with dementia - nothing is a more powerful learning tool than walking a mile in the shoes of that person.

Conference participants will get to know Making the Connection - a two part program. The first part allows the trainees to experience for a very short time what it is like to have the symptoms of dementia and aging (The Dementia Experience). The second part is a workshop that gives practical advice to trainees on creative approaches to support. These approaches are based in what the Society has learned from listening to people with dementia, their family caregivers, and people working in the field.
Concurrent Session 1.3.1.1
Room: Nelson

The Implementation of a Bill Of Client Rights

Presenters: Jane Paterson, Centre for Addiction and Mental Health, Toronto, Canada; Jennifer Chambers, Centre for Addiction and Mental Health, Toronto, Canada

In December, 2004 the Board of Trustees of the Centre for Addiction and Mental Health (CAMH) in Toronto adopted the Bill of Client Rights. This Bill promotes the dignity and worth of all people who use CAMH services and was created through an extensive period of negotiation and collaboration involving CAMH staff, its Empowerment Council, # (which is composed of clients of CAMH), and many clients. This Bill sets common high standards for the treatment of all clients who use the services of CAMH.

It supports principles of empowerment that affirm the importance of the client voice in ensuring the integrity and quality of CAMH services.

Because staff have a responsibility to know and uphold the rights contained within the Bill, we have embarked on an extensive education process to familiarize staff and clients with the content of the Bill of Client Rights and the implications of this on service delivery. This education process consists of an e-learning strategy that was developed collaboratively among CAMH staff and clients. Also, all clinical teams and support services are currently receiving training on the Bill of Client Rights in sessions that are jointly conducted by CAMH clients and senior staff. These sessions occur in the teams that staff work in, in order to maximize the interaction between the presenters and staff. Each session is conducted by a pair of presenters, one CAMH staff and one client. This initiative is also being evaluated. In this session we will describe the collaborative process that led to the development of the Bill of Client Rights and the education strategy surrounding its implementation where staff and clients are partnered to deliver this training.

Concurrent Session 1.3.1.2
Room: Nelson

Building In Patient’s Voice in Daily Practice: Springboard to Improving Practice Outcomes and Accountability in Nursing Staff

Presenter: Rosanna DiNunzio, Centre for Addiction and Mental Health, University of Toronto, Toronto, Canada

Nurses must find ways to practice that demonstrates accountability, decision-making, and taking initiative accordingly. However this still remains a struggle in many inpatient hospital settings. At the Centre for Addiction and Mental Health, Toronto, Canada, the Schizophrenia Program underwent a collaborative endeavor with nursing staff and patients to review the care delivery system of Primary Nursing and facilitated a process of increasing accountability and improving practice outcomes in staff.

The collaborative approach of utilizing staff and patients in the research process and data collection allowed for the comprehensive and innovative approach to sustainable practice change. This presentation will focus on 3 recommendations that specifically ensured the patient’s voice was incorporated and documented in daily practice. These include:
1. Create 360 degree- feedback mechanisms to enhance self-reflection of staff.
2. Create mechanisms where the nurse can validate the patient perceives a “Positive attitude in every client interface”.
3. Create program standard where the patient and/or family sign and report (through the Interdisciplinary Plan of Client Care) that “Goals are accomplished through direction of the Patient”.

Primary Nursing has the potential to improve outcomes of hospital care, but will not do so without ensuring client-centered care practices. In implementing the above recommendation staff can demonstrate increased accountability, decision-making, and take initiative accordingly. This is made possible by an infrastructure to ensure the patient’s voice was incorporated into daily practice. This presentation will review process and curricula development for repositioning the role of patients in daily care.
An Interdisciplinary Approach to Improve Health Literacy in the Rural Elderly

Presenters: Jan Peeler, Western Kentucky University, Bowling Green, USA; Serena Britt, Western Kentucky University, Bowling Green, USA

Additional Authors: Marilyn Gardner; Susan Jones

Health literacy is a growing concern in health care delivery and education. Research indicates that health literacy is directly related to health outcomes, length and frequency of hospitalizations, and health care expenditures (Kovner & Harrington, 2000; Davis & Magilvy, 2000). The frequency of chronic illnesses in the elderly (Parker, 2003) and the decrease in health literacy skills in the elderly, target this population as a vulnerable group in health literacy.

In order to address the important need in the underserved, rural elderly populations of south central Kentucky, an educational intervention program was developed by an interdisciplinary group of faculty from the departments of nursing, social work, and public health. Funded by the Office of Rural Health Policy, Health Enhancement for the Rural Elderly (HERE) was created with the conceptual design being to enhance the health of the rural elderly through empowering them with increased health literacy. The increased health literacy results from the implementation of the multidimensional advocacy program that includes the development of area specific health resource guides, the implementation of educational modules, and the distribution of educational videos and brochures. Throughout this process, an advisory board with community members in various health related professions and students from various fields worked together with the faculty in its intervention process.

Health resource guides were developed and distributed to two rural counties in south central Kentucky. Record keeping, monitoring, and qualitative data were used for process evaluation purposes. Inferential statistical analyses were employed to explore relationship between variables and to determine the effectiveness of the various programs. Twenty-nine rural elderly residents of Butler County, Kentucky and forty-five from Edmonson County, Kentucky were recruited and participated in the implementation of educational modules designed to increase their health literacy. Initial evaluations indicate a positive experience for the participants, students, and faculty. Immediate feedback from the participants indicates an increase in health literacy. While there were no differences between treatment and control groups, there were differences with education levels. Those that were less educated were: more trusting of physicians and more embarrassed with reference to discussing health concerns. Treatment participants reported feeling significantly less confused by medical health insurance forms but didn’t feel less in need of help to fill them out.

The current medical educational system inadequately prepares students for interdisciplinary collaboration (Fineberg, Wenger, & Forrow, 2004). Despite the crucial need for healthcare professional students to learn interdisciplinary collaboration (Ehnfors & Grobe, 2004), very few schools for health professionals include any interdisciplinary experiences, either classroom or clinical, as part of their course work (Larson, 1995). Thus, in order to prepare future health professionals to function effectively in an interdisciplinary health system, educational programs must also be redesigned. Through revision, these programs are to be responsive to and address the previously mentioned challenges and obstacles to an interdisciplinary health care setting. Interdisciplinary educational programs that have been tested empirically within health professions have yielded positive results including increased role understanding and respect for other disciplines (Buck, Tilsen & Andersen, 1999; Fineberg, et al., 2004; Mogensen, Elinder, Widstrom & Winbladh, 2002). Additionally interdisciplinary experiences have been shown to improve understanding of the health care delivery system and have a positive impact on the students’ professional performances, patient interactions and health career preparation (Buck, et al., 1999). Thus exposing the session participants to an interdisciplinary model meant to improve health literacy can be beneficial to those that may work in a health care related profession.
Patient Empowerment Through e-Health Approaches - An Empirical Analysis of Barriers and Drivers

Presenter: Karl Stroetmann, Empirica Institute for Communications & Technology Research, Bonn, Germany

Additional Authors: Veli N. Stroetmann; Kevin Cullen; Alexander Dobrev; Tobias Huesing

Introduction: Deployment of eHealth services to involve patients has been primarily guided by technological possibilities rather than understanding their widely differing needs. A real partnership and more client autonomy requires an evidence-based paradigm shift.

Method: A comprehensive model was developed of eHealth related interests, needs and activity patterns, user characteristics and requirements, health service access mode preferences and contextual factors. From this, hypothesis development and their translation into empirical measures/questions followed.

A multi-country population survey (10 EU Member States, 9,800 interviews) on eHealth as a means for informed choice, shared decision making, greater patient autonomy and proactive interaction with health professionals was conducted. An extensive set of demographic variables was collected.

Results: The analysis identifies main barriers to integrating the patient's voice into health services. The low level of ICT use among patients lies at the heart of relatively low levels of electronic communications – in spite of strong interest in access to health records and bilateral exchanges.

Where used, eHealth strongly contributes to patient empowerment. However, the incentives for allowing the patient's voice to become part of the healthcare process seem limited. Improving user-friendliness, taking into account the needs of various at-risk groups, is mandatory.

Conclusions: Patients have shown a strong desire for contributing to healthcare processes. The patient’s involvement in health professional education can be twofold: indirect – professionals need to be informed about patients’ autonomous action habits (developments should be part of the curriculum); and direct – a regular two-way ICT based exchange of general information, specific knowledge and information sources will benefit both professionals and patients e.g. through information quality control.
Empowerment as Treatment and the Role of Health Professionals

Presenter: Penny Powers, Thompson Rivers University, Kamloops, Canada

The speaker presents the argument that the concept of “empowerment” has been co-opted by health professionals and re-defined as an intervention to produce compliance. Empowerment as it is taught to social agents such as nurses, pharmacists, physicians, psychologists, social workers, etc. is a coercive strategy that is justified by its outcomes. Health professionals, as a result of their extensive education, believe they are performing a service by empowering individuals to make correct choices in their lives. Patients are considered empowered, however, if and only if they make the correct choices as defined by the health care provider. For their part, people who are the targets of empowerment strategies are provided with the illusion that they are being given all of the information necessary to make free and informed choices. Instead, the choice is pre-determined and supports the worldview and ideology of the health care system in a capitalist economy. The process of empowerment as it is practiced in the health professions is a technology of the self which results in the dependency of individuals and populations. The case of empowering marginalized populations will be analyzed.

Education for Empowerment of Breast Cancer Survivors: Ensuring a Voice

Presenter: Scott Secord, Princess Margaret Hospital, Toronto, Canada

Additional Authors: Audrey Friedman; Joyce Nyhof-Young; David Wiljer; Pamela Catton

Cancer is a life altering and emotionally debilitating experience. There is an identifiable gap in the patient care experience that demonstrates the need to consider where the patient perspective fits in. Princess Margaret Hospital (PMH) is developing a Breast Cancer Survivorship Program, with the goal of ensuring that the patient’s voice is an integral part of their treatment plan. The model will focus on what support looks and feels like to them through individualized survivorship plans.

Confidence and knowledge to ask questions and utilize support can help reduce the negative impacts of disease. Participation in the ‘Education for Empowerment’ curriculum will allow patients to gain knowledge, locate resources and learn from the collective wisdom of survivors.

The pilot program will be delivered using an innovative collaborative partnership model including peer survivors, community cancer organizations and stakeholders at PMH involved in patient education and clinical programs. Patients will be offered a series of courses with the aim of creating a more empowered survivor. Program evaluation will examine key areas of knowledge, coping skills acquisition and any changes in how survivors perceive their sense of self-confidence and preparedness.

Participation in the Program will optimize the well-being of survivors, increase knowledge, skills and confidence to self-advocate and care for themselves. Improved navigation of the health care system will result in improved access to appropriate support and follow-up. We will share the steps taken in program design and the pilot implementation process.
Concurrent Session 1.3.2.3  
Room: Denman

Preoperative Education: Maximizing the Learning Potential

Presenter: Nicola Spalding, University of East Anglia, Norwich, UK

Preoperative education is widely used by healthcare professionals throughout the world to help patients prepare for a hip replacement. Many beneficial health and wellbeing outcomes have previously been demonstrated through quantitative research, but there is little research which includes the patients’ perspective.

The purpose of this study was to gain an understanding of patients’ experiences of preoperative education and how it affects their health and wellbeing. By elucidating the patients’ perspective on the process and outcome, future programmes could be tailored to maximise its effectiveness.

An action research case study was undertaken in one National Health Service Trust in the United Kingdom. Data were collected over one year from written patient evaluations, interviews with patients, and with patients’ spouses. The interviews took place immediately after attending a preoperative education programme and also within a week following surgery. From the data, vignettes were compiled portraying patients’ experiences. These were used by the multidisciplinary team who delivered the programme to understand more of the educational processes, reflect on their current practice and plan improvements.

Rich narrative data were obtained from patients. The vignettes enabled the multidisciplinary team to appreciate a different perspective to their own lived experience. Subsequent analysis of themes identified the empowering potential of preoperative education. Empowerment is achieved by building patients’ trust and confidence through preoperative educational processes. Trust and confidence can ensure that patients take greater control of their health and well being. Consequently, many improvements were made in respect of the programme to maximise the empowering potential.

Concurrent Session 1.3.2.4  
Room: Denman

Patient Education Prescriptions: Tailored Health Information, Cultural Translations, and Community Learning Networks

Presenters: Robert Luke, Princess Margaret Hospital, Toronto, Canada; David Wiljer, Princess Margaret Hospital, Toronto, Canada

Additional Authors: Lynda Atack

This paper reports on a current project exploring how advanced technologies can work to deliver tailored information (educational prescriptions) to patients. Information is prescribed to patients within customized educational programs, accessed online within Community Health Care centres, hospital clinics, physicians’ offices, Long Term Care facilities, community pharmacies, in the patient’s home or other healthcare settings. Two community groups are working with us in the materials development processes to create culturally relevant and appropriate online material in a variety of languages. These “cultural translations” of clinical education material enable community participants to learn new skills in creating online educational media, and be able to see themselves as active and engaged participants in determining their own health and in fostering better community health overall. In addition, materials are made adaptable for people with various disabilities so that the widest possible reach is achieved in the provision of clinically reliable patient education materials. We are measuring the impact of these tailored educational prescriptions on levels of empowerment, compliance with disease management directives, and the effects of community learning on patient satisfaction. We hypothesize that patients will be better able to learn how to manage chronic illness by accessing educational programs in their language of choice, and adaptable for any disabilities. This form of patient education will empower patients more so than with the provision of traditional educational materials, and will further reinforce active learning and the acquisition of digital literacy skills commensurate with using information and communications technology.
**Patient Participation and the Use of Multiple Methods to Research and Teach Student Nurses: Results from an Exploratory Study**

*Presenter: Aled Jones, School of Health Science, Swansea University, West Glamorgan, UK*

This small, multi-method, exploratory study was designed to evaluate the learning and teaching of patient centred interpersonal skills within an undergraduate nursing programme in the UK. An innovative approach to the study design included collecting both quantitative and qualitative data from 4 different sources.

**Phase 1** – Interactions between student nurses and patients were tape recorded, transcribed and analysed using conversation analysis (CA) techniques. The interactions were also subjected to non-participant observation.

**Phase 2** – A total of 10 patients completed a 14 point questionnaire asking the patients to agree or disagree with questions regarding the students’ interaction skills.

**Phase 3** – Examples of transcripts and tape recordings of nurse-patient interaction were used as a teaching aid during group work focussing on communication/patient participation. The students were asked to evaluate the usefulness of using research data during such teaching.

**Results:**

**Phase 1** - Demonstrated a “task-centred” approach to interaction by students resulting in an administrative, rather than patient-centred, approach to communication. It was also noted that the students’ posture and other non-verbal skills restricted the patients’ participation at key times of the interaction.

**Phase 2** - The patients’ questionnaire demonstrated broad satisfaction with the student nurses’ communication skills.

**Phase 3** - The use of the research material as a learning and teaching resource resulted in students (n=48) evaluating the group sessions as “very helpful” (n=47) or “helpful” (n=1) in learning about patient-centred communication and barriers to participation.

**Conclusion:** The multi-method approach used during this study has contributed greatly to the development of patient centred practice in the undergraduate nursing curricula and importantly from a variety of perspectives e.g. theory, research and patient views.

**Teaching Partnerships: Using the Ages and Stages Questionnaire to Validate Parents’ Knowledge**

*Presenter: Pam Nicol, Faculty of Medicine and Dentistry, University of Western Australia, Perth, Australia*

A survey of final year undergraduate medical students found that only 45% felt confident in performing a developmental assessment on a child. Yet, this is a core curriculum outcome. The objective was to plan, implement and evaluate an experiential student-centred program that will increase fifth year undergraduate medical students’ confidence to assess the growth and development of a child and their participation in learning in partnership with the parents. A ‘Parents-as-Teachers’ student-centred program was implemented using a parent-completed, child development early detection system, the Ages and Stages Questionnaire (ASQ). The program was designed using a social constructivist epistemology and involved the students and the parents completing an assessment of the child’s growth and development. The students were asked to reflect on the two methods and the process. Descriptive and interpretative analysis was made of the reports subsequently written by the students. There was a 70% agreement between student assessment and the parent’s assessment. Key themes to emerge from the interpretative analysis demonstrated students benefited from this program. Students valued the experiential structured learning; they increased their confidence in developmental assessment and their awareness of the value of a partnership with parents. However, some students continued to doubt the reliability of parental report. The parents perception of their role and of the students’ competence is currently being evaluated. The results may be used to develop an interdisciplinary program to include nursing students that is relationship rather than student centred.
A Collaborative Approach to Learning Shared Decision-Making

Presenters: Beth Lown, Harvard Medical School, Mt. Auburn Hospital, Carl J. Shapiro Center for Education and Research, Cambridge, USA; Janice Hanson, Uniformed Services, University of the Health Sciences, Department of Pediatrics, Bethesda, USA

Objective: This educational study investigated attitudes and behaviors for shared medical decision-making and measured changes in participants’ self-assessed attitudes and abilities.

Participants: The study included 41 (20 women, 21 men) experienced primary care physicians and 44 (30 women, 14 men) patients with chronic medical conditions.

Methods: Each of four focus group/workshop sessions incorporated a mini-didactic dialogue in patient/physician pairs about past experiences with medical decision-making, generation of written descriptions and preliminary categorization of patient and physician attitudes and behaviors that facilitate shared decision-making, and small group development of implementation strategies. A retrospective pre/post, Likert scale questionnaire was administered after each workshop.

Results: Response rate was 82/85 (96%). Dependent t-test analysis showed no change in physicians’ but significant change for patients’ pre and post-workshop self-ratings for expressing preferences when there is more than one treatment choice. Pre- and post-workshop ratings by physicians and patients on five other statements changed towards agreement (p<0.05 to 0.001.) Items were: “The patient and physician should discuss together how a decision will be made when there is more than one treatment choice;” “I can describe the skills involved in shared decision-making;” “I feel confident in my ability to collaborate in making treatment decisions;” “I feel motivated to collaborate in making treatment decisions;” “I can implement the skills involved in shared decision-making.”

Conclusions: An educational workshop that engages patients and physicians in collaborative dialogue resulted in enhanced ability to describe attitudes, behaviors and strategies to facilitate shared decision-making and confidence and motivation to implement them.
Service User Involvement in Postgraduate Mental Health Education

Presenters: Richard Khoo, Institute of Health and Social Studies, Anglia Polytechnic University, Chelmsford, UK; Andy McVicar, Institute of Health and Social Studies, Anglia Polytechnic University, Chelmsford, UK

Background and Aims
The involvement in education of people who use health and social care services, and their carers, has been called for (Department of Health 1994; NHS Executive 1996). This primarily has occurred in undergraduate education (English National Board for Nursing, Midwifery and Health Visiting 1996), yet the focus of postgraduate study on innovation, professional growth, and service development might more likely be anticipated to have a positive impact on practice. Few universities involve service users in the presentation of postgraduate mental health education. This retrospective study evaluates their impact on students within a university that has done so for several years.

Method
Questionnaires were sent to all students who had completed Masters-level modules that had substantial service user involvement. All students were experienced practitioners, and currently employed. The modules, and courses of which they are a component, were designed in 1993/94 by educationalists and senior representatives of user groups, and continue to be managed and monitored by personnel who include user representatives. 26/41 questionnaires were returned and 10 of these respondents were also later interviewed by telephone to elaborate on their responses.

Results
All respondents were either enthused (21% of questionnaire returns) or very enthused (79%) by the user contributions; none considered their involvement was poor. Many felt challenged by the user contribution, and a majority (87%) felt that they had benefited personally and professionally from the involvement of service users in the programme. Most (64%) reported improved collaborative working as a consequence of the programmes, and significantly from the perspective of postgraduate study outcomes and practice development, reported that they had implemented user-focused initiatives in their practice as a consequence of undertaking their studies.

Conclusions
The findings suggest that a contribution by service users to postgraduate programmes can motivate practitioners to implement changes to their practice in innovative ways.
The Case of the Missing Letter in IECPCP

Presenters: Yhetta Gold, Winnipeg, Canada; John Gilbert, College of Health Disciplines, University of British Columbia, Vancouver, Canada

What role is there for the patient in “Patient Care”? How is the health care professional trained to listen to the patient? Is this an issue? Should there be a collaborative effort to involve the patient in his/her own care? The Interprofessional Education for Collaborative Patient Centred Practice (IECPCP) initiative is a federal led program to address the health human resources crisis and patient involvement concerns in Canada. It is one component of a pan-Canadian health human resources strategy. IECPCP, with partners, wants to change the way health providers are educated.

We want to assure the active participation and collaborative involvement of several health care disciplines and professions. Improvement should be evident in population health/patient care, patient safety and improved communication and satisfaction by both patients and providers. Through opportunities for research and implementing of best practices, within a conceptual framework, significant data will be available to education systems for health professionals. There is a process to provide 20M in learning and teaching projects across Canada. Nevertheless a fundamental issue remains. How does the patient become an effective decision-maker in the whole initiative? This question will be answered through the IECPCP program in the variety of ways that are appropriate for the diversity of patients across Canada.

Education for Partnership: How Can Doctors Learn to Engage Patients?

Presenter: Alison Chisholm, Picker Institute Europe, Oxford, UK

Author: Andreas Hasman

Patients’ expectations of their doctors are changing. Many patients now want more choice of treatment, more information about options available and more direct involvement in decisions relating to their treatment. They want a more engaged role in their own healthcare – in partnership with their doctors.

Medical education plays an essential role in developing, disseminating and reinforcing good medical practice. This study asks whether current training programmes (e.g. communication skills training) are effective in equipping doctors to facilitate patient engagement. 21 interviews were carried out with key decision-makers in medical education and training in the UK to identify key themes and issues. Interviewees were drawn from medical schools, postgraduate deaneries, Royal Colleges and other regulatory bodies. Based on the outcome of the interviews, electronic databases and key publications were systematically searched for studies (published in English between 1995 and 2005) on the effectiveness of educational programmes or interventions that build doctors’ ability to engage patients.

The search identified six relevant systematic reviews and two randomised controlled trials. Although these studies provided some evidence that existing educational programmes improve certain aspects of medical practice, the efficacy and efficiency of such programmes, as means to patient engagement in health and healthcare, was not evident. Medical educators need a stronger evidence-base in order to make informed changes to the way in which medicine is taught and learned. Future research should aim to provide systematic evidence on patient-centred outcomes of medical education, and on the comparative impact of different programmes.
Concurrent Session 1.3.4.3                   Room: Beach

Enhancing Ethical Practice in Prenatal Screening: An Educational Imperative

Presenter: Eleanor Milligan, Centre for Social Change Research, Queensland University of Technology, Brisbane, Australia

Informed consent, based on patient autonomy, is seen as anchoring medical intervention to ethical acceptability. While ‘informed consent’ forms have become an established part of antenatal care, emerging research suggests most women do not understand the purpose or implications of the procedures ‘consented’ to. Hence, the assumption that consent equates to the appropriate knowledge and understanding required for ‘informed’ engagement evaporates and the ethical integrity of such intervention unravels.

As the process of becoming ‘informed’ to consent is essentially educational, the importance of learning in the clinical context is critical. However, there is limited awareness at either a practical or theoretical level of education being the fundamental pre-requisite to ethically robust intervention. While the ethical agenda holds ‘informed’ consent to be the benchmark of ethicality, the significance of learning in preserving moral integrity is given insufficient weight by current protocols and the link between sound educational practice and ethical probity remains unacknowledged.

The observed breakdown in learning may stem from a failure to recognise the complexities of cognitive processes in bioethical practice. The transmissive learning pedagogy adopted clinically cannot accommodate the patients’ existing knowledge, historical or interpretive frameworks, thus, cannot provide a suitable platform to support the deeply relational and embedded nature of learning identified by cognitive learning theory.

This paper seeks to briefly describe current clinical protocols, explore the shortcomings of the transmissive learning model, then sketch the complexities of the pedagogical task ahead, given the personal, social and institutional constraints that exist. As educational failure translates into ethical failure, addressing this problem becomes, firstly, an educational imperative.

Concurrent Session 1.3.4.4                   Room: Beach

The Knowledge Economy and Health Care: A Usurping of the Patient’s Voice?

Presenter: Florence Myrick, Faculty of Nursing, University of Alberta, Edmonton, Canada

Additional Authors: Deborah Tamlyn

Over these last three decades we have witnessed, if at times unwittingly, a major shift in the direction of health care, a shift that concurs with a change in the political climate. Indeed, one might say that we have been swept into the vortex of a neoliberal politic in which market justice prevails. In keeping with this wave of change, unfortunately, we have also experienced what can only be described as the erosion of the health system. A system that was once based on a social justice model that was patient-centered and designed for the common good, has thus become transformed into one that reflects a market justice influence, one in which health is increasingly becoming a commodity and not an individual right. Many who seek health care are required to wait inordinate periods of time to be attended to in emergency departments, and when admitted are frequently required to lie on a stretcher in an open corridor, in public view, for days at a time. Once considered an appalling occurrence has alarmingly become the norm. The authors discuss the impact of this trend toward a knowledge or market economy approach to health care and within that context explore how such an influence is rendering silent the patient’s voice. Strategies are discussed for policy development and solutions are explored. Questions are raised as to how health care professionals can begin to make a greater impact on policy decision making.
The Comensus Project: Community Engagement and Service User Support

Presenters: Lidia Koloczec, Comensus Project, University of Central Lancashire, Preston, UK; Lisa Shoja, Comensus Project, Faculty of Health, University of Central Lancashire, Preston, UK; David Liberato, Comensus Project, University of Central Lancashire, Preston, UK; Nat Solanki, Comensus, University of Central Lancashire, Preston, UK

Additional Authors: Mick McKeown; Soo Downe; The Comensus Team

This workshop will describe the work of the Comensus Project, including preliminary research findings, and pose questions for discussion relating to emerging themes.

The Comensus Project has been established in the Faculty of Health at the University of Central Lancashire, UK to promote systematic involvement of health and social care service users in the complete range of Faculty enterprise, including teaching and learning, research and strategic development. The project is about both development and evaluation, and involves elements of systematic literature review, mapping of relevant activity, and action research cycles. Complimentary research is addressing the important issue of value in this context. Three broad objectives are:

1. To map relevant Faculty work in involving service users, identifying strengths and weaknesses, and to undertake a systematic review of published literature on systematic approaches to user involvement in higher education.
2. To develop a forum for engaging a diverse group of health and social care service users in productive discussions and debate about relevant Faculty activity, affording a degree of influence and working towards realising reciprocal exchanges between community and university resources.
3. To build upon partnerships with community and voluntary sector groups to bid for funds to establish a social enterprise initiative aimed at providing employment opportunities for individuals who can contribute to teaching and research from a service user perspective.

The Comensus Project is a work in progress. Its development raises a number of issues pertinent to the conference themes regarding well-being, equalities, and empowerment. The workshop participants will be encouraged to discuss emerging ideas from our work, including:

- What do we mean by service use and service users as descriptive terms? And what are the implications for sense of identity?
- What is the social and material value attached to the enterprise of user involvement? For individual service user participants? For participating university staff? For the Faculty as a whole?
- What contribution is made to individual and collective well-being associated with solidarity and partnerships? And what are the threats to this?
Empowering Educators and End-Users: The Use of PAR (Participatory Action Research) to Foster Collaborative Health Education and Research with Six First Nations Communities

Presenters: Verlé Harrop, Institute for Information Technology, e-Business e-Health National Research Council, St. John, Canada; Sharon Mah, Communication Studies, University of Calgary, Canada; Angela Nash, Fredericton, Canada

Additional Authors: Kendall Ho; Mamoru Watanabe; Jennifer Sterling Pierre

eUSER Can, a CIHR funded project, 2004 - 2005, evolved out of the European Commission SIXTH FRAMEWORK PROGRAMME PRIORITY 1.1.2 Information Society Technologies Project. eUSER Can was led by University of British Columbia, with co-investigators, NRC IIT e-Health and University of Calgary.

In each of the three provinces, researchers worked collaboratively with two First Nations communities using Participatory Action Research (PAR) methodology. The goal of eUSER was twofold: 1) to investigate end user health issues and 2) to assess the integration of information communication technologies in First Nations communities.

PAR, based in the constructivist paradigm where knowledge is formulated between researcher and participant researcher, enables research to focus on the needs of the First Nations communities, while developing research capacity in the communities (McNiff, 2002). The National Aboriginal Health Organization (NAHO, 2003) advocates the use of PAR in First Nations communities and it has been successfully implemented (Routledge/Falmer, 2002).

Panel members will answer the following questions:

1. What is PAR?
2. Is PAR an effective tool for mutual engagement of First Nations communities and researchers in acute interventions, chronic disease management, prevention and wellness?
3. Is PAR an effective educational strategy for engendering collaboration and overcoming barriers between health professionals and First Nations peoples?
4. What other methodologies (such as narratives) would complement PAR in ensuring respectful community engagement and meaningful input from First Nations communities?
5. Will PAR reposition the role and increase the voice of First Nations communities, individuals and patients in health professional education and research partnerships?
How Can I Help You Today? Learning from Expert Patient Teachers

Presenters: Andrea Armitage, University of Leeds, UK; Chris Essen, University of Leeds, UK; Julie Symons, Simulated Patient Medical Education Unit, University of Leeds, UK; Shelley Fielden, Medical Education Unit, University of Leeds, UK; Sam Samiciuk, School of Health Care, University of Leeds, UK; Fiona O'Neill, Centre for Development of Health Policy and Practice, University of Leeds, UK; Rob Lane, Medical Education Unit, University of Leeds, UK; Penny Morris, Medical Education Unit, University of Leeds, UK

Additional Authors: Gill Bowskill

Improving care for people who have long term conditions is a key priority in many health care systems including in the UK. Policies, including the Department of Health sponsored Expert Patient Programme, highlight the need for education and support so that health professionals are prepared to enter into active and productive relationships with patients. This workshop will outline a collaboration between colleagues in the Faculty of Medicine and Health and a group of individuals who have a long term medical condition. We will share our learning from the project and demonstrate how this collaborative approach helped both the faculty team and the patients learn and how this learning is informing the development of teaching methods and materials that engage with the patient voice in an authentic and ethical way.

The workshop will include a demonstration of a scenario developed by the group that is used in teaching using a simulated patient model and will focus on the importance of recognising the fluid and ever changing nature of living with a long term illness that is often described using the metaphor of a journey.
Difficult Discussions in the Neonatal Intensive Care

Presenters: Dorotha Graham Cicchinelli, Colorado Pregnancy & Newborn Loss, Parker, USA; Mary Cohn, Denver, USA

THE GOOD NEIGHBOR MENTORING PROJECT: CREATING A WEB OF SUPPORTIVE RELATIONSHIPS BETWEEN FAMILIES AND MEDICAL STUDENTS

Patients and their caregivers serve as mentors in this first year medical school class that introduces students to relationship-centered care and the biopsychosocial model of care. We have teamed up with a community agency, Caregiver Companion, that provides respite care services to disabled persons being cared for at home. Students make home visits where they provide respite for a total of 10 -15 hours during the course of the semester in this service learning course. Small group support is provided to the students every other week where we discuss formal relationship building skills and skills of medical observation, empathic listening, supportive touch, and the importance of the service ethic in medicine. Students have reflective writing exercises; teach a health topic to the neighbor; and learn that patients will be some of their most powerful teachers. Neighbors and caregivers find in the students a listening ear and able-bodied assistance with chores or going to appointments. Caregivers are also given the gift of respite from their caregiving duties for a few hours. Students gain insights into the strengths needed to deal with chronic ailments; the devotion and importance of caregivers; medical/health literacy challenges; and the importance of longitudinal relationships in health care. The goal for the semester is to form a respectful relationship with a family in need of care. It is a cornerstone skill for all health care providers and appropriate to introduce in the first semester of medical school. Home visits are a powerful educational medium.
Optimising the Contribution that Patients Can Make as Teachers of Health Professionals

Presenters: Ruth Chambers, Faculty of Health & Sciences, Staffordshire University, Stoke-on-Trent, UK; Sara Buckley, Faculty of Health & Sciences, Staffordshire University, Stoke-on-Trent, UK

Aim: To explore models of empowering patients to act as effective teachers for health professionals.

Objectives:
• To share ways of enabling patients to learn basic skills in teaching and working with health professionals.
• To explore ways for patients to use their experience as a patient or carer in teaching health professionals about care they provide or services they deliver.

Format of workshop:
• We will share our experiences of involving patients as teachers in several settings (i) as a patient cohort working alongside a class of specialised nurses, physiotherapists and occupational therapists: providing perspectives, teaching eg patient literacy or self-management, influencing local service delivery planning; (ii) contributing to teaching on clinical audit to health professionals; (iii) enabling individual patient contributors to participate on the plenary podium of a healthcare conference.
• Workshop participants contribute their experiences.
• Workshop task: participants plan how to prepare and support patients as teachers for health professionals in two set scenarios.
• Plenary round up and discussion of workshop tasks.

Outcomes of workshop:
• Enhanced understanding of different ways of involving patients as teachers of health professionals: lecturing, small group facilitators, buddies, focus group participants, influencing the curriculum, co-students etc
• Increased understanding of the preparation and support necessary for patients to be enabled to act as effective teachers.
• Each has individual plan to recruit, prepare, support and involve patients as teachers in their own workplace.
Parallel Plenary Session 2.1.1.1  Room: Nelson

People with HIV as Educators of Health Professionals

**Presenters:** Patricia Solomon, McMaster University, Physiotherapy Program, Faculty of Health Sciences, Hamilton, Canada; Deborah Stinson, The AIDS Network, Hamilton, Canada

**Additional Authors:** Dale Guenter

The objective of this qualitative study was to evaluate the impact of being trained and utilized as educators of health professionals on people living with HIV (PHAs). This study also sought to understand the challenges and benefits of conducting a training program with PHAs. In collaboration with the local AIDS service organization, 7 PHAs were trained as “resource tutors” for a problem-based learning (PBL) environment. The training program sought to help them understand the pedagogical approach of PBL, to deal with difficult situations and questions, and to learn to facilitate reflection and discussion in a small group tutorial setting. The resource tutors participated in either tutorial or role play sessions with occupational therapy and physiotherapy students, and family medicine residents. Resource tutors kept a reflective journal during the training and educational sessions and participated in semi-structured interviews at the end of the project. The journals and interviews were analyzed through content analysis using an open coding technique. Themes were generated from the coding categories that reflected common experiences. Results showed that there was a positive impact on the resource tutors’ teaching skills, personal awareness, understanding of HIV, confidence in teaching and everyday life. Resource tutors experienced challenges related to understanding the terminology used in the sessions and were surprised at the extent to which they encountered stereotyping among the learners. Learner feedback indicated that they valued their interactions with the PHAs. This model of education has the potential to positively benefit patients living with a variety of illnesses and disabilities.

Parallel Plenary Session 2.1.1.2  Room: Nelson

Talking Cancer: Involving Patients and Carers in a Pre-Registration Nurse Education Programme

**Presenter:** Alison Clark, Nottingham School of Nursing, University of Nottingham, Queens Medical Centre, Nottingham, UK

**Additional Authors:** Glenys Shaw; Toni Flanagan

The word cancer still evokes fear in most people; it is associated with feeling stigmatised, pain, disfigurement and more importantly impending death (Hall BA 2003, Shaha Cox CL 2003, Maliski SL, Ramfelt E, Severinsson E, Heilemann MV, McCorkle R 2002, Bowes DE, Tamlyn D, Butler LJ 2002, Landmark BT, Strandmark M, Wahl AK 2001). In some cultures the word cancer is shunned; people hide the fact that someone in their families has/has had cancer (Dein 2004). Some Cancer is survivable - yet the cancer survivors’ story is rarely heard. This means that “having cancer” is seen as “bad news”. This paper will discuss an initiative to involve cancer patients, and their carers, in facilitating learning of students within an oncology component of a diploma in nursing education programme. The aim of the session is to foster a more positive outlook on cancer and approach to working with cancer patients, and their carers. Patient and public involvement is now a central issue to the development of current health policy and health action (Department of Health 2000). In working with members of various cancer groups the lecturer facilitated patients and carers to design and deliver an interactive classroom teaching session for nursing students to openly discuss cancer. The paper will address issues around working with patients and or carers to design educational events for students and then setting up a safe learning environment. A student and one of the patients have already presented their experience of this kind of educational activity, with the author, at the Royal College of Nursing 2004 Cancer Nursing Conference, and at a Sociology of Cancer Seminar at Warwick University 2004. The author would now like to share this experience on an international basis and explore relevant learning theory and its application to practice e.g. Lave and Wenger 1991.
Joint Learning: Musculoskeletal Education through Patient Partners

Presenter: Anne Lyddiatt, Patient Partners in Arthritis, Ingersoll, ON, Canada

Additional Authors: Mary Bell; Isabelle Simoneau

Patient Partners in Arthritis was established in Canada in 1995 as an adjunct to the musculoskeletal curriculum and is now used in thirteen of fifteen Canadian medical schools. The mission of the program is to improve healthcare given to people with arthritis. People with classic rheumatoid or osteoarthritis master musculoskeletal anatomy, physical examination skills, and communications methods that enable them to interactively demonstrate a musculoskeletal physical examination to health professionals and trainees.

The validity of the program was established by scientific evaluation at the patient, provider, and system levels and clearly demonstrated that people with arthritis can learn, and teach the physical examination and improve the skills of health professionals and trainees. Patient Partners benefit from program involvement through increased self esteem, improved communication with health professionals, social support, giving back to their community and advocacy mobilization. Health professional educators can extend their reach to more learners and provide the opportunity of practice and reinforcement of basic learning to their students by incorporating patient educators.

The Patient Partners in Arthritis program participants have been incorporated into undergraduate and postgraduate curricula in Faculties of Medicine, Nursing, Rehabilitation Medicine, and Pharmacy across Canada. They participate regularly in interdisciplinary continuing professional development activities such as the Getting a Grip on Arthritis project.

The Patient Partners in Arthritis program has improved interprofessional collaborative practice by empowering people with arthritis with the knowledge to facilitate behaviour changes in practicing health professionals and trainees.
Teaching with Parents and Patients in Medical School

Presenters: Janice Hanson, Departments of Pediatrics and Family Medicine, Uniformed Services, University of the Health Sciences, Bethesda, USA; Carolyn Jordan-Alexander, Clarksville, USA

Additional Authors: Virginia Randall

Objectives: 1. To elicit descriptions of competencies parents and patients find helpful in physicians. 2. To work with parents, patients and faculty to develop activities for medical education. 3. To implement these activities.

Methods: Focus groups, interviews and collaborative working groups with parents, patients and medical school faculty.

Results: Qualitative analysis identified competencies regarding self-awareness, communication, shared medical decision-making and advocacy. Collaborative working groups developed and implemented these six activities:

- Teaching Advocacy with Patients and Families: Parent-and patient-advisors work intensively with small groups of students regarding advocating for patients and families.
- Home Visits: Medical students visit people at home to discuss views about healthcare, observe the resilience of people who face health challenges, and enhance understanding of resources and interventions that help people live with disabilities in home and community environments.
- Medical Ethics with Parent Collaborators: In a bioethics course, discussions with parents put a human face on ethical decision-making in healthcare.
- Parent Presentations about Developmental Disabilities: Pictures, stories and a question/answer session translate diagnostic criteria into experiences from the lives of children and families.
- Case-based Learning with Parent Co-Teachers: One-hour sessions engage medical students with parents to address pediatric development and the approach to a pediatric interview.
- Research with Patients and Families: During a month-long elective, students construct a research project with a patient- and family-advisory group as the major resource.

Conclusions: Parents and patients delineate competencies that parent- and faculty-collaborators can translate into curricular activities in which students develop medically-relevant understanding of the context of children’s lives.
Patients and Families Assessing Medical Students’ Communication

Presenters: Kathy Zoppi, Indiana University School of Medicine, Indianapolis, USA; Beth Lown, Harvard Medical School, Mt. Auburn Hospital, Department of Medicine, Cambridge, USA

Additional Authors: Elizabeth Rider; Peg Hinrichs

Background: Medical school curricula emphasize the training of students in effective communication with patients, families, and colleagues. Most medical schools employ a variety of methods for teaching, including lectures; presentations by experienced patients or family members; interviews observed by faculty; standardized patients; group videotape reviews; and OSCEs (objective structured clinical examinations). Many medical schools are now employing patient and family feedback by incorporating real time feedback from volunteer patients, simulated patients, and actual patients and families.

Methods: At Indiana University, students are asked to collect patient ratings of their communication while on clerkships in family medicine and pediatrics [using the Rochester Communication Scale (Epstein et al, 2002) and comment sheets (Harris, 2003).] In addition, first year students are asked to request patient feedback at the end of each patient interview in year one. At Harvard University, students are given feedback on their interpersonal/communication skills by simulated patients during videotaped clinical formative and summative assessment exercises during each year of training using a communications tool based on the Kalamazoo Consensus Statement. Standardized patients also rate students using a modified qualitative measure of satisfaction with communication developed by the American Board of Internal Medicine. Giving patients a voice in medical education is challenging but meaningful to students in training.

Conclusions: Actual and simulated patient assessment of communication at each level of training would enhance the incorporation of patients’ and families’ perspectives in undergraduate medical student curriculum.

Students Experience of a Patient as the Teacher

Presenter: Annabel Kier, Welsh Institute of Chiropractic, University of Glamorgan, Wales, UK

Additional Authors: M. Webster

Back pain and its socio-economical cost are some of the major topics in today’s healthcare politics. It is therefore essential that the practitioners of the future not only understand the diverse causes of back pain but are capable of explaining to their patients the psycho-social concepts related to illness behaviour and fear avoidance. While the theories behind the bio-psycho-social model are integrated throughout the 4 year chiropractic degree at the University of Glamorgan, it became clear that final year student clinicians were having difficulties when conveying interpretations relating to illness behaviour directly to patients.

In order to facilitate the students learning, a patient who had understood and implemented the ideas underpinning illness behaviour and fear avoidance, was introduced to the class. The students experienced effective patient communication through her willingness to re-enact the setting, during which the rationalisation behind the concepts were explained in layman’s terms. Additionally the importance of these issues was emphasized, by her openly discussing how this understanding had influenced her perception of her back pain which subsequently decreased her fear avoidance.

The impact on student learning from the session was confirmed by a retrospective survey based upon the students’ perception of the value of the lecture and the utilisation of a patient as a teacher. The students perceived that they gained further understanding of the subject, felt more confident should they themselves have to convey the concepts and moreover the experience had encouraged further self-directed study of the subject.
Every Voice Counts: A Model for Meeting Educational Needs through Matching Patients and Health Professional Students

Presenters: Cheryl Descent, Queen's University Faculty of Health Sciences Glaxo Wellcome Clinical Education Centre, Kingston, Canada; Deborah Docherty, Queen's University Faculty of Health Sciences Volunteer Patient Glaxo Wellcome Clinical Education Centre, Kingston, Canada

Additional Authors: Lee Fisher Goodchild

Starting from the premise that the patient's voice and lived experience of health/illness is integral to the acquisition of knowledge and skills of all health care professionals, this presentation explores the unique challenges and opportunities created by bringing together volunteer patients and health care students in an integrated experiential education program setting that acknowledges the changing needs of both. The introduction of the legitimacy of the patient's voice at an early stage in the respective curricula models a powerful message.

The Queen’s University Glaxo Wellcome Clinical Education Centre (Kingston, Ontario) Community Volunteer Patient Program is a forum where community volunteer patients play a meaningful role in health professional education through the coming together in mutual learning of patient and student. The changing dynamic of students' learning needs and skill level combined with the evolving health challenges and articulation capacity of the patient, present unique opportunities for matching. Patients, from all ages, socio-cultural backgrounds and varied life experiences learn to tell their health/illness story, present their physical ‘findings’, and offer useful feedback to the student. Learning to listen and communicate respectfully, elicit relevant information, interact in a professional manner, develop hands-on examination skills and integrate theory with practice are some of the opportunities created for the student.

This program/model is directed primarily at pre-licensure rehabilitation, nursing, and medicine students. Patient-centred skills are reinforced at more senior levels of learning as volunteer patient and health care student interchanges increase in complexity.
Parallel Plenary Session 2.1.3.2
Room: Comox

Increasing the Patients’ Voice in Medical Education: the Development of a Patient Educator Programme in a UK Medical School

Presenter: Elaine Gill, Guy’s, King’s & St.Thomas’ Medical School, King’s College, London, UK

Additional Authors: Katrina Ramsay; James Hollands; John Rees

This presentation will describe the process and outcomes of setting up a patient educator programme in a UK medical school. Patients (with signs) and actors underwent a training course in physical examination and communication skills. Their role is to work directly with students using their own bodies for student practice. More importantly, the patients perspective is central to the learning experience and first hand. Patient Educators feedback to Students re: their communication skills, what it feels like to experience the physical examination, the sorts of concerns and anxieties patients may have in relation to the exam and offer tips and guidance for future patient centred learning. Physical examinations in the first round included respiratory, cardio-vascular, and abdominal systems.

Patient Educator Teaching Associate programmes are in evidence in the US, using actors. Patients as teachers is generating increased interest but there are few examples of how this can be done in practice with real patients. This is not simply an extension of simulated patient work as the PEs do not take on a pre-determined scenario role as in simulated patient learning or OSCE. Moreover, the philosophy underpinning the described programme demands that PEs are considered members of the educational team and not add on extras or utilities for physical examination practice in a purely technical way.

A four stage process will be outlined and outcome measures discussed. These include: student evaluation, Patient Educator evaluations and students performance in subsequent OSCEs.

Subsequently to the pilot study findings the programme was expanded and developed further. Additional data will be described relating to neurological and ENT examination and how the programme has progressed over an additional twelve month period. This data provides increasing evidence to support the value of such programmes from both the patients, learners and institutional perspectives.

Parallel Plenary Session 2.1.3.3
Room: Comox

Exploring the Challenges and Benefits of Nurse Educator/ Patient Educator Collaboration in Mental Health Nursing Education

Presenter: Lorna Bennet, School of Nursing, Memorial University of Newfoundland, St.John’s, Canada

The general consensus in the literature concerning patients as educators in professional education is that patients in this role are able to increase students’ awareness of clients’ expertise, to sensitize the learner to the challenges of the illness experience, and to feel supported in their personhood. However, partnering with patient educators in making decisions about class process and content, as well as choosing the appropriate level of autonomy for the patient educator and ultimately determining whether attitudes about mental illness are indeed changed through this approach, are just a few of the issues patient educator involvement raises. This presentation will outline core dimensions of the patient educator role in a third year undergraduate Mental Health Nursing course. The specific objectives for the presentation are to discuss the nature and scope of meaningful patient educator participation, to analyze the issues and challenges from an educational and ethical perspective, and to discuss the reciprocal nature of the benefits and learning outcomes for client, educator, and student. In addition, a discussion of aspects of collaboration that facilitated patient/nurse educator co-authorship of a publication in a professional journal will be included.
Concurrent Session 2.2.1.1  
Room: Nelson

Service Users as Teachers of Health Professionals - A Conceptual Framework

Presenter: Pennie Roberts, Manchester Metropolitan University, Manchester, UK

The work presented here is an examination of several projects undertaken by the author in conjunction with service users (disabled people and wheelchair users). It outlines a contextual framework which developed over twenty years experience working with service users in the design, delivery and evaluation of services. One project is presented in detail and this is the input wheelchair users had in delivering a two day mandatory programme for all those prescribing wheelchairs in North Derbyshire (district nurses, physiotherapists and occupational therapists). The sessions run by wheelchair users were innovative at the time and met with initial resistance from professionals. The evaluation of the two day programme showed a high level of satisfaction with the sessions run by wheelchair users and indicated that it was these sessions that changed the approach professionals had to the assessment and prescription for wheelchair use.

The contextual framework developed from involvement in a range of projects is presented and put into a higher education context. Involvement of service users (patients, clients, carers) in the design, delivery and evaluation of programmes leading to a professional health qualification is in its infancy. If such involvement is to be meaningful the principles need to be identified, articulated and grounded in evidence. The evidence base will be used to support the experiential learning from the range of projects that have been successfully run with full user involvement.

Concurrent Session 2.2.1.2  
Room: Nelson

Dylan's Gift: Teaching a Hospital to Care

Presenter: Beth Seyda, Compassionate Passages, Inc, Chapel Hill, USA

After the illness and death of her newborn son in 1997, Beth sensed one of the things she was suppose to do with this experience was to provide feedback to her healthcare team. Comments had been made to Beth by various team members that they could not imagine what it must be like to go through something like this. She gave them a glimpse by sharing her story with them.

Her professional expertise as a consumer researcher and giving consumers’ a voice gave Beth the confidence to write 30+ pages that chronicled what was helpful and what was frustrating about her experience. She also included specific recommendations around the themes that arose. Not sure how they would react or if they would even read it, Beth sent copies to her healthcare team.

Beth soon learned that her narrative was well-received, and more importantly, it prompted changes to be made in her healthcare system. Beth will present how her suggestions improved care for children/families, including helping design a new children’s hospital. Additionally, Beth will share how “speaking up” led to being invited to join the Hospital’s Ethics Committee and partnering with physicians to conduct research on physician-patient communication.
Concurrent Session 2.2.1.3  Room: Nelson

Stories from the Heart: Using Life Review to Elicit Narratives of Illness and Recovery in Women Following Myocardial Infarction

Presenters: Michele Bowers, University of British Columbia, Vancouver, Canada; Sally Halliday, Sally Halliday Counselling and Consulting Services, Vancouver, Canada

The contributions of Counselling Psychology in medicine are multifold and have an important place within the biopsychosocial model of disease. Departing from a biomedical perspective, the Counselling Psychologist's lifespan approach explores personal meaning making and views the individual in a more holistic manner, thus emphasizing the subjective world of the individual. Illness and health are explored in the context of the individual's location in the life cycle as well as in their lifestyle and relationships (Woolfe, 1996).

A recent study demonstrates how research and practice in these areas can be bridged using an interprofessional approach. Action research using Life Review provided the methodology for exploring how a small group of 6 women constructed their experience of recovery following myocardial infarction (MI) as they engaged in a weekly reflection and writing practice. Six autobiographical themes were used to guide participant's written accounts.

Study findings demonstrated that women's constructions of recovery were often varied, complex and extended beyond the disease process itself as six common themes emerged including a) loss, b) uncertainty, c) changes in self-concept, d) self-care, e) care and support, and f) caring for others. Although women experienced various losses associated with MI, these were embedded within their larger life stories. Eliciting the patient's voice through their autobiographies was beneficial to all women in the study and served to inform health-care providers with a more comprehensive understanding of women's recovery experiences and needs following MI. Implications for developing a program of psychological care for patients following MI are discussed.

Concurrent Session 2.2.1.4  Room: Nelson

Integrating the Voice of Patients / Survivors / Families in the Cancer System

Presenter: Emmie Luther-Hiltz, Cancer Patient Family Network, Cancer Care Nova Scotia, Halifax, Canada

The Cancer Patient Family Network was created in 2002. It is an initiative of Cancer Care Nova Scotia designed to keep cancer patients/survivors and their families informed and involved in the cancer care process. The Network facilitates the sharing of information, fosters and promotes grassroots support for cancer patients and offers its Members a voice in the delivery of cancer services. Much can be learned, based on the experiences and feedback of those who have experienced the cancer system firsthand, about how we can improve the cancer care system. The challenge is often how to reach that audience and how to support their involvement in the process. There are patients and family members, particularly at the end of treatment, who want to maintain contact with the cancer system, be informed about the Nova Scotia cancer system and have the opportunity to provide input on future initiatives. The need for a formal communication channel for the cancer patient/survivor community was originally identified for development in “A Plan for Action” – The Comprehensive, Integrated, Accountable Cancer Management Strategy” submitted to the Nova Scotia Provincial Government in 1996. The Cancer Patient Family Network Roundtable held in 2002 provided the foundation to create the structure and framework to move this initiative forward. Creating and accessing opportunities to encourage the informed involvement of patients/survivors/family members as valued partners in the cancer care system is an essential component of patient-centred care.
Concurrent Session 2.2.2.1  
Introducing the Voice of the Older Person into Health Professional Education

Presenter: Catherine Monaghan, Queen's University Belfast, Northern Ireland

Background of the study
The assessment of carers’ need has become central to the government policy on informal carers. A well-defined framework for assessment does not exist in practice. A research study to evaluate the community health care professionals' perspective on the assessment of carers’ needs was carried out.

Methods
The study utilised a quantitative research approach. The data obtained from the questionnaires were analysed using a computer data analysis package, SPSS. A randomised convenient sample consisting of 76 community health care professionals was used. The sample included Community Nurses, Social Workers, Occupational Therapists and Physiotherapists.

Results
The Older People and Mental Health Programmes of Care were the two largest areas where duplication of carers’ needs assessments were reported most. Patients and carers views have been recognised in policy to help address these issues. In addition the need to involve patients in education is recognised. The patient’s voice in shaping policy, practice and education is therefore paramount.

Discussion
A review of the undergraduate-nursing curriculum is taking place. This presentation will explore how the vision to work in collaboration with clients and carers in relation to health professional education is addressed. Overcoming barriers to patient participation will also be examined.

Concurrent Session 2.2.2.2  
Enhancing Undergraduate Nursing Education: The Patient and the Family

Presenter: Judy Seccombe, Universal College of Learning, Palmerston North, New Zealand

Contact with disabled people in nursing education is recognised as important in the development of positive attitudes and empowering nursing practice. The recipients of nursing care are well situated to describe the impact of that care, sharing their various feelings of comfort, pain, grief, fear and whether the nurse made a difference. People who have experienced the health care system generally welcome opportunities to contribute to student nurses’ education in this way.

This paper will present a tripartite model of education used in a disability unit, which incorporates the elements of theory, clinical experience and individual personal encounters. Collaborating with disabled people and their families and incorporating their stories into the education of student nurses provides tangible experiences and exemplars to underpin theoretical concepts. Practical issues surrounding the use of patients and their families in this model are discussed.
Concurrent Session 2.2.2.3  
Room: Denman

**Project DOCC - Delivery of Chronic Care: Family as Faculty in Medical Education**

**Presenters:** Maggie Hoffman, Project DOCC, Oyster Bay Cove, USA  
**Additional Authors:** Donna Appell

Project DOCC - Delivery of Chronic Care is a groundbreaking training program for new doctors that has a simple goal: to improve each patient’s quality of life by teaching physicians-in-training the effect of chronic conditions on patients and their families. Project DOCC was developed by three mothers of children with chronic illnesses and disabilities. They shared the perception that their children’s physicians, however clinically skillful, lacked an understanding and knowledge of the realities of care at home, and of the importance of referrals to community-based resources to help and support them. They designed a training model for pediatric and family practice physicians - parents are the teachers. In 1994, Project DOCC launched its first residency training program. Since then, the program has been expanded and is currently taught in 21 hospitals across the US, and in Australia.

DOCC believe that a partnership between caregivers and physicians is the best way to teach this approach to care. Caregivers need to help residents see, hear, and feel what their patient’s lives are like outside of the clinical setting. Young physicians begin to understand and accept the inherent complexity and responsibility of treating people with chronic conditions.

DOCC’s pediatric curriculum is built around three components: the home visit, the interview, and a panel presentation. Parent Teachers are carefully trained about how to best bring their knowledge to residents, and a positive approach that they must bring to their interactions with young doctors.

DOCC has also developed a presentation for older adult patients and their family caregivers. Project DOCC is also developing a transition program to explore the issues of transferring services from pediatric providers to adult internists.

The co-directors will share the philosophy and design of the program.

Concurrent Session 2.2.2.4  
Room: Denman

**Counseling Practicum: Patient’s Stories in Family Medicine**

**Presenter:** Kathy Zoppi, Department of Family Medicine, Indiana University, Indianapolis, USA  
**Additional Authors:** Scott Renshaw; Mary Dankoski; Shobha Pais; Dustin Wright

**Background:** Family Medicine residents are trained in behavioral sciences but this often is training about patients, rather than by or with patients. This innovative counseling practicum uses a reflecting team approach to patient encounters, placing the patient narrative about chronic illness at the center of group educational training.

**Methods:** The goal of practicum training is to improve resident physician communication and counseling skills through supervised counseling of patients by peers and behavioral faculty preceptors. Trainees are R2 and R3 family practice residents, who are taking a required longitudinal behavioral science rotation in a group over a 1.5 year span. Residents complete 6 half-days of training over three years. Each resident identifies and schedules a 1-hour session with a continuity patient (and any relevant family members). Patients who are medically and/or psychosocially complex are selected. The resident sets pre-session goals with 1 or 2 faculty supervisors and 2-4 peers; counsels the patient (and family) for half of the one-hour session while being observed live in real-time through video equipment. Mid-session feedback is given, and a 15-minute post-session enables the resident to reflect on his/her interactions with the patient. Feedback is specifically given regarding skills in counseling, communication, and doctor-patient relationship issues. The sessions are taped (with patient consent) and can be viewed at a later date, but emphasis is on immediate feedback in the teachable moment.

**Results:** Patient feedback has been positive; residents demonstrate improved outcomes in empathy, confidence and connection with patients.
Incorporating Patient Narratives in an Interdisciplinary Course

Presenters: Wendy Hall, School of Nursing, University of British Columbia, Vancouver, Canada; Marion Clauson, School of Nursing, University of British Columbia, Vancouver, Canada

This presentation describes a course offering for midwifery, medical, and nursing students that incorporates mothers’ narratives about their breastfeeding experiences and infant sleep problems. Funding was granted by Federal Government, under the auspices of the College of Health Disciplines, to promote interdisciplinary education for health professionals. This short course rests on concepts of interprofessional collaboration and a patient-centred perspective.

The content focuses on enhancing breastfeeding support and preventing infant behavioural sleep problems. To place the emphasis on women’s and families’ experiences, narratives are incorporated that capture 252 Australian women’s breastfeeding experiences from 2 days to 12 weeks post birth and 26 British Columbian parents’ experiences of infant sleep problems. The breastfeeding narratives included positive aspects of breastfeeding, support, helpful strategies, women’s expectations and factors affecting confidence, and their perceptions of pressures about breastfeeding. They also reported unhelpful and conflicting advice, lack of resources, and unanswered questions. The sleep narratives included perspectives about sleep, gaining a framework to tackle sleep problems, challenges for parents’ around infant sleep problems, parents’ support systems, and parents’ expectations.

The narratives will be interwoven with evidence-based literature about the physiological and emotional components of breastfeeding and infant sleep problems. The course will also incorporate women’s attendance at classes to share their experiences. The paper includes the implications of the course for interprofessional and patient-professional collaboration and effects on faculty, students, patients, and learning environments.

One Patient’s Narrative: The Health Care Professional as Patient - a Different Perspective

Presenter: Deborah Docherty, Queen’s University & Hotel Dieu Hospital, Kingston, Canada

Postmodernism has been one influence on the emergence of the legitimacy of the narrative. Postmodernism has likewise called into question and invited examination of the power differential between the “expert” and the “learner”. While health professional curricula have struggled to acknowledge this differential, the successful integration of the notion of the patient as the source of knowledge about her/his lived experience of health/illness, has not always been apparent. Much work remains to be done to see health care become a viable and effective partnership. As a Medical Social Worker for 25 years, a person living with Multiple Sclerosis, an active volunteer in Queen’s University’s experiential learning programs for rehabilitation, nursing and medical students, and latterly, as a graduate student, I have experienced an intriguing overlap of perspectives. The social construction of illness, the sophisticated and complex system of health care delivery and the academic world of teaching and research, have afforded me an opportunity for reflection. Further, as noted Canadian sociologist, Arthur Frank, put it, this overlap of perspectives has been a call to action. An obligation to share/teach/mentor those who may not understand the lived experience of illness, was created. This presentation will consider both the developmental aspects of patient hood, from passive recipient to active participant, as well as the challenges and opportunities present to alter the position of both the patient and the health professional’s role in the health care system.
Concurrent Session 2.2.3.3
Room: Comox

Alzheimer’s Narratives: Voicing the Experience of Patients and Caregivers

Presenters: David Flood, Drexel University, Philadelphia, USA; Rhonda Soricelli, Drexel University, Philadelphia, USA

Alzheimer’s Disease, a growing medical and societal problem, is also uniquely devastating at a personal level. How, though, can we access this level—humanize the disease and understand its impact on patients, caregivers, and families? While this question is important for the healthcare community, to help them address their clientele’s needs, it is equally important for those facing the diagnosis of Alzheimer’s, as patients or caregivers, and for the general public, so that they might develop better understanding of and empathy for those in Alzheimer’s grasp.

One effective approach is the study of Alzheimer’s narratives. Whether patients’ first-hand accounts of their slowly losing battle, caregivers’ personal stories of coping with loved ones who become less and less recognizable, or fictional accounts from varying perspectives, these narratives are instructive for us all. They allow the authors to give shape to their experience in an attempt to understand it and Alzheimer’s meaning to them. Writing about the experience can be therapeutic in other ways, too—reestablishing contact with the larger world beyond the present shrinking one, sharing often painful stories in the hope they will be helpful for others. And they provide portals for all into the personal reality of Alzheimer’s.

While our own work with Alzheimer’s narratives is limited to educational settings for health care students and professionals, we believe these narratives are therapeutically useful for those who write them and educationally valuable for patients, caregivers, and the general public alike.

Concurrent Session 2.2.3.4
Room: Comox

Slow Motion Ethics: Viewing Professional-Patient/ Family Encounters from the Patient/ Family Perspective

Presenter: Daryl Pullman, Faculty of Medicine, Memorial University of Newfoundland, St. John’s, Canada

Whether in acute or chronic care settings, health care professionals face increasing demands upon their time and resources. As acute care facilities have moved toward quicker and sicker discharge planning, those who work within those facilities are required increasingly to attend to the sickest patients, while those employed in chronic care settings now serve a higher need population. Many health professionals move at a frenetic pace in often futile attempts to meet patient needs and administrative demands. In this hustle and bustle the lives of individual patients often coalesce into an indistinct mass of examinations, tests, and reports.

When viewed from the perspective of the health professional, the foregoing looks and feels as if someone has pushed the fast-forward button on the VCR of life. When viewed from the perspective of the patient, however, a different picture emerges. For the patient his or her individual health care problem is often the most significant aspect of his or her life. Every detail of the encounter with the health care professional can take on significance and meaning. Hence for the patient these rare, often brief, and frenetic exchanges play out in slow motion.

Slow motion ethics borrows on recent work in narrative theory to reframe the professional-patient encounter. This presentation includes a variety of examples from palliative, acute, and chronic care settings to illustrate some aspects of narrative theory in general, and the practical utility of slow-motion ethics in particular.
Patient and public involvement is integral to policy development and implementation in Wales. A number of policy documents including the Review of Health and Social Care in Wales (2003) and Signposts 2 (2004) identify the importance of the public and service users being involved in a number of areas. However the acid test is implementation. The rhetoric has been translated into reality via a number of different initiatives within the School of Care Sciences, University of Glamorgan, South Wales.

In the context of education the agenda of service user involvement is integrated into all aspects of curriculum development, delivery and evaluation of teaching programmes. Building on this philosophy a pilot is being undertaken to involve service users in the selection process of student nurses entering graduate level programmes on the BN mental health programme.

A specific example to demonstrate how policy has been translated into practice is a service user being involved in the development of a module looking at working with clients in acute care environments. His input helped to shape the design of the module, its content and how it might be delivered. Influence was real as suggestions from the service user were incorporated into the module descriptor which was later successfully validated.

We believe that service user input via a variety of roles e.g. as a student, a lecturer, a member of a curriculum planning or research group and as an interviewer is fundamental to the quality assurance mechanisms which determine the way we operate.
Patient and Public Involvement in the Development and Delivery of Pre-Registration Occupational and Physiotherapy Education Programmes

Presenters: Elizabeth Bond, School of Health Sciences and Social Care, Brunel University, UK
Additional Authors: Margaret Gallagher; Christine Craik; Sandra Naylor

The UK Department of Health has recommended public involvement in the education of health care professionals. Statutory and governing bodies also expect the patient's perspective to be central to the student's learning experience at pre-registration level.

This paper describes the process of initiating public involvement in the education of health professionals and the development of an ethical framework for including views from patients and communities. It reports the outcomes of involving and sustaining patient and carer involvement in curriculum design and delivery of Occupational Therapy and Physiotherapy pre-registration programmes. The educational implications of this approach to collaboration including an initial evaluation of this strategy will be discussed.

Community networks were approached and snowballing techniques were used to identify participants and to improve diversity. Semi-structured guided discussion groups were used to gather views as part of the first phase of a triangulation method for consultation. Data were analysed through thematic analysis.

Preliminary analysis of the views of a diverse range of representatives identified four main themes:

a) Interest and enthusiasm for patient and carer consultation
b) Expectations of patients and carers about the competencies of new graduates
c) Barriers to an effective consultation process
d) Factors that enable meaningful collaboration with patients and carers

Patients and community groups have welcomed this initiative and would like to be more involved in the education of health care professionals. The challenge is in turning the expectation into a manageable reality.
Parallel Session 2.2.4.3  Room: Beach

Child and Parent Voices in Developing Future Nursing Curricula

Presenters: Angela Chakrabarti, Faculty of Health Edge Hill, Aintree Campus, Liverpool, UK; Brenda Roberts, Faculty of Health Edge Hill, Aintree Campus, Liverpool, UK

The impetus for consumer participation in developing and shaping future health care provision has become an imperative within the UK. The last fifteen years have seen an increased focus on the issue of child rights and the need for children to be viewed as active participants in shaping and developing health care and its provision. These rights have been enshrined in legislation. The United Nations (1989) Convention on the Rights of the Child and in the UK, the Children Act (1989) provide strong evidence of this. This notion is further endorsed in the Patients: Charter Services for Children and Young People (1996). The NHS Plan (2000) supports the need for health care professionals to engage in active partnership with patients in the development of services. Similarly The National Service Framework (2003) highlights the need for active consultation with children. Nurse educators are charged with the responsibility of ensuring that nursing curriculum is designed to produce future nurses who are fit for purpose fit for practice (DoH 1999). This project highlights the processes of gaining access to children and parents in a large regional Children’s NHS Trust. By listening to parent and child voices, their clear messages and implications for future nurse programmes were identified. Thus enabling evidence based action plan to be developed with parents, service providers and pre registration nursing students. Resulting in an informed nursing curriculum and at the same time ensuring that future nurses are fit for purpose.

Parallel Session 2.2.4.4  Room: Beach

Learning from our Patients and Families, Teaching to our Students

Presenters: Helen Frederickson, Faculty of Nursing, University of Toronto, Toronto, Canada; Sandra Devlin-Cop, Faculty of Nursing, University of Toronto, Toronto, Canada

The Faculty of Nursing, University of Toronto has integrated Family Centred Care [FCC] throughout its’ innovative second entry two year nursing program. FCC is a philosophy of care which fosters family collaboration, partnership and empowerment. FCC guides policy and program development, facility design, decision-making, and daily interactions at all levels throughout the hospital and the health care system (Sodomka, 2001; Webster & Johnson, 1999). While our hospital partners are beginning to collaborate with families, we are leading the charge at the academy. We have incorporated FCC through a variety of strategies including role playing, video taped interviews to enhance interviewing skills, standardized patient’s provides the students with feedback from patients on communication skills as well as clinical practice, reflective journal writing encourages personal critical reflection and guest speakers/family panels share the lived experiences. Student led seminars promote critical analysis of the social, political, institutional, ethical and cultural for children and their families.

Throughout this critical appraisal, students are expected to describe innovations that support patient and family partnerships within the curriculum and institutions where they are practicing. We will continue to further incorporate FCC into our program including our adult population.

Incorporating FCC within a health care curriculum enhances students’ understanding of families’ illness experience, incorporates the family in the care of the child and enhances the nurse-family relationship. This holistic approach effectively addresses the complex issues that impact the health care needs of the child and family. Utilizing FCC results in greater patient and family satisfaction, in addition, research shows that there are shorter hospital stays and improvement and more appropriate resource utilization in and out of hospitals.
Assessment Techniques for Measuring Skills and Attitudes towards Disabled People

Presenters: Margaret Byron, University of Bristol Centre for Medical Education, Bristol, UK; Paul Bradley, The Peninsula Medical School, Plymouth, UK

Additional Authors: Caro Howell

Examples of disability equality teaching in UK undergraduate healthcare courses are limited and where it exists at all it is rarely formally assessed. Research has shown that disabled people rate a health professional's attitude as more important than their knowledge or skills when it comes to ensuring equitable treatment and access to healthcare. Yet assessing attitude is extremely difficult and our research has shown that existing tools such as the Attitude Towards Disabled People scale are far from ideal, despite being commonly used.

The University of Bristol and the Partners in Practice project have developed two assessment tools for measuring healthcare student's clinical competencies and attitudes around disability. One is an Objective Structured Clinical Examination (OSCE) station on communication with people with hearing impairment where both the patient and assessor use hearing aids and lip read. The second is a 'Reversed OSCE' where a group of students observe a disabled person interacting with various healthcare workers (played by actors) and individually write down anything that strikes them as noteworthy. The scenario is based on the disabled person's real life experiences of healthcare provision and involves both good and bad practice in areas that range from body language and vocabulary to clinical and communication skills.

In the workshop the following areas will be explored:
1. The case for attitudinal assessment
2. Examination of current assessment tools
3. Direct assessment of undergraduate medical student's skills by disabled people using an OSCE format
4. Development and analysis of the 'Reversed OSCE' format.
Working Together: Patient, Community and University Reflections on Personal and Professional Development

Presenters: Andrea Armitage, University of Leeds, UK; Chris Essen, University of Leeds, UK; Julie Symons, Simulated Patient, Medical Education Unit, University of Leeds, UK; Shelley Fielden, Medical Education Unit, University of Leeds, UK; Sam Samociuk, School of Health Care, University of Leeds, UK; Fiona O'Neill, Centre for Development of Health Policy and Practice, University of Leeds, UK; Rob Lane, Medical Education Unit, University of Leeds, UK; Penny Morris, Medical Education Unit, University of Leeds, UK

This workshop will report on a series of reflective discussions held between newly appointed ‘patient voice’ teaching and development staff at the Faculty of Medicine and Health, University of Leeds, with patients, carers and service users already involved with education and training, and medical and nursing faculty and students. Part of quality enhancement efforts for teaching, the sessions are video recorded, reviewed and disseminated in an iterative evaluation framework. This is to inform the efforts of the wider faculty to engage with the local community, for example, in exploring Patient Safety in education and care, and in establishing a Panel of Expert Patients to contribute to curriculum development. Findings will also be disseminated widely and online video resources, for example, are being explored. The reflections include: the effects on the participants, both personal and professional; the development of support, partnership, leadership and strategic direction to further this work; implications for community and patient groups and for the institution of the university. This workshop will use brief summaries and excerpts from the sessions as a basis for exploring issues and challenges arising for the workshop participants, to inform the wider debates of the conference.
Workshop Session 2.2.W3  
Room:  Parkside

Building a Foundation for Community Engagement in the Faculty of Medicine at the University of British Columbia

Presenters:  
Vince Verlaan, Faculty of Medicine, University of British Columbia, Vancouver, Canada;  
Peter Granger, Department of Family Practice, University of British Columbia, Vancouver, Canada;  
Patricia Boston, Division of Palliative Care, Faculty of Medicine, University of British Columbia, Vancouver, Canada;  
Evan Adams, Division of Aboriginal People’s Health, Faculty of Medicine, University of British Columbia, Vancouver, Canada;  
Betty Calam, Faculty of Medicine, University of British Columbia, Vancouver, Canada;  
Andrew Morgan, Faculty of Medicine, University of British Columbia, Vancouver, Canada

Additional Authors: Leah May Walker

Three years ago, the Ministry of Health Planning initiated a program to support the Faculty of Medicine to engage more actively with underserved populations in urban, suburban, rural and remote areas across British Columbia. Entitled The Strategic Teaching Initiative, this program accelerated the development of innovations in community-responsive medical education that the Faculty has been generating in recent years.

As a subset of the STI, a group was formed with the specific mandate of providing: “Support for Communities, Practitioners and the Health Care System to strengthen Faculty partnerships with its constituent communities in the integration of study and service to ensure the educational programs are responsive to public needs and better able to inform service planning efforts.”

Each division and program funded under this category worked separately to meet this mandate through a variety of experimental advocacy, research and educational initiatives. Recently, we committed to share resources, best practices, models of partnership, and the challenges of creating medical education programs that are more responsive to needs, and which give patients a voice in their development and implementation. We are also linking our work in order to magnify our impact in the Faculty of Medicine overall, and are supporting this by developing common interpretation of needs, capacity, and community, and by developing tools to evaluate these and outcomes of initiatives.

In this interactive workshop, we will present principles for and cases of our emerging models of successful partnerships and examples of our challenges in sustaining collaborative partnerships.

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Workshop Session 2.2.W4

Learning from the Patient’s Voice; Involving Patients as Co-researchers with Health Professionals

Presenters: Elizabeth Boath, Faculty of Health & Sciences, Staffordshire University, UK; Ruth Chambers, Faculty of Health & Sciences, Staffordshire University, UK

Aim: Learning from patients who participate in research as co-researchers

Objectives
• To share ways of enabling patients to learn basic research skills to participate as informed co-researchers with health professionals
• To explore ways for patients to use their experiences in teaching health researchers about all stages of a research project - planning, methodology, interpretation of results and dissemination of research findings.

Outcomes of workshop
• Enhanced understanding of different ways of involving patients as co-researchers with health professionals for all stages of a research project
• Increased understanding of the preparation and support necessary for patients to be enabled to act as co-researchers.
• Each participant has individual plan to recruit, prepare, and engage patients as co-researchers in relation to their own work situation.

References
Workshop Session 2.2.W5

Bull's Eye-The Patient's Voice at Front and Center: Educating for Advocacy at Sarah Lawrence College

Presenters: Rachel Grob, Health Advocacy Program, Sarah Lawrence College, Bronxville, USA; Marsha Hurst, Health Advocacy Program, Sarah Lawrence College, Bronxville, USA

The Sarah Lawrence Health Advocacy graduate program is built around the patient’s voice and experience. In the Health Advocacy Master’s Program, there is no way to separate the patient from the educational content or process.

For health advocates, attentiveness to “voice,” to the experiences of real people as they struggle with issues related to health and health care, is the primary commitment underlying professional identity. The patient/individual is therefore always placed at the center of attention and concern when we educate for advocacy. We begin with a focus on the experiences and perspectives, needs and strengths, history and aspirations individuals bring to bear on their own situations, and the ways “voice” is heard, silenced, ignored, and answered within the care systems and social structures that frame health and illness. By starting here, we make sure that the actual person whose life is affected by any given advocacy intervention is solidly in front of us from the outset. Then, throughout the curriculum, we keep our eye trained on that person as we reach out from the personal to consider advocacy at the level of collective voice: in the community, in associations of people similarly disabled or experiencing similar illness, reaching out to the health care system as a whole.

This presentation will explore how the patient’s voice is integrated into every aspect of our graduate program. Students encounter voice during their education in many ways:

- Illness narratives: patient’s or caregiver’s voice defining feeling, meaning and experience of illness;
- Giving/enabling voice: finding your own voice; reappropriating experience; moving voice from the personal to the political (from private to public; or, as Arthur Frank conceptualizes it, giving public voice to survivorship);
- Patient/consumer voice in program development, implementation, political process, policy-making (e.g., organizations like Medicare Rights Center and Commission for the Publics Health “collect” testimony of consumers who have experienced financial or bureaucratic barriers to care); voice as a strategic tool; what are the mechanisms for voice to be heard?
- Patient/consumer voice in organizing advocacy: “Who owns advocacy?” How can/do self-advocates and those advocating for others work together?
- Representative voice, speaking for a constituency: Who speaks for the patient? Consumer? Community? Who speaks in legislative or regulatory settings? How is consumer representation organized in government agencies? Who are “independent” members of IRBs and ethics committees? How are representatives integrated into the larger groups or which they form a part?
- Voice as “case”: Construction and use of the “case” for law, bioethics; Ethics of harnessing voice for strategic purposes;
- Voice as a “model of knowledge”; counterpart to supremacy of scientific methodology as pathway to understanding; using the particular to understand the universal;
- Body as voice—reading the body, reading the mind;
- Artistic expression of voice—what do we as advocates learn from art?
- “Aggregated” voice; political movements; organizing a collective voice;
- Barriers to voice; facilitators of voice;
- Obligations of health advocates (in any setting) to listen to, solicit, enable the voice of consumers/patients/families so it can be heard.
Empowering Patients with Information: Educating Students to Find Appropriate Information of High Quality and Share it with Patients

Presenter: Jim Henderson, Health Sciences Library, McGill University, Montreal, Canada

For patients to make informed choices, they require reliable, complete information about their health and its improvement and about their illness, including its nature, prognosis, and process, treatment alternatives, and coping strategies. Communication of information is recognized as a factor in the success of care outcome. How to convey information in the professional-patient interview and in counseling and patient education sessions is already included in professional education.

This paper argues that information is the essence of the professional-patient interaction and, therefore, that the quality of the information shared with the patient is as important as how it is conveyed. More attention to tailoring information to suit individual patient learning styles and abilities is suggested. Sources for patient information, such as Internet sites, nurse-staffed information lines, printed reference books, and patient handouts, will be identified and quality measures discussed. Attention is paid to issues of reliability (level of evidence), literacy (including health literacy), language and level of technical complexity. To deal with the limitations of time and the effects of emotional reactions on memory in the professional-patient interview, new modes of information delivery, such as information prescriptions and e-mail, are considered. A conceptual approach will be developed, recognizing the need for students to adopt new electronic sources of information as they are introduced in the future. This framework will be used to discuss what students need to learn to enable them to find and share appropriate information that effectively addresses patients’ needs for information and empowers them to participate in decision-making.

Virtual Reflections: Online Blogs and Self Help Groups Addressing Mental and Physical Disorders

Presenter: Joanne Levine, School of Social Work, Wichita State University, Wichita, USA

Blogs and online self help groups which address living with mental and/or physical illnesses, or living with someone who has these, are proliferating on the World Wide Web. These websites provide a wealth of patient narratives, invaluable learning tools for students in the helping professions who strive to increase their understanding of how patients and their loved ones struggle to cope with illness. These “virtual reflections” are free, easily located, and allow students to gain insight and knowledge about how people all over the world struggle to cope with a wide range of disorders.

This presentation will provide information about where to locate blogs and online self help groups, share ways to guide and maximize students’ learning from them, and discuss reactions of graduate social work students who located mental health blogs and online self help groups when participating in a graduate –level mental health class taught by this presenter.
Concurrent 2.3.1.3

Room: Nelson

e-Health Promotion Programs: Empowering Underserved Consumers to Make Decisions About their Health

Presenter: Kevin Lyons, Center for Collaborative Research, Thomas Jefferson University, Philadelphia, USA

Additional Authors: Kathleen Swenson-Miller; Diane Cornman-Levy

This presentation will discuss a project developed in response to the call for new approaches to health care delivery and the recognition of the increasing health disparities among members of underserved communities. The project was developed in response to the recommendations from the PEW Health Commission Report, Healthy People 2010, and goals derived from the ICIDH-2 (World Health Organization’s International Classification of Functioning and Disability). These reports suggest that there is a need to: 1) develop new models of integrated community health approaches that are effective in improving the health of communities, 2) develop new models by which to prepare health profession students to be leaders in interdisciplinary, community-based practice, 3) establish community-academic partnerships to help address the complex needs of underserved populations, 4) use communication and information technology effectively and appropriately, and 5) promote the health and community integration of individuals with disabilities.

The project was designed to educate interdisciplinary teams of occupational and physical therapy students to work with residents of transitional housing sites. The purpose of the project is to use interactive electronic health communications to develop health promotion programs for disabled individuals who are making the transition from homelessness to self sufficiency. The project was implemented through a community-academic partnership composed of university faculty, City officials and leaders of community social service agencies. Students learned to work as members of interdisciplinary teams and, through collaborating with residents and housing staff, develop a health promotion web site so that formerly homeless individuals were empowered to take control of their health.
Involving Patients in Online Learning

Presenter: Kieran Walsh, BMJ Learning, BMJ Publishing Group, London, UK

Additional Authors: Luisa Dillner

BMJ Learning is an electronic learning service for family physicians and hospital doctors. The BMJ Publishing Group is committed to publishing content that improves patient outcomes – we have patient panels for all of our products. Preliminary research with these panels showed that patients wanted to advise us on what their physicians should learn about. They also wanted to comment on the language used in the learning modules.

Members of the BMJ’s patient advisory group review BMJ Learning modules and comment on their language and tone as well as their clinical emphasis. Our advisers tell us when we make the error of calling patients “epileptics” as opposed to “people with epilepsy”. They point out when we write “start treatment with streptokinase” instead of “discuss with the patient the advantages and disadvantages of treatment with streptokinase and recommend starting this”. Our learning modules also contain fictional case scenarios involving virtual patients. Our reviewers often think that our virtual patients are unrealistic – for example they always take their medication exactly as prescribed. As a result we have made them more realistic – some of them complain to their physician and we then test our users’ skills in dealing with these complaints. Following the success of this process we asked a patient to write a learning module on the role that patients can play in advising other patients with chronic diseases. Our users were very positive - they felt that doing the module was “enlightening” and “time well spent”.
Concurrent Session 2.3.2.1  Room: Denman

Expert Patients and their Experience of Health Services

Presenter: Claire Gately, NPCRDC, University of Manchester, UK

Expert Patients Programme (EPP) is being piloted by the Department of Health in the UK and is a lay-led group treatment designed for use with a wide range of chronic disease conditions. The structured programme consists of six 2-hour sessions and aims to improve self-efficacy, enabling participants to more effectively manage their condition and empower them to become key-decision-makers in their own care. Recent health policy initiatives in primary care are increasingly centred around the desirability of a greater and more assertive role for patients in their communications with health professionals. Yet research to date suggests a certain diffidence on the part of many patients in challenging health professionals. The EPP may begin to change this dominant picture.

Qualitative interviews were carried out with a purposefully selected sample of people taking part in a randomised controlled trial (RCT) of the EPP. The interviews were undertaken before and after people took part in EPP in order to explore any changes participants have made in their use of services and any differences in their relationships with professionals. This seminar focuses on the relationships individuals have already established in primary and secondary care prior to entering the trial and findings of post-EPP changes will also be presented.

Concurrent Session 2.3.2.2  Room: Denman

The Chronic Disease Self-Management Program

Presenter: Patrick McGowan, Centre on Aging, University of Victoria, Victoria, Canada

The Chronic Disease Self-Management Program (CDSMP) is a lay-led patient education program. It is led by pairs of trained lay leaders to groups of eight to ten people once each week for 2 ½ hours for six consecutive weeks. Course participants are persons with chronic health conditions and their families. This type of education does not take the place of traditional doctor-patient or professional-patient education but is complementary to and reinforces such education. In the program participants obtain new information, learn new skills and abilities and develop higher levels of self-efficacy to manage and cope with chronic health conditions. The sessions are highly interactive, with emphasis on strategies to help individuals manage more effectively. Skills mastery is accomplished through weekly contracting to do specific behaviours and through feedback and modeling is accomplished by lay leaders with chronic conditions and uses frequent group problem-solving sessions.

Patient self-management programs were initially developed at Stanford University and have been implemented in British Columbia since 1989 for persons with arthritis, osteoporosis, tuberculosis and more recently for persons with any type of chronic health condition. It is being implemented in Chinese and in Aboriginal communities. Presently, the University of Victoria – Centre on Aging is implementing this program in each of British Columbia’s Health Regions. Program descriptions and BC evaluation results can be found on patient self-management is being planned for September, 2005 in Victoria. Please refer to the conference website at www.newperspectivesconf.com.
Concurrent Session 2.3.2.3  Room: Denman

**What Motivates Heart Disease Patients for Physical Activity and Training?**

**Presenter: Liv Bjerknes**, Faculty of Health and Social Sciences, Bergen University College, Bergen, Norway

My presentation is about a walking-group consisting of heart patients. Studies in rehabilitation of heart patients have indicated that useful knowledge can be obtained from listening to each other and exchanging of experiences. In my study the main subject is how to cope with chronic disease and physical activity.

**Objective**: To gain knowledge about how activities for heart patients can be organized, based on their needs.

**Actual topic**: What motivates people with heart disease for training? How do organized walking trips in groups influence coping with the disease and the living for the participants?

**Method**: Focus group, participating observation and interview. I will follow a group of people with heart disease who have been walking in mountains together for years.

**Theory**: The study is related to Bandura and his concepts of “self-efficacy” and outcome expectancy” (Bandura, A. 1997) Theory of salutogeneses will also be used (Antonovsky, A 1994).

Concurrent Session 2.3.3.1  Room: Comox

**Radiation Therapy from the Inside Out**

**Presenter: Fiona Mitchell**, BC Cancer Agency, Vancouver, Canada

**Additional Authors**: Ann McCutcheon

Attendees will have the opportunity to walk through radiation therapy without the “benefits” of the side effects! Using a blend of reality TV and humour attendees will be provided with not only a clinical perspective of treatment, but also the reflections of Ann, a true survivor and her experiences.

**Objectives**: On completion of this session, the participants should be able to:

- understand how treatment is received - what we do well and what we could do differently
- appreciate, on a new level, what side effects happen (physically, mentally, and emotionally)
- understand radiation treatment from the inside out!
Listening to the Voices: A Parent’s Perspective

Presenter: Linda Sullivan, Florida State University, Tallahassee, USA

Often times in health care, providers mistakenly take on the attitude of they know best and they do understand. In the world of parents struggling with a painful diagnosis bestowed upon their child, the health care provider, while empathetic, cannot begin to understand what it is like to live the experience on a daily basis.

With the incidence of autism and other related disorders on the rise, health care providers need to remain open to parents experiences, concerns and suggestions. It is important that we do “listen to the voices” so that we can understand best how to care for and support families living the experience of a child having autism. Patients are often our best teachers if only we would listen to them.

This presentation will discuss current trends in treatment of children with autism or other disorders in the PDD spectrum, while exploring several families’ personal experiences and comments with regards to how their children have responded to traditional and non-traditional treatment.

The Question Was: Could I Find a Way to Live with AIDS?

Presenter: Jacob Peters, Toronto, ON, Canada

Early in the pandemic, in 1984, when no one knew how to deal with my symptoms, my illness was a mystery. From what I suspected, I believed my life was over. I was terrified, confused and suicidal. The question was: could I find a way to live with AIDS?

Diagnosed in 1985, I despaired in loneliness until I began to speak about my condition with my late cousin and AIDS activist, Dr. Andrew Zysman, who was also HIV positive. He encouraged me to turn my photographic interest toward documenting the history of AIDS.

By attending AIDS conferences around the world, beginning in 1989 at Montreal, I developed a career as a photojournalist. That surprised me because I didn’t believe that I could do anything with a death sentence imposed upon me. My interest in life was rekindled. I learned to better cope with my illness.

With the pandemic’s persistent expansion I think it is important to share what I have learned.

My evolving and growing portfolio, which documents what I have witnessed and experienced over the past two decades, will inform medical students, practitioners, caregivers, PHAs, and people at risk of HIV infection, on matters emanating from living with Acquired Immune Deficiency Syndrome.
The Patient Voice Project: Teaching Creative Writing to the Chronically-ill

Presenter: Austin Bunn, Arts Share, University of Iowa, Iowa City, USA

Chronically-ill hospital patients are the bearers of a complex and complicated story—about their condition, about their life before and after, and how this experience has changed their sense of what is possible. This isn't a story that patients get much practice telling. The patient carries around a “broken story”, one that has a clear beginning (symptoms and diagnosis) followed by a vast ocean of middle without an ending.

In an effort to study this “broken story”—through journaling, visualization exercises, and directed writing assignments—the Patient Voice Project offers free creative writing classes to chronically-ill hospital patients at the University of Iowa Hospital and Clinics. Taught by graduate students at the University of Iowa's Writers’ Workshop M.F.A. program, the classes are conducted in one-on-one sessions and are designed to give patients an opportunity to think about narrative and storytelling as a pathway of healing.

Participants in the Patient Voice Project meet with an instructor for 10 weeks. Each session lasts for one hour, once a week. The structure of the hour is flexible, but typically includes an in-class writing exercise, discussion of outside writing and a “topic” for the class: character, choice, structure. Sample exercise questions have been: Sketch a character portrait of your doctor; Tell me the story of the day of your diagnosis; What does the safest place in your world look like?

The main structural component of the project is a pair of chronologies developed by the patient: one list of “benchmark” experiences in their lives and one list of “benchmark” experiences of their illness. The course seeks to braid these two “stories” together and find correspondences: concepts of wellness and peak experiences, home and travel, growth, etc. For the conference, I will present our exercises and provide a sampling of patient responses.
Advocacy As Alchemy: Empowering Patient Experience for Teaching and Service

Presenter: Martha Gaines, University of Wisconsin, Madison, Schools of Law, Medicine and Nursing, The Center for Patient Partnerships, USA

The Center for Patient Partnerships (“CPP”) is a multidisciplinary learning lab where students from nursing, medicine, law, social work, counseling psychology, industrial engineering, pharmacy, business and public policy come together to learn from patients about their health care experiences. Students, supervised by professional staff (MD, JD, MSE, MSSW), provide advocacy services to patients diagnosed with life threatening and serious chronic illnesses.

Services include helping patients and their families: better understand their diagnoses and treatment options; clarify and apply their own values in the treatment election process; communicate effectively with health care providers; appeal insurance denials and, where necessary, strategize other means to access desired care; learn about complementary and alternative treatment modalities; adjust psychologically to a serious diagnosis; deal with the financial and social consequences of illness; understand and reconcile medical bills, negotiate reasonable payment plans and secure forgiveness of medical debt; consider and complete powers of attorney for health care and living wills; talk with family members about end of life care and, through it all, find and maintain the natural source of hope that defines us as humans.

The patient services experience is part of two classes taught by CPP faculty entitled “Consumer Issues in Health Systems and Health Care Delivery” and “Patient Centered Care Providers.” The workshop will explore CPP’s teaching goals, development of our program and lessons learned from our first 4 years using several actual student/patient experiences. The goal will be to encourage dialogue and sharing about various “live patient” models of teaching.
Lights, Camera, and Action - Strengthening the Consumer/Survivor Voice

Presenters: Shawn Lauzon, Ontario Peer Development Initiative, Toronto, Canada; Raymond Cheng, Ontario Peer Development Initiative, Toronto, Canada

This workshop will present the findings from a participatory evaluation of four mental health Consumer/Survivor Initiatives (CSIs) in Ontario. This evaluation was part of a larger study called the Community Mental Health Evaluation Initiative, a first multisite study of community mental health programs in Canada. It was planned and conducted with the involvement of a wide range of players, including government, community providers, family and consumers. It is designed to provide information relevant to policy. The presentation will conclude with a description of the various activities undertaken to disseminate the findings of the CSI study, including the screening of the DVD entitled "From Madhouse to Our House".
Workshop Session 2.3.W3

Action Replay: Enhancing the Patient's Voice in Health Professional Education

Presenters: Diana Kelly, Division of Medical Education, Guy's, King's & St. Thomas' School of Medicine, London, UK; Geoff Wykurz, School of Integrated Health, University of Westminster, London, UK

What gets in the way of hearing the patient/client's voice? This workshop provides an opportunity to ‘play’ for a while and to imagine how things might change. What happens if we freeze an encounter, re-wind the tape and re-work a scenario to enhance the inter-actions with patients and clients?

The aims of this workshop are: to consider new perspectives on patient/client involvement, to attune our sensitivity to the patient’s ‘voice’ and to develop ideas to enhance patient participation for use with health professional and patient training.

The workshop will be experiential, involving participants in an exploration of innovative ways of interacting with patients that respect their views, expertise and contribution. It will begin with a short presentation outlining some basic principles for patient/client involvement in health professional education. We will then present a variety of scenarios involving interaction with patients, which participants will have the opportunity, in small groups, to ‘re-play’. The workshop will provide an opportunity to reflect on and to re-enact how patient-participation can be enhanced.
Narrative analysis is a qualitative methodology which seeks to understand “local knowledges” of human experience that are individualized and contextualized. Its theoretical and philosophical background draws from sociology, psychology, existentialism, sociolinguistics, nursing, and medicine. Narrative knowledge is derived from people’s stories in which they express their identity, relationships, and emotions. Patient narratives are increasingly being utilized as data to help health care professionals understand the subjective illness experience.

The job of the narrative researcher is to decode, recognize, recontextualize, or abstract the illness experience in the interest of reaching a new interpretation of the raw data from the patient interview or narrative description of their experience. Data analytic strategies will be demonstrated with the purpose of arriving at a core story (Emden, 1998). The whole transcript is analyzed for the presence of stories and segments of the text are selected for more detailed analysis. Common themes are synthesized across transcripts. Participants will discuss the analysis of the subjective meaning of the illness experience.

In this two-hour workshop, participants will discuss the philosophical and methodological background of narrative analysis. Two kinds of patient narratives will allow us to consider the patient’s voice. Literature based patient narratives, and data from research studies will be used to demonstrate a narrative analysis approach. Participants will also be given an opportunity to develop their own narratives of significant patient care experiences. For patient participants, there will be an opportunity to develop a narrative of their illness experience to share with their health care provider.
Ending the Journey - Talking with the Elders

Presenter: Randi Gage, Aboriginal Nurses Association of Canada, Loon's Cry Consultants, Winnipeg, Canada

A presentation directed to the Adult Senior population and their family members who will care for them when they begin to end their life's journey.

Context: In North America, death and dying has moved from a family right of passage, to hidden away in a cold hospital setting and has become an event to fear. Children are not allowed to see the cycle of life played out in a loving and safe setting. Death and Dying have become something that happens away from the family and is not regarded as a natural thing. With the change of the family structure, the removal of the family with generations under one roof, and the portrayal of death and dying by all of the media, the end of life has lost its touch. Today many who are facing the end of their life are requesting the right to end their journey in a place that they love, surrounded by those they love to the very end.

Setting: In a workshop setting, the discussion of what can be expected, when one reaches the time of life where ending their journey is not that far away. The topics presented are to assist those attending to better understand that it is their right to ask questions, get proper answers and arrange what they want when the time comes to leave this world. The workshop is generally in comfortable seating, with tables and refreshments available. As well, breaks are frequent and if someone becomes upset, discussion stops until the person(s) are able to go on.

Objectives: To open the pages of the book of death and make the journey an event that is a beautiful experience, not a lonely wandering, painful trip.

Design:
1. Current Material Review conducted
2. Current Materials reworked to a friendlier format
3. Creation of overhead presentation was developed
   a. Because most of my work in with Aboriginal Elders who are not comfortable with much of today’s technology, overheads make the presentation more comfortable for them.
4. There was no recruiting of participants, workshops are presented when requested by First Nations communities through out Canada
5. A Compassionate Care college course has been established in Winnipeg and will begin 26 July 04, to support the new federal legislation to allow family members to take paid Compassionate Leave of Absence from their job to care for their terminal loved one.

Subjects:
1. When dying you have to face a number of changes
2. The seven tasks of dying
3. Fears of the dying
4. Definition of “Family”
5. The five stages of grief
6. The four tasks of grief
7. Grief flashbacks
8. The family guilt
9. Three pahses following a death
10. A Creed for the dying:"Treat Me Nicely, As I Dye, Please"

Interventions: During the training sessions and sharing circles (participants set comfortably in a circle and each speaks with out interruption on what is bothering them. No one is judged, what is said in the circle stays in the circle), care is given to allow each participant time to come to terms with the information that he or she is hearing. Participants are allowed time to come to terms with his or her own mortality.

Main Outcome: Through the sharing of the truths of Death and Dying, removing the mystery and fears of the events, a better death and dying experience will be available to the participants and those they care for, (the Adult Senior) who care for them. (their loved one who is left behind)

Results: A peaceful and beautiful death experience for all that take part in the care.
Workshop Session 2.3.W6  Room: Pacific

The Silent Voice Of Mr. George

Presenters: Penny Cash, School of Nursing, Faculty of Health and Social Development, University of British Columbia - Okanagan, Kelowna, Canada; Donna Kurtz, School of Nursing, Faculty of Health and Social Development, University of British Columbia - Okanagan, Kelowna, Canada; Susan Van Den Tillaart, School of Nursing, Faculty of Health and Social Development, University of British Columbia - Okanagan, Kelowna, Canada; Fay Karp, School of Nursing, Faculty of Health and Social Development, University of British Columbia - Okanagan, Kelowna, Canada; Joan Bassett-Smith, School of Nursing, Faculty of Health and Social Development, University of British Columbia - Okanagan, Kelowna, Canada

As a way of raising nurses’ awareness of the patient’s voice, this workshop revolves around a nurse’s real life story while working on a surgical ward. With the unfolding narrative about Mr. George, the patient, participants will become engaged in the parallel acts of meaning making between a nurse and patient. Moral and ethical dilemmas surface between the nurse/patient, nurse/hospital, and patient/hospital resulting in a highly politicized context. The emerging context is the reality of today’s nursing practice. Using a critical post modern perspective, the story highlights issues encompassing moral agency, ethical decision making, advocacy, nurse-patient relationships, and power.

Mr. George’s hospital experience is shared through the eyes of the nurse as a play read narrative. The invisible self of Mr. George becomes present through the nurse’s journal entries. Powerful new understandings of his experience, although silenced, become very real and tangible. As the narrative proceeds, so do the moral and political struggles that arise during his hospitalization. While Mr. George remains physically invisible, his journey is felt profoundly though visual text. Powerful personal and professional meanings for patients, clients and health care professionals will be illuminated.

Questions to stimulate workshop discussion include:
1. What health care practices marginalize people from receiving optimal health care?
2. How can we disrupt power relationships within traditional health care environments to support the legitimacy of people’s voices?
3. What questions need to be raised to ensure that the people’s interests are being served?
4. How can health care professionals support each other in ways that promotes quality work environments?
Poster 01

The Use of Standardized Patients in an Advanced Communication Skills Curriculum For Pediatric Residents

Presenter: Débora Silva Diaz, School of Medicine, University of Puerto Rico, San Juan, Puerto Rico

Background: Good Doctor-Patient Communication is essential to deliver adequate Medical Care. The ACGME will require evidence of residents’ competence in communication skills by 2006. A communication skills curriculum for Pediatric Residents was developed at the UPR School of Medicine. Standardized Patients (SP’s) were trained to teach, give feedback and evaluate each of the curricular components. We analyzed the effectiveness of using SP’s to train residents.

Methods: Five SP’s underwent 14 hours of training in Communicating Bad News. First year Pediatric Residents were divided into an intervention and a non-intervention group. The intervention group participated in 4 workshops given by SP’s in which they learned and practiced how to give bad news. Both intervention and non-intervention were tested by means of a two-station OSCE.

Results: Residents in the intervention group found the teaching strategies to be effective in their learning process, feedback from the SPs to be complete and thorough and felt prepared to give bad news while those in the non-intervention group did not. They also performed significantly better than those in the non-intervention group in the OSCE.

Discussion: Residents in the intervention group felt the workshops led by SPs were a key element in their learning process. In conclusion, using SP’s to teach communication skills was an effective educational strategy.

Poster 02

Focus Group Contributions: People in Recovery from Substance Abuse Assist in Developing Standardized Patients

Presenter: Holly Fussell, Oregon Health & Science University, Portland, USA

Additional Authors: Colleen Shannon-Lewy; Bentson McFarland

Focus groups are well suited for collaborating with community members while also contributing to research. This design allows those who will benefit from the results of research to speak to the issues. Focus groups also increase the face validity of measures designed to assess topics experienced first hand by participants.

A “feasibility” study: We conducted a “feasibility” study seeking to develop realistic standardized patient (SP) protocols of substance abuse clients with co-occurring problems. This task was conducted amidst concerns that standardized patients appear unrealistic when portraying complex cases. Therefore, we used multiple methods to ensure realistic and accurate portrayals of people dealing with substance abuse.

The focus group: A focus group was conducted to assess the authenticity of our SPs. Participants were community members in recovery from substance abuse. We showed the focus group videotaped footage of two mock interviews illustrating interaction between SP and interviewer. The research team then solicited quantitative and qualitative responses to three guided questions, including, 1) How realistic is (name’s) physical appearance, 2) How realistic were (name’s) emotions, and 3) How realistic were (name’s) reactions to the counselor? Additionally, participants were asked, “How should substance abuse counselors be evaluated?” Results indicated mixed reactions to the two SP’s respectively, indicative of the focus group’s ability to discriminate between quality of SP’s portrayals. This procedure provided rich, diverse and crucial information for the development of realistic standardized patients in this context.
**Poster 03**

**Healthcare Attitudes: Are Standardized Patients Different?**

**Presenters:** Colleen Shannon-Lewy, Oregon Health & Science University, Portland, USA; Holly Fussell, Oregon Health & Science University, Portland, USA

Standardized patients (SPs) are individuals who are coached to simulate physical and psychological symptoms, in order to train and assess provider clinical skills. Accordingly, SPs are exposed to medical education, and the assessment of both medical and interpersonal skills. Therefore, it is likely that they form opinions of their own health care providers based on these experiences. All SPs who were in a database from a Pacific Northwest medical school were sent surveys asking about their attitudes towards healthcare. Over 60% of SPs returned their questionnaires (N= 200, 60.4%). Of these, 123 had had previous experience as an SP (experienced SPs), while the rest had been recruited but not yet had any SP experiences (new SPs). Experienced SPs thought that medical students had good technical and interpersonal skills. They also thought that an SP exam should be required to receive a medical license. Compared to new SPs, experienced SPs were significantly more satisfied with their own providers’ interpersonal skills and felt more in control of their health.

Surprisingly, the amount of SP experience did not matter. Further studies are needed to determine what aspects of SP experiences impact these attitudes and whether these attitudes affect their health.

**Poster 04**

**The Development of Complex Psychological Standardized Patient Cases**

**Presenters:** Colleen Shannon-Lewy, Oregon Health & Science University, Portland, USA; Holly Fussell, Oregon Health & Science University, Portland, USA; Julie McDougal, University of Alabama at Birmingham School of Medicine, Birmingham, USA

**Additional Authors:** Bentson McFarland

Standardized patients are frequently used to portray people with assorted ailments. These cases often have complicated histories that include psychopathology. There has been criticism that SP’s are not realistic in these roles. We hypothesized this problem may reflect inadequate case development and inaccurate case portrayal. Drug and alcohol addiction requires complex cases often involving a complicated life history, psychological co-morbidities and intense physical symptoms. We decided tested whether or not SPs could accurately portray individuals with drug addiction. Four cases were created.

**Case Development:** A literature review was conducted, and common issues were elicited from counselors and psychiatrists. The SP “script” included a complete life story, with a social/medical/family/drug history, symptoms, timeline, and co-morbidities as well as details related to work, insurance and relationships with others. Some symptoms and issues on the timeline were described in detail; others were left vague.

**Case Portrayal:** Care was taken to portray symptoms of addiction including attitudes toward treatment. Feedback on SP performance was provided at multiple times throughout the development process from drug and alcohol counselors, physicians, and a focus group of people in recovery from addiction. The latter was particularly useful in providing information about personal perspectives on addiction.

Each SP will be interviewed by 30-50 drug and alcohol counselors for feasibility. Initial feedback is positive. Our preliminary conclusion is that SPs can portray complex cases; however, case development must be extensive and feedback from experts is invaluable.
Innovations in Experiential Learning: Exploring Teaching Methods that Enhance Cultural Competency in Aboriginal Health in the Faculty of Medicine at University of British Columbia

Presenters: Betty Calam, Department of Family Practice, University of British Columbia, Vancouver, Canada; Leah May Walker, Department of Family Practice, University of British Columbia, Vancouver, Canada; Lindsay Crowshoe, Department of Family Medicine, University of Calgary, Canada; David Diamond, Headlines Theatre, Vancouver, Canada

There are huge disparities between the health of Aboriginal and non-Aboriginal Canadians. Curriculum that focuses on Aboriginal Health issues in the Faculty of Medicine at UBC is in development. Initially it consisted of two lectures over two years to undergraduate medical students in their Doctor, Patient & Society course and one for postgraduate residents. These sessions were designed to explore Aboriginal perspectives on health. We wanted to expand opportunities for medical trainees to explore their own attitudes in working with Aboriginal patients, to engage directly with Aboriginal people and their health issues, and to practice culturally sensitive communication skills in the context of physician-Aboriginal patient interactions.

We formed a group consisting of a theatre director, who works on theatre projects with various Aboriginal communities, Aboriginal and non-Aboriginal physicians involved in medical curriculum development, and an educational coordinator with a background in teaching drama. We started a process of discovery and innovation toward using theatre techniques to create an experiential activity that would incorporate Aboriginal perspectives on health and resonate with learners in the medical school.

We planned a pilot session for all UBC Faculty of Medicine residents in May 2003. We included Aboriginal community members in the development and implementation of the learning activity. The poster will describe our process of building the session, the use of patient narratives, the questions that arose before, during, and after the event, as well as our evaluation of the process.
Learning to Work with Community to Develop and Deliver an Experiential Interprofessional Aboriginal Health Elective

Presenter: Helen Novak Lauscher, Continuing Medical Education, University of British Columbia, Vancouver, Canada

Additional Authors: Anna Lee; Robert F. Woollard; Leah May Walker; Lesley Bainbridge; M. Peter Granger

Several health professional programs at the University of British Columbia with an interest in Aboriginal Health, interprofessional education, community participation, and experiential learning have united to engage with community partners in developing an Aboriginal Health Elective. The proposed interprofessional course builds upon a rural placement program and HIV/AIDS course that model student teams engaged with communities.

The primary goal is to develop and maintain relationships with Aboriginal peoples in communities, and engage students and teachers in meaningful experiential learning. The model must be sustainable and beneficial for all partners including community members, students, and academic programs. The elective will be co-designed with community partners to address learning opportunities for interprofessional groups of students in partnership with urban and rural communities.

Interprofessional education is enhanced when the academy reaches beyond itself to engage community. This collaboration will challenge academic inflexibility and profession-specific curricular limitations while fostering reciprocity and mutual learning. With community partners, we aim to address the lack of education in Aboriginal Health across professions, recognize communities as educators and foster cultural safety in the learning context.

The development team represents a diversity of expertise and has created a welcoming and sustainable context for innovative education. It is our hope that the Aboriginal community members, students and faculty will share this spirit. Next steps involve developing respectful and sustainable relationships with interested communities, working with community partners to develop curricular and experiential components, piloting the course, and developing an evaluation framework to assess student learning, community satisfaction and interprofessional teamwork.
"Not Just...Another Indian Dollar?"  Aboriginal Communities Collaborating in the Development of Educational Programs for Health Professionals

Presenter: Gina Dawn Scarpino, Division of Health Care Communication, University of British Columbia, Vancouver, Canada; Melissa Niemeyer, Division of Health Care Communication, University of British Columbia, Vancouver, Canada

Additional Authors: Cathy Kline, William Godolphin, Angela Towle

The need to improve health care for Aboriginal people is a stated national priority in Canada. At the University of British Columbia medical school we aim to improve health care communication between physicians and Aboriginal people by the development of educational interventions based on the needs and experiences of community members.

In a preliminary study, semi-structured interviews and focus groups were conducted with 20 Aboriginal community members and 9 health professionals (some of whom were Aboriginal) who worked with Aboriginal patients. This study indicated that Aboriginal peoples’ previous experiences with the health care system, physicians and/or other Western influenced authority figures affect their communication with health care providers; these barriers may be overcome when the patient feels that s/he has a voice and the time for it to be heard. However, the study also showed the need for more in-depth information in order to better understand these issues and to develop an appropriate educational intervention. It was also clear that a different approach to engaging with Aboriginal people would be required.

In a follow up study, in-depth interviews and focus groups were held with 26 Aboriginal people. A model of consultation more fitting to the culture of the community was used. Themes that were explored included history, culture, experiences of care (positive and negative), consequences or negative health outcomes and potential educational interventions. Focus groups were also held with undergraduate medical students to find out what, and how, they would like to learn from Aboriginal people. A model for curriculum development has emerged from this work. It engages Aboriginal people and students, is in keeping with traditional teaching in the Aboriginal community and is bridged and filtered by educational leaders at the university.
**Poster 08**

**First Nations Patient Advocacy**

**Presenter: Deborah Senger**, Aboriginal Health Program, BC Women’s Hospital & Health Centre, Vancouver, Canada

BC Women’s Hospital & Women’s Health Centre administers the Aboriginal Health Program. This program provides First Nations Patient Advocacy (FNPA) services on site for 1st Nations patients of BC Women’s Hospital and Women’s Health Centre, BC Children’s Hospital and Sunny Hill Health Centre for Children.

The role of the FNPA is to ensure that 1st Nations Patient’s overall needs are met through Patient Advocacy based on cultural sensitivity. Results from study emphasized the need for appropriate Aboriginal Healthcare services that were culturally sensitive. For the past 10 years, the FNPA met the overall needs of Aboriginal patients on site that reflects upon culturally appropriate Advocacy services. The Advocate assists families to navigate through the hospital system, feel comfortable to ask questions regarding care and treatment and to feel safe in an unfamiliar setting.

Services include the provision of care packages, spiritual support and emergency clothing. The FNPA liaises with on site Healthcare Professionals in Advocating on pertinent Healthcare issues that arise on behalf of our Aboriginal patients and their families. Concerns or issues conveyed by an Aboriginal patient and/or caregiver are directly addressed through the voice of the FNPA with the support of the Aboriginal Health Program. Patients and their caregivers are supported and comforted.

Through the FNPA, Culturally Sensitive Healthcare Education is provided to Healthcare Professionals inclusively to on site Social Workers, Nurses, Physicians and Spiritual Care. One to one education services are rendered where applicable on site. The FNPA continuously bridges the gap between Aboriginal patients/caregivers and on site Healthcare Professionals by providing culturally sensitive education related to pertinent Healthcare issues.

**Poster 09**

**Stories and Narrative in Health Professional Education**

**Presenter: Christian Blickem**, CARE (Centre for Applied Research in Education), University of East Anglia, Norwich, UK

The poster presentation will be based on my experience of working as part of a multi-disciplinary, multi-professional, cross-organisational research team whose purpose was to develop and implement a stroke education programme for service users and their carer/relatives on a stroke rehabilitation ward. The initial findings led us to believe that in order to provide a meaningful educational programme, the different health professionals involved needed to share a common perspective on patient experience even as their professional roles and care duties may differ.

As a response to this we developed “factionalised” patient and carer case studies to illuminate different patient and carer experiences of the service in the belief that this material would: 1) help professionals understand the fragmentation or ‘dissection of self’ experienced by the patient when exposed to different working practices rooted in different professional perspectives; and 2) help the researchers formulate an educational programme that was not just ‘patient-centred’ or sympathetic to professionals but one that would set in motion processes that would build alliances between these groups rather than place them in antagonistic positions.

The presentation will discuss how the research evolved in terms of design and methodology and will reflect on the processes that were set in motion when “factionalised” patient experiences were narrated to hospital staff. It considers both the intended and unintended consequences of such story-telling i.e. how the narratives initially opened up a space for critical reflection by allowing some distance between patients and staff (readers/listeners) but also how the narratives generated an empathy in staff for patients in the stories. Our contention is that this empathy allows a rather different sort of ‘gaze’ in a clinical setting – one that sees the patient gazing at the professional. We suggest that this might in turn, opens up the possibility of a different way of relating to patients.
Poster 10

Parent's Experience of Breaking Bad News in Pediatric Departments

Presenters: Dominique Detemmerman, Department of Child Surgery, University Clinics of Brussels Erasme Hospital, Free University of Brussels, Belgium; Isabelle Lambotte, Department of Psychology, University Clinics of Brussels Erasme Hospital, Free University of Brussels, Belgium

Additional Authors: Nicole Delvaux; Francine Gillot-de Vries

Objective: Parents of children with life threatening or terminal diseases were interviewed about their experiences of the way in which they were told the diagnosis. Parents and health care professionals were asked how satisfied they were with the initial discussion about the diagnosis.

Design: Qualitative and longitudinal (just after the disclosure and six months later) survey using semi-directive interview and self-assessment questionnaire related to the bad news disclosure practice, to parents’ views on how diagnosis of their children should have been handled and to parental emotional health.

Setting: Departments of Child Surgery, Paediatric Neurology and Intensive care.

Subjects: 31 families (42 mothers and/or fathers, informed and consenting), physicians and nurses were included in the study. Main sample characteristics: child’s age between 3 months and 16 years old, brain injuries including traumatic brain injury, cerebral tumor and severe neurological affections.

Results: Data demonstrate the relationship between the way to break bad news and the parental emotional experience.

Conclusion: Results allow some recommendations for informing families about their child’s illness or disability. From this analysis we set up a training program for health professionals to guide them in breaking bad news.
Poster 11

Client-Centered Practice: Easier to Say than Do

**Presenter:** Debbie MacLellan, Department of Family and Nutritional Sciences, University of Prince Edward Island, Charlottetown, Canada

Additional Authors: Shawna Berenbaum

This research sought to determine the meaning that dietitians ascribe to the client-centred approach to nutrition counselling and identify the important issues inherent in this approach to practice. A two-round Delphi survey with 57 dietitians followed by 25 indepth interviews was used to collect the data. Results indicated that participants were struggling to find a balance between their beliefs about what a client-centred approach ‘should’ be and what was possible given the realities of their workplaces. Most indicated that they had experienced barriers to delivering nutrition counselling services using a client-centred approach. The most frequently cited barriers were: unrealistic client expectations, limited time allocated for nutrition counselling, family member’s expectations, client’s educational level, and doctor’s expectations. When asked to identify the factors that help them use a client-centred approach to delivering nutrition counselling services, most participants indicated past positive experiences using the approach. Working as part of a team that uses a client-centred approach was also seen as helpful by more than half of the participants. Participants were also asked to provide suggestions for improving their ability to deliver client-centred nutrition counselling services. The need for additional education and/or training in nutrition counselling and the development of resources and tools to assist them in using a client-centred approach were cited most frequently. These results suggest a need to examine the way that we educate and train dietetic students in Canada in order to overcome some of the barriers to client-centred practice and improve the way we deliver services to clients.

Poster 12

Professional-Family Collaboration in Family-Centred Early Childhood Intervention

**Presenters:** Chih-Hung Yang, School of Behavioural and Community Health Sciences, Faculty of Health Sciences, University of Sydney, Australia; Zakia Hossain, School of Behavioural and Community Health Sciences, Faculty of Health Sciences, University of Sydney, Australia

Current trends in early childhood intervention (ECI) have been towards family-centred service delivery which involves families in the trans-disciplinary team. Including parents’ perspectives in intervention process can facilitate the family-centred services. Such approach highlights professional-family collaboration in designing services to meet the needs of the whole family and optimise the child’s developmental outcome. It is believed that the success of ECI will rest on the quality of professional-family collaborative relationships. Therefore, developing effective relationships with families is a critical ability for professionals to develop.

Working together with parents can be challenging. It requires significant changes regarding the relationships on an equal basis and skills necessary for effective collaboration. While ECI has recognised the value of involving families in service delivery, the family centeredness seems not beneficial in all circumstances and there remain problems about the collaborative practice. In an effort to remedy the situation, it needs to move beyond rhetoric which family centeredness is treated as knowledge only to direct service delivery.

This paper argues that parents can play a role as teacher and family centeredness should incorporate the value of empathy into collaborative practice. Professionals should show full concerns in collaborative process by listening to individual families’ stories and feelings. The future staff training needs to be innovative focusing on empathy competence. This paper is based on my PhD research which in part, focuses upon professional-family relationships in ECI. The research is at its initial stage and data collection is in progress. Some of the preliminary results will be incorporated in this paper.
Poster 13

Health Professionals' Management of Fibromyalgia: Based on Patients' Expectations, Questions and Satisfaction of a Multidisciplinary Fibromyalgia Education Program

Presenters: Katherine Cotton, Occupational Therapy Rheumatology Services, University of Alberta Hospital, Edmonton, Canada; Lois Flakstad, Physical Therapy, Rheumatology Services, University of Alberta Hospital, Edmonton, Canada

Additional Authors: Danielle Skeith; Paul Davis

Objective: Patient education programs are one of the most valuable clinical resources for patients dealing with fibromyalgia. The objective of this study was to evaluate patient satisfaction of 60 subjects enrolled in the University of Alberta Hospital three-day fibromyalgia education program. This included how well the program had met these patient's expectations.

Methods: A session evaluation questionnaire as well as a custom designed satisfaction survey was utilized to measure patient satisfaction. Agreement and Likert scoring systems were used to analyze results from the questionnaires.

Results: Every mean score was greater or equal to 2.9 out of 5. Statistical improvement of FIQ scores were observed during analysis of pre and post program mean scores, 67.5-59.1 (P < 0.002).

Conclusion: Overall results demonstrated that patients were satisfied with the fibromyalgia education program but a number of inclusions and modifications to the program were suggested by participants to optimize their self-management of this difficult condition.
Poster 14

Improving Understanding Among Patient and Doctors: An Approach for Collaborative Policies

Presenters: Roger Ruiz Moral, Unidad Docente de Medicina de Familia de Córdoba, Cordoba, Spain; Juan Jose Rodriguez Salvador, Ortuella, Spain

Additional Authors: MJ Fernández; A Yun; J Martínez de la Iglesia; JC Arboníes; MA Cabanás; I Fernández; L Pérlula; JM Parras; D Prados

Aims: To improve understanding among patients and physicians for developing future collaboratives approaches in health care and medical education

Methods: 4 focus groups where held among patients and doctors, two facilitators conducted each session. The critical incident methodology was used as start point for explaining and discussing individual shocking experiences in the relationship between doctor and patient. The group discussion were recorded and transcribed.

Results: 43 family physicians and 41 patients or caregivers attended the groups. 63% of patients belong to a Patient Association. Patients expected from doctors: clinical competence, competence for listening and understanding the real needs of persons as human being; skills for caring were also demanded by patients. Physicians claimed their interest in patients as persons but they demanded from them to be considered persons as well. Doctors felt frustration when they did not get "scientific evidence", frequently they did not recognize the power of active listening, they felt that often the conditions of practice put them into a straitjacket.

Conclusions: Respect, humanity and sensibility are mutual virtues and key features for creating a confidence climate and reaching mutual understanding. All participants agreed that practical ways to get these aims were empathy, genuine interest, keeping enough time when attend patients, and to realize that each patient has different pace for adapting to his/her condition. For both, to care the caregiver had to be keep always in mind. All highlighted the paramount importance of encouraging this kind of encounters among patients and doctors in the clinical settings.

Poster 15

Children's Voice in Pediatric Nursing Care - How Can We Hear It?

Presenter: Arja Suikkala, Department of Nursing, University of Turky, Turku, Finland, Finland

Additional Authors: Tiina Pelander; Helena Leino-Kilpi

Background: The United Nations Convention on the Rights of the Child (1989) states that children not only have the right to opinions of their own with regard to issues affecting them, but also have the right to voice these opinions. It is very important to investigate children’s experiences, but this has been studied quite inadequately from the point of view of nursing. For example, studies concerning pediatric care usually have been focused to parents.

Aim of the project: To describe the quality of pediatric nursing care from children's perspective.

Research question: What methods are suitable for children to evaluate quality of care?

Methods, Samples and Settings: Interviews (n=40) and drawings (n=35) were collected from 4 to 11 years old children; and with questionnaire with drawing task aged 7 – 11 years children (n=330) from five university hospitals in Finland during their hospitalization in 2005.

Results: The limited verbal ability of the youngest children makes the drawing method particularly useful with this group of patients. An interview is vulnerable due to various factors that affect the reliability of the data; however, events important to the child are fairly resistant to that. Questionnaires are suitable to school age children, but the length should be limited and pilot tested beforehand.

Conclusion: The different methods should be used and tested with children. It is the only way to find out what is significant and meaningful to them and the way to improve the pediatric nursing care from their perspective.
**Poster 16**

**The Dialogue in the Helping Group - Consequences for the Education**

**Presenter: Margunn Rommetveit**, Faculty of Health and Social Sciences, Bergen University, Norway

Through videotape the helping group has been followed for 1 year. The mother and father of a multihandicapped boy are collaborating with the professionals to make plans and to make some efforts to give him a better life. Through microanalysis (Erickson 1982a, 1982b) of the videotapes I want to look closer at the dialogues in the meetings. What is characteristic for the dialogue when it goes in an appreciative way? (Schibbye, 1988) What about the dialogue when it comes to some disharmony?

**Poster 17**

**Educating the Patient in and for Pharmaceutical Care Expectations**

**Presenters: Mary Indritz**, College of Pharmacy, University of Minnesota, St. Paul, USA; **Peter Morley**, Peters Institute of Pharmaceutical Care, College of Pharmacy, University of Minnesota, Minneapolis, USA; **Linda Strand**, Peters Institute of Pharmaceutical Care, College of Pharmacy, University of Minnesota, Minneapolis, USA; **Robert Cipolle**, Peters Institute of Pharmaceutical Care, College of Pharmacy, University of Minnesota, Minneapolis, USA

Pharmaceutical care practitioners have a social responsibility to provide care to all patients. Patients understand how care and service feel based on prior experiences and perceptions. However, in merging philosophy and practice it is difficult for patients to fully understand and appreciate what pharmaceutical care encounters include and how health improves. This gap is closed by teaching the pharmaceutical care philosophy and model to patients through reviewing service expectations. Teaching pharmaceutical care to patients involves looking for reliability, responsiveness, assurance, empathy, and tangibles from practitioners.

Service includes answering questions, untangling logjams, fixing what is broken, soothing the irate, reassuring the timid and is recognizable as it makes positive, lasting impressions on patients through meeting expectations, satisfying needs while making relationships between patients and practitioners enjoyable and trustworthy. In practicing pharmaceutical care, practitioners take responsibility for identifying, resolving, and preventing drug therapy problems, which includes assuring that patients’ drug therapies are appropriate for each medical condition, the most effective and safest drug therapy is used, and patients are able and willing to take the medication as intended. The practice is a generalist and collaborative model applied in all settings (community, clinic, hospital, long-term care), built on shared decision-making and patient autonomy, and used to care for all patients with all types of diseases taking any type of drug therapy.

The resulting demand for the practice, through empowering patients, is in bringing patients’ voices back to health professional education to increase the value and quality of future recognizable pharmaceutical care encounters.
Poster 18

Promoting Access to Health Care for Francophones in British Columbia

Presenters: Darryl Quantz, Vancouver Coastal Health Authority/Provincial Health Services Authority, Vancouver, Canada; Helene Cameron, White Rock, Canada

Additional Authors: Suzanne Barclay; Ted Bruce; Yves Trudel

British Columbia’s Francophone community is a vibrant and diverse population. In spite of being one of Canada’s official languages, there are no existing policies regarding service delivery in French within any of the health authorities. This presentation will describe a joint project between the Vancouver Coastal Health Authority (VCH) and Provincial Health Services Authority (PHSA). Although many Francophones are fluent in English, many still desire to have services in their first language. Driven by the results of both community/patient consultations and previous Francophone health reports, a number of approaches were identified to improve access to health services for the Francophone population. The first was the linkage of Francophone primary care patients to available French speaking health professionals. This was complemented by the development of French health information resources, including a website and print material. The second was the development of a resource package to provide parents of children with special needs referral and health education information in the French language. This was complemented by the creation of linkages between the French School Board (Le Conseil Scolaire Francophone) and provincial resources/care centres such as the BC Autism Assessment Network, Sunny Hill Health Centre and BC Children’s Hospital. The project represents an opportunity for health authorities to respond to the needs of a frequently overlooked patient group identified through active partnerships and community participation processes.
Enhancing Psychosocial Oncology / Palliative Care in Newfoundland and Labrador: A Community-Based Supportive Care Professional Development Program

Presenters: William Haynes, Social Work Department, Dr. H. Bliss Murphy Cancer Centre, St. John’s, Canada; Valerie Barrington, Oncology Social Work Department, Dr. H. Bliss Murphy Cancer Centre, St. John’s, Canada

Background:
This project initiated as a result of frequent requests to the Dr. H. Bliss Murphy Cancer Centre from health care professionals throughout the province for enhanced continuing education regarding psychosocial oncology and palliative care. Community based health care professionals throughout the province cover a wide geographical area and are often the sole source of intervention to address a diverse range of local health needs. Necessity demands they have expertise in many areas, but they often operate in relative isolation, with limited opportunities to specialize in their professional practice, or access advance knowledge and skills to support their role in providing psychosocial support and palliative care. This project aims to support the work of community-based health care professionals by reducing their sense of isolation, providing advanced knowledge and skills as well as becoming an accessible resource for case consultation.

Goal of the Project:
- Cultivate long term, sustainable relationships with health care providers
- Strengthen knowledge, skills and competencies in psychosocial oncology and palliative care
- Enhance the quality of supportive oncology care to patients and families in Newfoundland and Labrador.
- To incorporate experiences of cancer patients and families into the development of continuing education curriculum for health care professionals.

Design and methods:
Three Phase Project:
Phase 1: Networking and Needs Assessment (12 months)
Methods: Focus groups: professionals, patients and family meetings, summary report, teleconference, individual meetings, summary report
Phase 2: Development, Test Piloting and Delivery of Education Services (18 months)
Methods: Integrate needs assessment. Research and develop core content. Conduct test pilot and deliver education series.
Phase 3: Project Evaluation and Dissemination (6 months)
Methods: Course evaluation surveys. Teleconference focus groups. Summary report. Formal presentations.

Conclusions:
Phase 1 is almost complete. Focus groups with health care professionals and patient/families have been conducted within 19 communities throughout the province. A total of 206 health care professionals and 76 patients/families have taken part with approximately another 8 communities to be visited.
Poster 20

Curricular Applications of Physician-Patient Collaborative Research: Communication Competencies for Shared Decision-Making

Presenters: Beth Lown, Mount Auburn Hospital, Department of Medicine, Carl J. Shapiro Institute for Education and Research, Harvard Medical School, Cambridge, USA; Janice Hanson, Uniformed Services University of the Health Sciences, Department of Pediatrics, Bethesda, USA

Objectives: To derive and implement competencies for shared decision-making in medical education communications curricula.

Methods and Results: We led four focus groups of 44 patients with chronic diseases and 41 primary care physicians who together explored attitudes and behaviors that facilitate shared decision-making. Qualitative data analysis yielded 26 physician communication themes, and 17 patient themes. Physician themes representing observable behavioral skills were integrated into medical curricula across a spectrum of learners. These skills were included in a communications curriculum for the HMS medicine clerkship, including a web-based teaching module. At USUHS students in the family medicine clerkship practice reflecting patients' priorities and integrating them into a jointly developed plan. These skills were included in the objectives for standardized patient assessments at both HMS and USUHS. Independent analysis of data regarding students' performance of these skills at both medical schools is in progress. Patients and clinicians together practiced these skills in an AAPP national faculty development course. These skills will be represented in teaching modules for undergraduate, graduate, and continuing medical education in an AAPP interactive electronic WebText, doc.com.

Summary: Patients and physicians together explored communication competencies that facilitate collaboration in shared decision-making. These competencies were integrated into a variety of curricular innovations across the continuum of medical education.

Conclusions: Qualitative research to explore and define behavioral skills desired by both patients and physicians can be applied to curriculum development. Learners' skills performance can be assessed to inform individual and curricular quality improvement.
Poster 21

Making a ‘Democratic’ Consultation Process Inclusive for Learning-Disabled Adults

Presenter: Margaret Byron, Centre for Medical Education, University of Bristol, UK

Additional Authors: Paul Bradley; Shekar Bheenuck; Louise Jones; Claire Wickham

Partners in Practice (PiP) ran an extensive consultation to determine essential learning outcomes for healthcare students studying disability equality. The consultation used the Delphi process, an anonymous method of achieving consensus on a controversial issue among a group of people with very diverse opinions. The Delphi process is considered democratic because each participant’s contribution has equal weighting and anonymity ensures that no one opinion overly influences another.

The Delphi consultation document was available in various formats to ensure maximum accessibility. However, in order for learning disabled people to participate an entirely different format had to be devised. PiP collaborated with a local organisation called Circles Network to run a facilitated workshop enabling a group of learning disabled adults to complete a rewritten and reformatted consultation document. This workshop took place after the first round of the consultation was completed, enabling the group to consider their rankings against the average rankings of other participants. An animator illustrated each learning outcome or descriptor as it was discussed during the workshop and the resulting illustrated document is available on our website as an example of how complex healthcare related information can be made accessible. www.bristol.ac.uk/pip

The rankings of the learning disabled adults broadly correlated with the consensus reached by anonymous participants. A second workshop run with another group of learning disabled adults from a different organisation achieved similar results. However, involving disabled people in consultation calls into question the claim that the Delphi process is democratic.
Poster 22

A Systematic Review of Health and Social Service User Involvement in Higher Education

Presenter: Lidia Koloczec, Comensus Project, Faculty of Health, University of Central Lancashire, UK
Additional Authors: Soo Downe; Mick McKeown; The Comensus Team

Service user and carer involvement is rapidly becoming an essential component in higher education teaching and research. Many universities, within their health related courses, are involving service users and carers in a variety of manners in both teaching and research. What is unclear when perusing through literature on the subject, however, is the extent of this involvement.

This poster describes a systematic literature review of the involvement of health and social care service users and carers in teaching and research activities in higher education institutions.

The inclusion criteria were:
- Qualitative and quantitative research encapsulating systematic service user/carer involvement in higher education; involvement at any stage of a higher education programme of learning whether it be at the initial stage of programme design and development, at the teaching stage or at the assessment stage.
- Qualitative and quantitative research encapsulating systematic service user/carer involvement in higher education research.
- Papers in the English language

Exclusions:
- Unsystematic or one-off service user involvement projects in higher education teaching and research.

Thematic issues emerging from the literature review will be presented in this poster. Generally, the findings indicate that the published literature is relatively thin with regard to evaluative work and consideration of systematic approaches to user involvement. It was difficult to obtain a full picture of service user and carer involvement activity within institutions of higher education. A great deal of literature proved to be descriptive or narrative accounts of initiatives. A significant proportion of literature related to one-off projects and teaching sessions.

Many institutions of higher education appear to have formed links with service user and carer organisations within their localities. Effectively, the literature review highlights that involvement often appears piecemeal and fragmented. Consideration of grey literature and communication with individuals within various institutions of higher education indicates that a great deal of involvement is occurring yet co-ordination of such involvement is sparse. In certain institutions there appears to be no liaison between or even within departments. It would be very useful if more institutions of higher education published information regarding their activity within the field of service user and carer involvement.
Poster 23

Creating a Community Advisory Board for a Core Course in Undergraduate Medical Education at the University of British Columbia: An Overview of the Why, the What, and the How (2002-2005)

Presenters: Vince Verlaan, UBC Faculty of Medicine, Vancouver, Canada; Keith Ahamad, UBC Faculty of Medicine, Vancouver, Canada; Kim MacDonald, UBC Faculty of Medicine, Vancouver, Canada

During their first two years of medical school, UBC medical and dental students take a non-clinical course called Doctor, Patient, and Society (DPAS). The object of DPAS is to prepare future physicians to understand and adapt to the changes in healthcare systems, doctor’s roles, and the healthcare needs of the Canadian population and beyond. The ‘essence’ of the course can be captured by three words: ‘evidence’, ‘context’ and ‘compassion’.

In 2003, the course directors for DPAS were faced with both a rapidly expanding number of incoming medical students and a steady decline in the number of community-based health-oriented organizations, their clients and patients who were willing to assist with core DPAS learning activities.

A DPAS Community Advisory Board (CAB) was created in response, founded on principles of mutual benefit for patients, community members and groups, and our students. Another core principle was that stronger community and patient voice in developing and implementing revised DPAS course activities would improve medical education.

The DPAS CAB has now helped to make more than 30 changes in the way DPAS is delivered, and more than 30 agencies have participated. Mebrat Beyene from the Self-Help Resource Association of BC noted that... “it is a daunting task to access “giant institutions” like the Faculty of Medicine to affect change...the DPAS CAB is essential for providing community input to influence medical education.”

One CAB-inspired change in DPAS is a new web-based database ensuring and complete communications between students, patients, DPAS staff, and community-based organizations.
Poster 24

Uncovering the Limits of Patient-Centeredness: Implementing a Self-management Trial for Chronic Illness

Presenters: Anne Rogers, National Primary Care R&D Centre, University of Manchester, UK; Anne Kennedy, National Primary Care Research and Development Centre University of Manchester, UK; Andrew Robinson, Hope Hospital Salford, UK,

Research evaluating self-management of chronic conditions points to the effectiveness of interventions changing the health behavior of individuals. However, we know little about how self-management is negotiated within health services by health professionals. The authors designed a qualitative investigation to illuminate the quantitative findings of a randomized controlled trial (RCT) of a self-management program for people with inflammatory bowel disease. They conducted in-depth interviews with physicians and patients, and qualitative analysis illuminated the nature of doctor-patient encounters and possible reasons for lack of change in patient satisfaction with the consultation. The findings suggest that factors inhibiting effective patient-centered consultations include failure of physicians to incorporate expressed need relevant to people’s self-management activities fully, interpretation of self-management as compliance with medical instructions rather than the a broader perspective taking on board lay knowledge, and the organization of outpatient clinics. Giving attention to these barriers is likely to maximize the opportunities for patient self-management of chronic illness based on a therapeutic alliance with health care professionals.

Poster 25

Death Before Dishonour: A Patient Narrative

Presenter: Deirdre Maultsaid, Burnaby, Canada

*Death Before Dishonour* is a Patient Narrative about a mother’s decision on the night of her son’s emergency surgery. The writer criticizes the gang mentality that requires young men to be tough. The mother’s voice confirms that a bedside manner of frank talk, and unconditional kindness can restore her child’s health and empower her to make wise decisions during a crisis.

A medical crisis presents a patient with experiences that can influence lifelong attitudes toward healthcare professionals. From *Death before Dishonour*, a lyrical, intimate narrative, healthcare educators and professionals can experience the crisis and patient’s attitude from the mother’s point of view. Healthcare educators could use such narratives to demonstrate and communicate the thoughts, feelings and sensations patients experience during a medical crisis. This narrative, as a form of interpretive research, is a teaching tool that can bring new understanding and professional development for healthcare educators. Patient narratives can help others gain a deeper understanding about how patient-centered curricula can enhance health professional education and enrich healthcare practices.
Poster 26

Passages of Patiency: Some Problems of Text, Role and Voice

Presenter: Stephen Wallace, Warranwood, Australia

While the notion of ‘agency’ is generally well understood and valorized in healthcare, the notion of ‘patiency’ has received less attention, even since Parson’s landmark description of the ‘sick role’. These terms are often seen as binaries which are well defined, distributed and accepted roles in the health arena. My work in co-authoring patient narratives has examined the boundaries and translations (if not transgressions) of these role divides. Narratives with cancer patients describe how the notions of ‘patiency’ are negotiated and much less clearly defined than might appear on first analysis. It seems that learning to practise in the ‘life-world’ as a (novice) patient require performances of both ‘agency’ and ‘patiency’. Using opportunistic samples of traditional healthcare agents (social workers and psychologists) and other patients, I describe how power, gender, and expertise produce a complex assemblage of patiency /agency in even the most ‘professional’ of patients, and how this complex distributes power(lessness) across various actors, especially when they are enrolled by a ‘non-patient ’in co-producing their own patient narratives. I also examine some of the ‘textual’ problems of documenting this passage with various patients.

Poster 27

When Management of Diabetes Alters "Life": Implications for Educating Health Professionals

Presenters: Geraldine Ellison, College of Nursing, University of Oklahoma, Tulsa, USA; Kathleen Rayman, College of Nursing, East Tennessee State University, Johnson City, USA

Even though the accumulated evidence in diabetes research supports that near normal glycemic control should be attempted for most people with diabetes, adherence to aspects of management that can result in improved glycemic levels is notably poor. Through three qualitative studies we sought to understand the experience of learning to self-manage Type 2 diabetes from the perspective of those who managed well, those who were new to management, and those who were unsuccessful in management. This presentation will focus on the “lessons learned” from women’s experiences of coming to terms with both the intrusive nature of managment and their individual reactions to it. An inductive interpretive approach was used in all studies.

Data were drawn from groups of women with different experiences in self-management. The first study focused on 17 women who were nominated by providers as “exemplars” of management. The second focused on 14 women who were either within six months of diagnosis or intensive control, and the final study focused on 10 women who were “poor” managers - those providers identified as not managing well.

Lessons learned include: (1) motivation is rarely an issue in learning to manage; (2) self-blame and intense emotions characterize early phases of management and are not viewed as legitimate management issues; (3)rigidly following rules precludes experimentation and attending to bodily cues which are necessary for successful management; (4) successful management becomes possible when providers invite women to reflect on and share their experiences; (5) more diabetes education is not always the answer.
Poster 28

What Do Patients Expect from their Community Pharmacists?

Presenter: Rosemin Kassam, Faculty of Pharmaceutical Sciences, UBC, Vancouver, Canada

Additional Authors: John Collins

Background: The objective of this study was to test the hypothesis that community pharmacies providing disease management programs were more likely to meet patient expectations than those engaged primarily in assessment and counseling of new/refill prescriptions and nonprescription medications.

Methods: Nineteen community pharmacies serving as clerkship sites for senior year pharmacy students participated in the study; eight provided disease management through their students (treatment arm) and eleven provided traditional care (control arm). A 15-item survey was developed asking patients to rate their expectations in any pharmacy with respect to six PC domains [developing a relationship, assessing patients, clarifying the role of medications, developing a pharmacy care plan, working collaboratively with other health care providers and providing follow-up to patients] and the extent to which these expectations were met in this pharmacy, using a 5–point Likert letter scale of agreement/disagreement. Follow-up telephone calls were made to selected subsets of respondents who had volunteered their names to test for the survey’s appropriateness, ease of understanding, clarity of language and time required to complete it.

Results: A total of 147 patient satisfaction surveys were returned. There were no differences in baseline expectations between the two arms. In general, patients’ situational experiences at this pharmacy were less satisfactory than their baseline expectations for any pharmacy (F=9.00, p<0.05); however, the treatment sites performed significantly better than the control sites (F=4.95, p<0.05).

Conclusions/Implications: Our study demonstrates that baseline patient expectations are high and that these expectations stand in significant contrast to the patients’ experiences.

Poster 29

Addressing Poor Breast Cancer Outcomes for African-American Women with Low Health Literacy Through the Use of Participatory Health Education Materials Development

Presenter: Mae Morgan, Department of Community Health and Preventive Medicine, Morehouse School of Medicine, Atlanta, USA

Additional Authors: Laurence Cohen; Valarie Grant; E. Bridget Jones; Feremusu Kamara; Kendra Richardson

Cancer is the second leading cause of death in African-Americans, accounting for one in five deaths. The poor cancer results seen in African-Americans may be a consequence of a group which is more likely to have low health literacy skills. Persons with low health literacy may not be able to understand information about health and may not be aware of cancer screening tests. Results from several studies have found that African-Americans are less knowledgeable about cancer, less likely to engage in cancer risk-reduction behaviors, less likely to perceive the importance of early detection, and more likely to believe in cancer myths. Barriers to cervical and breast cancer screening in African-Americans include lack of knowledge resulting from low health literacy, lack of access, and cultural and logistic factors. A teaching module was designed, based on the teachings of Paulo Friere, consisting of a myth and fact session, a video, and a pamphlet. Qualitative research modalities were utilizing focus groups to identify the most effective strategies. The participants were found to be quite knowledgeable about breast cancer. They indicated that existing materials did not emphasize the undesired consequences of undiagnosed breast cancer, which would be necessary to reach some African-Americans. In addition, comments were made with regards to lifestyle factors and other revealing key factors in the health of African-American women. The use of participatory materials development may prove to be beneficial in addressing poor health outcomes among those with low health literacy.
Poster 30

Laypersons' Health Information Seeking Behavior in Japan

Withdrawn

Poster 31

Therapeutic Education of Diabetics: A Preliminary Experience of a Psycho-educational Course

Presenters: Giulia Lamiani, Chair of Medical Psychology, University of Milan, Italy; Elena Vegni, Chair of Medical Psychology, University of Milan, Italy

Additional Authors: Raffaella Balestrieri; Loredana Odone; Egidio A. Moja

The efficacy of group education in managing chronic diseases is well known. The aim of this contribute was to present a psycho-educational course realized with diabetics at the San Paolo University Hospital, Milan. The course's objectives were classical: to improve self-management, to avoid compliances, to improve quality of life. However, an innovative aspect was introduced: beside working on a cognitive and behavioral level, a particular attention was paid to the emotional level in order to reach an improvement in the quality of life. Patient involved were 8 Type II diabetics, insulin and non insulin dependent. One patient was accompanied by his wife as care giver. The course was run by a nurse, a psychologist, an educator and took place in the Hospital. A diabetologist and a dietician were involved as experts during specific moments of the training. 8 meetings of one hour and a half, every 15 days were scheduled. The first meeting consisted of an interview to assess individual needs. The second aimed to talk about illness perception through the Photolanguage method. Other meetings concerned: the diabetes and its measure, the diet, the complications. It was planned a particular meeting on the emotional dimension of being diabetics and a round table to address questions to the health professionals. The course, based on a pedagogy centered on patient, was realized with active learning methods as role playing, group discussion, exercises. As pre post test, participants were given a questionnaire on the problem solving ability (CdR) and on the quality of life (SF36). Data analysis is still ongoing.
Poster 32

The Effectiveness and the Efficiency in Health - "To Educate the Patient to Demands Appropriated in the Optical for One Greater Efficiency in Health"

Presenter: Andrea Calamusa, Department of Experimental Pathology - Health Communication Observatory, University of Pisa, Italy

Additional Authors: Annalaura Carducci

The ability of citizen to determinate one’s health depend main from its degree of “sanitary schooling”, meaning capacity to realize and decide about one’s health. For having competent citizens is indispensable first of all a deep cultural action, to remove the prejudgments on the infallibility of medicine and to inculcate the concepts of scientific evidence, efficiency and effectiveness. Such process is delayed from the fact that these knowledges are totally absent in the public who does not possess not even the concepts of uncertainty of science and probability, while between same sanitary operators the objective criteria of the Evidence Based Medicine must be still asserted completely, above all in the field of the information and the education. In fact there are many initiatives of social communication, information and education about specific thematics, however not always such actions are programmed and estimated according to quality criteria and introduce therefore critical aspects involving the contents, the shape and the language of the messages proposals. Some surveyings show that thought information important in order to take decisions find various operating interpretations between the sanitary ones and between the patients. Is therefore important to try the maximum precision of the data to communicate and to personalize the most possible contents in order to adapt them to the requirements of the single ones. An other fundamental aspect is the comprensibility of the information also for the bands of public with level of instruction more low: for this scope is essential the use of images, simple words and short phrases, but not always the sanitary staff has acquired adapted comunicative competences in such sense. Used words condition also the tone of the messages: when it is spoken about health as well-being appears terms with a positive connotation, while if the topics of the disease are faced, the words become denied to you. The distance of “sanitary schooling” demands the involvement of institutional subjects and not, for the creation of a more aware citizen.
The relationship between the nursing student and the patient has received little attention in nursing research. Research interest has centred mainly students’ perspective showing that the relationship with a patient is an important part of learning process. This poster presentation describes the impact of the relationship on both students’ learning and patients’ well-being.

Data were collected in spring 2000 by interviewing 30 nursing students and 30 patients at one university hospital in Finland. The students were receiving practical training in eight medical wards where the patients stayed for three or more days. Students’ clinical placements account for 36-40% of the 3.5-year polytechnic degree programme (Bachelor level). The data were analysed using inductive content analysis.

Findings indicated that both students and patients benefit from student-patient relationships. For students, the relationship promoted their personal and professional growth. Students’ improved competence was reflected in higher level of skills and knowledge in nursing. Their strengthened career motivation with trust in their own abilities was related to increased confidence and self-esteem. Only few students had feelings of failure because of lack of competence in technical or interpersonal skills. For patients’, the relationships with students were connected with their satisfaction with students’ genuine presence and with the help and assistance given whenever needed to make them feel physically and mentally well. A more rapid recovery through increased compliance was also mentioned by some patients.

The findings have implications for students’ clinical learning in which patients are involved in both learning and treatment.
Understanding Lived Experience of Health and Illness: Student Perspectives From Innovative Clinical Placements

Presenters: Sheryl Reimer Kirkham, Trinity Western University, Langley, Canada; Lynn Van Hofwegen, Nursing, Trinity Western University, Langley, Canada

Concepts of community-centered practice have moved to the forefront of health professional education priorities. Clinical learning experiences remain vital to facilitate students to bring theory and practice together (i.e. praxis). Yet the changing Canadian health-care environment, with cutbacks in traditional community care programs, often confounds the increased educational priority given to concepts of community-centered practice and frequently results in a shortage of traditional clinical placements. Health professional educators are increasingly turning to innovative sites for nursing practica.

A descriptive study was undertaken to explore nursing students’ experiences in specific innovative clinical settings. The poster draws upon data analysis from focus groups and interviews with students, clinical instructors, and mentoring RNs in aboriginal, correctional, rural, international, and parish settings. Aims of the two year study included: a) to describe the learning experiences of generic baccalaureate nursing students in these settings; b) describe the experiences of clinical nursing instructors and professional nurses involved in supporting student learning in these settings; c) evaluate innovative clinical settings for attainment of student learning goals; d) examine the service component of innovative clinical placements; and e) examine ethical, legal, and academic issues associated with the utilization of these settings for the attainment of student learning goals.

Each of these settings has been used for a number of years to provide community clinical practica within a baccalaureate program. The poster presentation will elaborate attributes of these innovative clinical settings and highlight findings that indicate students not only achieved the community course objectives, but also captured the broader vision of community nursing and engaged with their communities. Catalysts and challenges for creating transformative learning environments in innovative community clinical settings will be addressed.
Poster 35

The Assessment by Patients of Medical Students’ Professional Attributes

Presenter: Jill Thistlethwaite, Department of General Practice and Rural Medicine, James Cook University, Townsville, Australia

Additional Authors: David Hartman; David Macintosh; Jan Veitch

Two important and current concerns in medical education are: 1. How to assess professional attributes during medical training in a reliable and robust way so that by qualification doctors behave in an appropriate way with their patients; 2. How to involve patients in medical education, moving from the concept of expert patients and patients as teachers, to patients as assessors.

Rationale: While all medical students undergo repeated and exhaustive assessments of their knowledge, reasoning and problem solving skills, it has proved more difficult to devise valid and reliable methods of assessment of professionalism. Patients, both ‘real’ and ‘simulated’ are already involved in the assessment of communication skills; this project pilots an assessment of professional attributes by ‘real’ patients in hospital and in the community.

Method: At James Cook University School of Medicine we have devised an assessment sheet, called a 360 degree appraisal form, to be used by patients who interact with students in all clinical settings. This sheet asks patients to rate medical students on four professional attributes: personal behaviour, empathy, respect and communication skills. Patients are also asked to comment in free text.

Patients who fill in the sheets for years 1-3 and year 6 students are asked for consent to be contacted for interview. The interviewer explores the patients’ feelings about assessing students, how prepared they felt, whether they were able to make a judgement and what would help them in this process.

Results: The results of the interviews and a discussion of the process will be outlined.
Poster 36

The Good Neighbor Mentoring Project: Creating a Web of Supportive Relationships between Families and Medical Students

Presenters: Janet Hortin, Indiana University School of Medicine, Lafayette Center for Medical Education, Lafayette, USA; Clinton Bahler, Indiana University School of Medicine, Lafayette, USA

Additional Authors: Veronica Baumgartner

Patients and their caregivers serve as mentors in this first year medical school class that introduces students to relationship centered care and the biopsychosocial model of care. We have teamed up with a community agency, Caregiver Companion, that provides respite care services to disabled persons being cared for at home. Students make home visits where they provide respite for a total of 10-15 hours during the course of the semester in this service learning course. Small group support is provided to the students every other week where we discuss formal relationship building skills and skills of medical observation, empathic listening, supportive touch, and the importance of the service ethic in medicine. Students have reflective writing exercises; teach a health topic to the neighbor; and learn that patients will be some of their most powerful teachers. Neighbors and caregivers find in the students a listening ear and able-bodied assistance with chores or going to appointments. Caregivers are also given the gift of respite from their caregiving duties for a few hours. Students gain insights into the strengths needed to deal with chronic ailments; the devotion and importance of caregivers; medical/health literacy challenges; and the importance of longitudinal relationships in health care. The goal for the semester is to form a respectful relationship with a family in need of care. It is a cornerstone skill for all health care providers and appropriate to introduce in the first semester of medical school. Home visits are a powerful educational medium.
Poster 37

Patients' Conception of Autonomy after Orthopedic Care at the Interprofessional Student Ward

Presenters: Anders Nilsson, Department of Södersjukhuset, Karolinska Institutet, Stockholm, Sweden; Margaretha Forsberg Larm, Department of Södersjukhuset, Karolinska Institutet, Stockholm, Sweden

Background: The patient's autonomy was illuminated in this interview study. The patient's autonomy is an important concept in health care's daily ethical issue. Historically, a paternalistic stand has been a common approach in health care; hence there is the need for further knowledge in order to increase the understanding of the concept of autonomy. In accordance with the law, care and treatment should occur in collaboration with the patient. Earlier research showed that despite care programme and continuous education, health care personnel still have fragmented understanding of patient’s situation, and that patient is often seen as an object.

Aim: The aim of this study was to describe how patients conceive their own autonomy, during admission at an orthopaedic interprofessional student ward.

Method: Data was collected through semi structured telephone interview, and the analysis has been inspired by the phenomenographic research approach.

Findings: The narratives gave rise to three themes; participation, reception and integrity. To accomplish participation, the informants described that they need information and knowledge. They described own input and responsibility as important factors related to participation in the care. Internal hindrances and resources toward participation were richly described. The reception was described extensively, and with big variation. It was mentioned that communication supports their autonomy. Communication was described as giving room for patient's own strength. Caregiver’s characteristics was brought forth and described as human and professional. Integrity was difficult to conceive as a concept, yet highlighted indirectly in the narratives.

Conclusions: The study gives an indebt understanding of how the informants conceive autonomy. The study has a clinical anchorage that gives it possibility of developing a new knowledge on participation and reception, which can consequently improve the quality of nursing care and patient’s wellbeing.
Syncope Trust And Reflex anoxic Seizures group (STARS) was established in March 1993 at the request of a Paediatric Neurologist. It was founded by a mother whose child had finally been diagnosed after three and half years of various hospital visits, tests and mis-diagnosis. The child was experiencing up to eight reflex anoxic seizures per day. STARS is a voluntary organisation.

SYNCOPE is the result of the temporary cutting off of the supply of oxygenated blood to the brain resulting in loss of consciousness and collapse. This is usually due to a drop in blood pressure or a change in the heart rhythm causing a drop in the amount of blood the heart pumps (the cardiac output), or a drop in the amount of oxygen being carried in the blood. If the blood supply tapers off slowly, as when the blood pressure falls, several warning symptoms develop such as light-headedness, fading of vision and buzzing in the ears before the loss of consciousness and posture. If blood flow ceases more abruptly, as when the heart stops pumping completely, then any warning lasts only for a few seconds before loss of consciousness; more dramatic features appear including stiffening spasms and jerks. Many doctors call this type of fainting fit an anoxic seizure, which has nothing to do with the epileptic fits or seizures of epilepsy.

REFLEX ANOXIC SEIZURES (RAS) occur mainly in young children but can occur at any age. Any unexpected stimulus, such as pain, shock, fright, causes the heart and the breathing to stop, the eyes to roll up into the head, the complexion to become deathly white/grey, often blue around the mouth and under the eyes, the jaw to clench and the body to stiffen, sometimes the arms and legs jerk. After 30 seconds or so, the body relaxes, the heart and breathing resume and the person is unconscious. One or two minutes later the person may regain consciousness but can remain unconscious for well over an hour. Upon recovery the person may be very emotional and then fall into a deep sleep for two to three hours and looks extremely pale. RAS attacks may occur several times a day/ week/ month. The attacks appear to come in batches.

The Aims of STARS:

• To act as an information and support group
• To bring about public and professional awareness
• To gather more information and to aid research

STARS offers:

• Information and reports on the various types of Syncope including Reflex Anoxic Seizures (RAS)
• Leaflets, literature, videos and web-based information
• Newsletters, regional, national & international meetings
• Freephone 24 hour Helpline (0800 028 6362)
• Linking with similarly affected individuals and families
• A network of volunteers working throughout the UK to promote the aims of STARS within their local community
• Working with Government Departments, NHS and forming alliances with other similar charities to help influence improvements in all aspects of arrhythmia

STARS was a member of the AAAW (www.aaw.org.uk), which culminated in the launch of the Arrhythmia Awareness Week at the Houses of Parliament (12th May 2004). Dr Roger Boyle, National Director for Heart Disease, announced the introduction of a new chapter into the National Service Framework specifically on arrhythmias. The Public Health Minister, Miss Melanie Johnson, confirmed that AAAW helped influence, together with others, the decision to introduce this new chapter.
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