Patients and health care providers experience the health system differently and have different priorities and needs. Unless health workers understand their patients and families, they can’t put their needs at the centre of health care. Research is a powerful way to build understanding of patients’ needs and experiences, which is essential for a responsive health system.

This ‘tip of the iceberg’ summary of patient-focused abstracts from the 2008 General Practice and Primary Health Care (GP & PHC) Research Conference illustrates some specific examples of the way access to health care, consumers’ health literacy, and health workers’ attitudes and knowledge interact to affect the outcomes of care.

**BETTER UNDERSTANDING WHAT PEOPLE NEED LEADS TO MORE APPROPRIATE, ACCESSIBLE AND ACCEPTABLE CARE**

Aboriginal women in Tamworth NSW accessed antenatal care later than advisable. They wanted continuity of provider and an aboriginal health worker during pregnancy and childbirth. The community must be the centre of dialysis care for Western Desert Dialysis Mob, to ‘keep our spirit alive and strong’. Otherwise, dialysis is not ‘care’. Patients with osteoarthritis in rural areas seek help mainly when they are desperate because self management has failed. Older Western Australians found colonoscopy screening was generally acceptable if referred by their GP, but being male, having private health insurance, or having had a previous colonoscopy predicted those most likely to agree to a colonoscopy.

**PATIENTS’ LACK OF KNOWLEDGE ABOUT THEIR CONDITION AFFECTS THEIR CARE**

Rural patients in North Queensland experienced delays in diagnosis of colorectal cancer because they knew little about the signs and symptoms before they were diagnosed. Women were not well informed about preconception care unless they sought out the information. Women from high socio-economic areas frequently sought advice from alternate practitioners or on-line.

**ACCESS TO CARE WITH MINIMAL TRAVEL AND FINANCIAL COSTS TO PATIENTS REDUCES BARRIERS**

Time and costs of travel were difficult during outpatient treatment for colorectal cancer for patients in rural Queensland, with a limited range of available specialist services. Rural people with osteoarthritis cannot always access the physical therapies they value. Access to a GP for preventive preconception care was a barrier for rural women, while cost was a barrier for women in low socio-economic areas.

**SELF MANAGEMENT OF CHRONIC ILLNESS AFFECTED BY GP AND PATIENT PERCEPTIONS**

Patients use complex processes to make decisions about managing COPD, which might not appear rational to an external observer. Consumers’ perceived they ‘knew enough’ about the management of their chronic conditions but health professionals disagreed. General practice patients with COPD experience significantly reduced quality of life, whereas asthma patients’ quality of life is only moderately affected.

**PATIENTS DISSATISFIED WITH HEALTH WORKERS’ KNOWLEDGE AND ATTITUDES**

Patients with skin diseases such as psoriasis, eczema and acne felt their GPs needed orientation to the psychological effects of skin diseases. Adolescent males, members of the gay community and occupational users of performance and image enhancing drugs (PIEDS) considered health professionals require evidence-based
training on these drugs. Their negative reactions and lack of knowledge create barriers to seeking support.11 Obese and overweight women thought that GPs' attitudes reflected the social and cultural constructions of obesity, so body size often obscured other relevant health needs.12

**HOLISTIC APPROACH TO HEALTH CARE WOULD REDUCE GAPS IN SERVICE DELIVERY**

Anxiety after childbirth requires greater public health attention. Women under-report anxiety symptoms after childbirth, and have many reasons for not seeking help.13 Women diagnosed with gestational diabetes require ongoing support to sustain lifestyle changes after their baby is born.14 Individualised management plans based on the patient's own recovery goals may be better indicators of recovery than external assessments, as people are good at hiding their depression.15 Better integration of consumer health organisations into primary care systems could lead to benefits for patients with diabetes and arthritis.16 The actual skill level of carers of people with chronic illness is different to health care professionals' expectations of this role. Conflicts arise from the changing relationship between the carer and the patient.17 Health professionals and support organisations need to be proactive in providing timely and practical education for rural carers of people with dementia, as well as engaging with carers as partners in care and encouraging carer empowerment.18

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6 Improving the uptake of peri-conceptual folic acid supplementation: what do women think? D Mazza, A Chapman

7 Information use by people with Chronic Obstructive Pulmonary Disease C Ehrlich

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10 Skin patients and their doctors – an uneasy relationship: results of a qualitative study P Magin, J Adams, G Heading, D Pond

11 Experiences with and barriers to treatment among users of performance and image enhancing drugs (PIEDs) in Australia R Vial, R Ali

12 (Re)examining the multilayered meanings of being fat: developing 'new' strategies for working with overweight and obese female consumers of primary healthcare D Williams

13 Help-seeking behaviours of women experiencing depression and anxiety nine months after childbirth H Woolhouse, S Brown, A Krastev, S Perlen, E McDonald

14 “The ante-natal clinic managed me when I was pregnant but I don’t belong to them anymore”. Implications for health promotion for women who experienced gestational diabetes F Doran

15 Recovery from depression - what do patients say about it? C Johnson, J Gunn, R Kokanovic

16 Embedding Consumer Health Organisations into the Primary Care System: The Benefits for Chronic Disease Management A Mutch, F Boyle, J Dean, Ml Dick, C Del Mar

17 Set adrift in a boat without oars: The family carer’s experience of chronic illness management B Essue, M Mirzaei, YH Jeon, T Jowsey, C Pearce-Brown, L Yen, T Usherwood, N Glasgow, S Leeder, SCIPPS Team

18 Who cares for the caregiver? Support for caregivers of dementia sufferers in rural South Australia F White, K Willsher, O Cynthia, B Marina

**FURTHER RESOURCES**

At the Australian Institute for Primary Care, the Cochrane Consumers and Communication Review Group coordinates the preparation and production of systematic reviews of interventions which affect consumers’ interactions with healthcare professionals, services and researchers

Web: www.latrobe.edu.au/cochrane/

Australian Resource Centre for Healthcare Innovations (ARCHI)

Web: www.archi.net.au/e-library/patientexperience

National Resource Corporation Picker

Web: www.nrcpicker.com

Picker Institute is an independent, non-profit, educational organisation dedicated to the advancement of patient-centered care

Web: www.pickerinstitute.org/