#### Submission to:

Australian Commission on Safety and Quality in Health Discussion Paper on Care Patient- and Consumer-Centred Care Email: <u>mail@safetyandquality.gov.au</u>



# Submission to Patient- and Consumer-Centred Care Discussion Paper

# Women's Centre for Health Matters Inc.

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The Women's Centre for Health Matters (WCHM) welcomes the opportunity to provide a submission to the Australian Commission on Safety and Quality in Health Care on the Patient- and Consumer-Centred Care discussion paper.

This response is informed by the views and concerns of our partners with whom we work closely on the specific issues for and needs of ACT women, and with feedback from a variety of ACT women and service providers through focus groups and other consultation processes.

#### Introduction

The Women's Centre for Health Matters Inc. (WCHM) is a community-based organisation that works in the ACT and surrounding region to improve women's health and wellbeing. WCHM focuses on groups of women who experience disadvantage and uses social research, community development, advocacy and health promotion to empower these women to achieve the highest possible standard of health and wellbeing.

WCHM believes that health is determined not only by biological factors, but by a broad range of social, environmental and economic factors known as the 'social determinants of health'. We acknowledge that that the environment and life circumstances that each woman experiences have a direct impact on her health, and in many cases, women's poor health is rooted in social disadvantage. For these reasons, WCHM is committed to taking a 'whole of life' and social approach to women's health, that is also firmly situated within a human rights framework.

#### **Response to Patient- and Consumer-Centred Care Discussion Paper**

WCHM supports the ACSQHC's discussion paper *Patient-Centred Care: Improving Quality and Safety by Focusing Care on Patients and Consumers*. WCHM believes that a move toward patient- and consumer-centred care in Australia will improve the safety, quality, efficiency and effectiveness of the health system overall, and thanks ACSQHC for their well researched and thoughtful discussion of the future of patient- and consumer-centred care in Australia.

The discussion paper was useful because it paints a clear picture of what care that involves and centres on patients, carers and families looks like. The concept of patient-centred care was clear and understandable and the discussion paper thoughtfully acknowledged the nuances of the concept, reflected most often through the multiple names ascribed to it such as consumer-centred care, person-centred care, personalised care, family-centred care, and responsiveness.

The principles of patient-centred care were also articulate and understandable, and encompass its most important and fundamental aspects.

As women are the primary seekers of health care and health information for themselves and for their families, WCHM believes that a shift toward placing patients, carers and families at the centre of health care will greatly benefit women, their families and their communities.

We welcome the opportunity to participate in this consultation process and in writing this submission, have chosen to limit our responses to those areas in which we have the most knowledge and expertise, and to support our responses with evidence published by the Centre and its partners on the specific needs of ACT women.

### 1. The Social Determinants of Health

WCHM supports the principles of patient- and consumer-centred care set-out in the discussion paper. In particular:

- Eliciting and respecting patient preferences
- Engaging patients in the care process
- Emotional support
- Physical comfort
- Dignity
- Information, communication and education
- Continuity and transition
- Coordination of care
- The involvement of family and friends
- Access to care

To achieve these principles, however, services and service providers need to be sensitive to each individual's social, financial, educational, linguistic, cultural, historical and familial circumstances; the social determinants of health. These determinants greatly influence each individual's potential for health or illness, and affect their perceptions of health and illness, access to care and information, responsiveness to care, and ability to be proactive in the way that the patient- and consumer-centred principles laid out in the discussion paper idealise.

An approach to health care provision that acknowledges the determinants of each individual's health creates equity in health outcomes across sex and gender, sexual orientation, cultural and linguistic background, social and economic circumstance, disability and age.

WCHM believes that in order to realise equitable outcomes for all Australians it is necessary and appropriate to do away with a 'one size fits all' approach, and the recognition of difference is the first step to achieving this goal. Emphasising the importance of understanding each individual's determinants of health will ensure that care in Australia truly is patient- and consumer-centred.

**Recommendation:** To include understanding of and responsiveness to each individual's determinants of health as a principle of patient-centred care, to ensure that equity is achieved throughout the Australian health system.

# 2. Gender Sensitivity in Health Service Delivery

As mentioned above, gender is one of the determinants of an individual's experience of health, illness and disease, responsiveness to treatment, access to care and access to information. WCHM advocates that all individuals should be able to access care and information that is *available*, *affordable*, *accessible* and *appropriate*. These 'four As' form the basis of WCHM's definition of gender sensitive health service delivery and are integral to achieving and maintaining good health and wellbeing.

Women and men are different, both as a result of biological differences and because of the differences in the ways that they live, work and play. Because of these differences, men and women have different needs in relation to their health and wellbeing, work and education, and informal and formal support networks. The differences in social roles assigned to women and men affect the 'degree to which women and men have access to, and control over, the resources and decision-making needed to protect their health',<sup>1</sup> for example, and this results in inequitable patterns of health risk, use of health services and health outcomes.'<sup>2</sup>

One example is found in the view in our society of women as nurturing, interdependent and family oriented. While these are all positive qualities in that they are protective of others, domestic responsibilities like caring limit economic resources and can increase women's vulnerability to poverty, affecting her own and her family's health.<sup>3 4</sup> Domestic responsibilities can also limit women's opportunities to weave their private and public worlds effectively,<sup>5</sup> which can then greatly increase the risk of isolation. Caring demands have also been found to create potential pathways to the "female excess of 'minor' physical and mental ill health, such as tiredness, headaches and chronic pain".<sup>6 7</sup>

WCHM believes that the principles of gender sensitive health service delivery are complementary to the principles of patient- and consumer-centred care as defined in the discussion paper. The guiding principles of gender sensitive health service delivery are:

 Women and men are not the same; many factors such as age, race, ability, language, sexual orientation, education and access to resources influence an individual's capacity to achieve optimal social, physical, emotional and economic wellbeing. Gender is no different.<sup>8</sup>

<sup>&</sup>lt;sup>1</sup> World Health Organization, 2002, *Madrid Seminar on Gender Mainstreaming Health Policies in Europe*, <u>http://www.euro.who.int/document/a75328.pdf</u>.

<sup>&</sup>lt;sup>2</sup> ibid.

<sup>&</sup>lt;sup>3</sup> Margaret Miers, 2002, op cit, 71.

<sup>&</sup>lt;sup>4</sup> Hilary Graham, 1993, When Life's a Drag: Women, Smoking and Disadvantage, HMSO, London.

<sup>&</sup>lt;sup>5</sup> Margaret Miers, 2002, *op cit*, 73.

<sup>&</sup>lt;sup>6</sup> ibid.

 <sup>&</sup>lt;sup>7</sup> Jennie Popay and Keleigh Groves, 2000, "'Narrative' in research on gender inequalities in health", in Ellen Annandale and Kate Hunt (eds.), *Gender Inequalities in Health*, Open University Press, Buckingham.
<sup>8</sup> Women's Health Association of Victoria, 2001, *op cit*.

- Service delivery and supports should strive for <u>equity</u> in outcomes. This does not mean that each individual should receive the same treatment and access to services but rather, that they receive the access and treatment they need to realize equal outcomes compared to other groups of women, and compared to men.<sup>9 10 11</sup> Equal outcomes between women and men benefit society as a whole.
- Women must be involved in decision-making about policies and programs surrounding service delivery and supports. This includes taking the necessary measures to ensure that disadvantaged women's voices are heard and responded to.<sup>12</sup>
- Staff employed to provide services and support need to be reflective about their own experience and perception of gender and use this to facilitate their understanding of others; never losing sight of the fluidity of gender across time, culture and social position.<sup>13</sup>
- Gender sensitive principles acknowledge the role that service providers may play in empowering or disempowering those in their care. Research has found that women's main complaints against their health practitioners, for example, arose from being objectified or stereotyped as unintelligent, infantile, incompetent or 'unbalanced' and having their illness misdiagnosed or ignored.<sup>14</sup>
- Men and women do have typical patterns in relation to health and wellbeing, employment and study and accessing supports, but these should be understood in tandem with the particularities of individual experience.<sup>15</sup>

The principles of gender sensitive health service delivery are complementary to the principles of patient- and consumer-centred care as defined in the discussion paper. Importantly, however, gender sensitive health service delivery has at its core an acknowledgement of the social determinants of health, which is currently missing from the realisation of patient- and consumer-centred care in the discussion paper. WCHM believes that care provision that is gender sensitive is better equipped to be truly patient-and consumer-centred.

**Recommendation:** To include the principles of gender sensitive health service delivery into the principles of patient-centred care.

<sup>&</sup>lt;sup>9</sup> The Women's Health Council, 2007, *op cit.*, 3.

<sup>&</sup>lt;sup>10</sup> *ibid*.

<sup>&</sup>lt;sup>11</sup> Carol Vlassoff and Claudia Garcia Moreno, 2002, *op cit*, 1714.

<sup>&</sup>lt;sup>12</sup> Women's Health Association of Victoria, 2001, *op cit*.

<sup>&</sup>lt;sup>13</sup> *ibid*.

<sup>&</sup>lt;sup>14</sup> Margaret Miers, 2002, *op cit.*, 74.

<sup>&</sup>lt;sup>15</sup> ibid.

# 3. Overcoming Communication Barriers

In order for services and providers to achieve patient- and consumer-centred care, they need to understand how to deliver appropriate care to population groups that may experience barriers in communicating with health professionals.

People of Culturally and Linguistically Diverse (CALD) backgrounds are one such section of the Australian population who have been shown to be less able to express themselves verbally and to be less assertive than people of non-CALD backgrounds.<sup>16</sup> In addition, 'individuals of CALD backgrounds may have a patriarchal view of the health care system where the doctors' view is never questioned or challenged'.<sup>17</sup> Such communication difficulties can lead to individuals of CALD backgrounds experiencing additional barriers to fully participating in health care decision making.

People with disabilities are another section of the population with diverse and restrictive communication barriers. In recent research, WCHM found that women with disabilities need to be able to access information in a format and style that is appropriate to their needs, which can limit the information sources available to them. Not being able to access a diverse spectrum of information in a variety of formats can limit the extent to which a woman with a disability can make informed decisions about her health. Considering that women are often the primary information seekers and decision makers for their families health as well, not being able to access the information they need in the most appropriate format can have ever further reaching consequences.

However, improving support for people of CALD backgrounds and people with disabilities is not simply a matter of offering bilingual support to individuals, translated materials and information in alternative formats. Specific patient- and consumer-centered care models should be developed that address the large diversity that exists within and between CALD groups and disabilities, such as differences in attitudes, beliefs and values; styles of communication; levels of self esteem, confidence and health literacy; lifestyle activities; social support networks; and socioeconomic status.<sup>18</sup>

Services and providers should be provided clear examples and support tools to adequately meet the cultural, linguistic and communication needs of individuals to enable them to become fully and genuinely involved in their health care. These support tools should be developed from the perspectives of people of CALD backgrounds and people with disabilities. Interviews and surveys can be conducted with people to work

<sup>&</sup>lt;sup>16</sup> Elizabeth Manias, 2010, "Medication adherence: caring for people of culturally and linguistically diverse backgrounds", in *Diversit-e*, Issue 3, pp. 24 – 25.

<sup>&</sup>lt;sup>17</sup> *Ibid*.

<sup>&</sup>lt;sup>18</sup> Ibid.

out their enablers and barriers to being actively involved in their care planning and decision making.<sup>19</sup>

Communication difficulties can prevent providers from engaging patients in the care process, sharing knowledge, and providing patients the information they need. A lack of understanding about the communication difficulties that individuals may experience when consulting health service providers, coupled with the time constraints placed upon providers, limit the extent to which patient- and consumer centred care can be realized.

#### **Recommendation:**

- 1. To develop models of patient- and consumer-centred care from the perspectives of people of CALD background for people of CALD background, to ensure that services and providers can easily and genuinely involve them in care.
- 2. To develop models of patient- and consumer-centred care from the perspectives of people with disabilities for people with disabilities, to ensure that services and providers can easily and genuinely involve them in care.
- **3.** Ensure that health services and providers have the support and tools they need to understand and overcome communication barriers with patients, carers and families.

# 4. Extending Patient- and Consumer-Centred Care Beyond the Hospital Setting

WCHM would like the discussion paper to better demonstrate how patient- and consumer-centred care principles can be realised beyond the hospital setting, particularly in the areas of disability, ageing and mental health.

### 5. Planning for the Future

WCHM would like to see a commitment from medical schools throughout Australia to incorporate principles of patient- and consumer-centred care into the foundational training of students. Incorporating the principles of patient- and consumer-centred care into medical school curricula is an efficient and effective way to ensure that the health workforce of the future understand and strive toward providing care that genuinely involves patients, carers and families.

<sup>&</sup>lt;sup>19</sup> Ibid.

# Conclusion

WCHM is confident that health care that is patient-centred will not only increase the overall effectiveness, efficiency, safety and quality of the ACT Health System, but will enable individuals to better manage their own health and wellbeing.

WCHM looks forward to participating further in the consultation process, and the development of patient- and consumer-centred care in Australia.

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