




**How does the  
Victorian Public Hospital Patient Charter  
meet the challenges of the  
new Victorian Charter for Human Rights and  
Responsibilities?**

FINAL REPORT

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  - Ballarat Regional Multicultural Council
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## 1. EXECUTIVE SUMMARY AND RECOMMENDATIONS

The key intention of this discussion paper was to analyse and make recommendations on the compatibility, or otherwise, of the existing Victorian Public Hospital Patient Charter and the Victorian Charter of Human Rights and Responsibilities. Health Issues Centre (HIC) was funded by the Statewide Quality Branch of the Department of Human Services (DHS) to carry out this initiative.

During the development of this paper, the Australian Charter of Healthcare Rights (ACHR) was endorsed by Australian Health Ministers and was indicated as becoming the key reference point from which all healthcare organisations across Australia would inform consumers of their rights.

As this paper was being finalised, the process to review the Victorian Public Hospital Patient Charter was still in development. All three of the above charters continue to be relevant for future and further consideration in the development of healthcare rights for consumers.

### 1.1 Findings

Seven key areas have been identified from the comparative analysis between the existing Victorian Public Hospital Patient Charter and the Victorian Human Rights and Responsibilities Charter (VCHRR). Five of these areas relate to the ongoing development and clarification of healthcare rights in Victoria. Two areas are relevant to the dissemination and development of human rights, in particular the VCHRR within a health context.

HIC suggests that these findings and recommendations are relevant to *any future consideration* in the development and dissemination of both healthcare rights and human rights within healthcare services and communities.

#### *Healthcare rights*

1.1.1 Healthcare rights need to be situated within a broader context of human rights in Victoria

1.1.2 Communication of healthcare rights needs to be part of a broader process by health services in building relationships with consumers and communities

1.1.3 There is a need for training and professional development on healthcare rights as well as human rights in healthcare for both consumers and healthcare providers

1.1.4 General healthcare rights need to be defined within a local context and be made clear in order to inform organisational policy development and day-to-day service delivery

1.1.5 Outstanding issues in relation to the content of the Victorian Public Hospital Patient Charter (e.g. the right to a second medical opinion, the rights of carers and families, and patient participation in decisions about treatment and choices) need to be considered and clarified within any future development of healthcare rights in Victoria.

## *Human rights*

1.1.6 There is a need both for a guiding framework and for resources to enable Victorian healthcare services to understand human rights including the VCHRR, especially in policy development and direct service delivery

1.1.7 Human rights including the VCHRR need to be made transparent to health and the healthcare context.

## **1.2 Recommendations**

The following recommendations have been developed based on the seven main areas of findings. The recommendations are directed firstly, to the DHS and secondly, to healthcare services.

*The following recommendations are for the consideration of the DHS.*

1.2.1 Develop a cohesive framework for understanding healthcare rights in Victoria within the broader context of human rights (VCHRR).

Such a framework should include:

- An understanding of the inter-relationship between human rights and healthcare rights
- Transparency of the VCHRR as it relates to healthcare
- Clarification of the meaning of healthcare rights and human rights as they apply to organisational policy development and direct day-to-day service delivery
- Opportunity for healthcare rights to be localised, reflecting the local context of each health service
- Practice examples and case studies of healthcare rights and the implementation of VCHRR in health services

1.2.2 Implement a program of training and professional development based on the above framework to build understanding and commitment to human rights and healthcare rights within health services. Such training should be based on dialogue and participatory learning methodologies. Further, training should be encouraged to be facilitated within healthcare services and include diverse levels of staff.

1.2.3 Implement a dual communication and dissemination strategy for consumers and community members about the meaning and potential of the VCHRR and healthcare rights for advocacy and improved services. This should include:

- a public communication and media strategy that reaches people *before* they have to access health services
- an outreach and community-based approach founded on dialogue and participatory learning methodologies. This can be delivered by health services within their communities and can be the basis for building and strengthening relationships with diverse communities.

1.2.4 Develop resources, based on case studies and direct examples about the use of the VCHRR and healthcare rights as they directly and transparently relate to health and healthcare services. Such examples can be drawn from different levels:

- Consumers, community members and advocacy groups who have used the charters for advocacy in treatment from their healthcare services
- Individual healthcare providers who have used the charters to consider their direct practice
- Health services that have revisited and changed policies based on experiences of staff and congruency with the charters
- Other organisations who are working on health specific cases, including the VEOHRC and HRLRC.

1.2.5 Use feedback from the consultation with Ballarat Health Services and community members in regard to the content of the existing Patient Charter to inform the development and clarification of healthcare rights in Victoria. The key issues to be further clarified and included are:

- Communication and a second medical opinion
- Clarification and affirmation of carer/family/personal advocate rights
- Participation should be based on open communication and collaboration between health service providers and consumers; participation and informed consent should be unconditional
- Information and contacts should be relevant to the local healthcare service and community.

*The following recommendations are for the consideration of all health services across Victoria:*

1.2.6 Include professional development on the implications of the VCHRR and healthcare rights for services as a priority for staff across the whole organisation and seek support from DHS

1.2.7 Document case studies and examples in which policies and practice are directly developed by staff input which reflect the different rights embodied in the VCHRR and made relevant to a healthcare context

1.2.8 Use the VCHRR and concomitant healthcare rights as an opportunity to outreach and strengthen relationships with communities, especially those with access and participation disadvantage.

## 2. INTRODUCTION

The key intention of this discussion paper was to analyse and make recommendations on the compatibility, or otherwise, of the existing Victorian Public Hospital Patient Charter and the Victorian Charter of Human Rights and Responsibilities. This was to be based on a review of core literature and consultations with health consumers and healthcare services. The paper was to be developed as a contribution to the review of the Victorian Public Patient Charter, which was to begin in June 2008.

However, a changing national context delayed this process in Victoria. The Australian Commission on Safety and Quality in Healthcare has developed the Australian Charter of Healthcare Rights (ACHR) after a national consultation and review of existing patient charters. The ACHR was endorsed by Australian Health Ministers on July 22, 2008 as a uniform reference point all for healthcare organisations across Australia to inform consumers of their rights. Despite the changing context, and in agreement with DHS, HIC continued to prepare this discussion paper to contribute towards informing future processes and the development of accompanying resources to further support health consumers and health services in their mutual understanding of healthcare rights in Victoria.

At the time of finalising this paper it was still unclear as to whether the ACHR would be the preeminent Charter across Australia. In the Victorian context, it is clear that three key 'charters' would need to be considered in the development of clear healthcare rights for consumers and communities – firstly, the existing Victorian Public Hospital Patient Charter; secondly, the Victorian Charter for Human Rights and Responsibilities and thirdly, the Australian Charter of Healthcare Rights.

### 2.1 Project Objectives

The project objectives were:

- To review the literature on existing comparisons between patient/consumer charters of rights within health settings and broader human rights
- To give informed and critical feedback on the Victorian Public Hospital Patient Charter as it compares with the values and rights included within the VCHHR, from the perspectives of both health service providers and health consumers and community members.

### 2.2 Project Methodology

The preparation of the discussion paper had three main components:

- (i) A focused literature review
- (ii) Coordination and facilitation of two learning and consultative workshops in collaboration with Ballarat Health Services (BHS) and the Victorian Equal Opportunity and Human Rights Commission. One workshop was held with key managers and staff of BHS and the second workshop was held with diverse health consumers of BHS and community members living in Ballarat.
- (iii) Analysis of findings from the literature review and the consultation and the development of conclusions.

### **2.2.1 Literature review**

This review was undertaken to identify countries that had in place both human rights legislation and patient charters in an attempt to find commonality, compatibility or gaps. It was intended to apply any knowledge gained from this process to the situation in Victoria. Over 100 documents were viewed and 15 were used. The literature review concluded that a comparative analysis between patient charters and human rights was not available. However, some useful findings in relation to human rights and health services were found and have contributed to the depth of the discussion and recommendations about the dissemination of both the VCHRR and the relevant charter(s). The literature review, which was carried out in January 2008, reviewed literature available from 2000 to 2007.

### **2.2.2 Consultation process**

It was established from the beginning that two separate consultation processes would be organised—one with health service managers and staff and another with 'informed' health consumers and community members interested in health and healthcare.

Ballarat Health Services (BHS) had been identified as one of the key public health services in Victoria which had actively undertaken a process of promotion of the Victorian Patient Charter amongst staff after it was discovered that very few of them understood or used the Patient Charter in their work. They had first presented their work at the 4<sup>th</sup> Australasian Conference on Safety and Quality in Healthcare in 2006. HIC approached BHS, which welcomed the opportunity to continue its work in promoting staff and service development on the Patient Charter and patient rights and responsibilities.

#### ***Rationale for the workshops***

First, the consultation would need to include an educational and training component on the content and interpretation of the VCHRR.

The VCHRR was new and it was clear that any training would also require the capacity to respond to and provide feedback about complex questions arising.

HIC sought the expertise of the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) in providing the educational training on the VCHRR. VEOHRC were able to facilitate the training on the content and context of the VCHRR despite heavy demands on their capacity.

Second, it was also important that in the training about the VCHRR, implications *for health services* be made transparent. It became apparent that the learning about the VCHRR would need to be made at two levels:

- a holistic learning about the VCHRR and the important matters the Charter raises in terms of human relations;
- a learning that is specific to health and health services.

It should be noted that it is not always obvious from the 20 political and civil rights encoded in the VCHRR which rights can be interpreted to relate to healthcare. This will be further discussed in Section 4, Discussion.

Third, the consultation would also need to include a guided process for comparing the rights contained in the Victorian Patient Charter with the VCHRR. The challenge in organising this comparison was to avoid it becoming an onerous task for participants and also to allow both overall and specific analysis and commentaries to emerge. This would necessitate a whole-day workshop.

### ***Workshops***

The consultation workshop with BHS managers and staff was held on 22 April 2008, and was attended by 14 BHS staff, which included the Director of Quality and Safety, Director of Residential Services, Manager of Population Health and Strategic Planning and the Team Leader Quality Mental Health.

The consultation workshop with health consumers and community members from Ballarat was held on 23 May 2008, and was attended by 12 people, including members from the Ballarat Aboriginal Cooperative, women in a local advocacy and support group on domestic violence linked with the Community Legal Centre, a member of the BHS Community Advisory Committee, a carer of a family member with a mental illness and also people who just wanted to have a say as consumers of BHS. BHS' Community Liaison Officer and HIC carried out outreach to diverse community organisations. This was important to gauging the breadth of experiences and views expressed as part of the consultation.

Both workshops were successful in attracting the breadth of interested participants and in terms of the learning and analysis offered.

HIC believes that this was due to both the outreach done to involve diverse participants as well as the nature of the consultation process, which included an opportunity for both personal and professional reflection, interactive learning and facilitated discussion.

In Appendix 1, comprehensive detail of the findings has been presented in a table which compares feedback and commentary from BHS service managers and staff on one hand, and consumers and community members on the other, to both the Victorian Public Hospital Patient Charter and the VCHRR.

In Appendix 2, detail of the process of both workshops is included. HIC believes that the content and facilitation of these workshops can act as a useful base for future learning and development workshops about human rights and healthcare rights across health services.

### ***2.2.3 Analysis and fusion of findings and development of recommendations***

The discussion has brought together learning from the literature review and the consultation to consider developments in two key areas:

- first, ongoing processes for the development and dissemination of healthcare rights within a Victorian context;
- second, the dissemination and learning of the VCHRR within a health context.

### **2.3 Limitations of Project**

This is a small project. It focuses on a brief literature review in which very little comparative work was found. Further, a consultation was undertaken with one regional health service. This resulted in providing some useful learnings related to BHS.

Collaboration was necessary and it was clear that this would affect the timeline available to the Project.

In addition, in the midst of the consultation, the context that had driven the development of the discussion paper altered.

However, HIC believes that the findings and recommendations arising from this Project continue to have a relevant contribution to the development and dissemination of both human rights and healthcare rights in Victoria.

### 3. LITERATURE REVIEW

#### *Comparative analysis between human rights and patient charters*

##### **Purpose**

This review was undertaken to identify compatibility and/or gaps from any comparative analysis between human rights legislation and patient charters, in particular in countries that had both. It was intended to apply any knowledge gained from this process to the situation in Victoria, where the Victorian Public Hospital Patient Charter (Victorian Patient Charter) existed prior to the legislative enactment of the Victorian Charter of Human Rights and Responsibilities (VCHRR). The review focused on literature dated from 2000 to 2007.

##### **Literature Review Strategy**

The terms that guided this review were developed after viewing Version No. 002 Charter of Human Rights and Responsibilities Act 2006 No. 43 of 2006 as at 21 September 2007 and Victorian Public Hospital Patient Charter.

Key word searches were conducted included the following words and phrases: Human rights; Patient rights; Health rights; Health and human rights; Health rights and responsibilities; Comparative studies; Human rights and patient rights; Human rights charters; Patient charters; the link between human rights and patient rights.

A search was conducted using the following databases:

La Trobe University – Melbourne Australia

Informit – [Humanities & Social Sciences Collection](#) and [Health & Society Database \(H&S\)](#)

Wiley Interscience – Humanities and Social Sciences and Medical, Veterinary and Health Sciences

Google

Dogpile

Over 100 documents were viewed and 15 pertinent to this study were cited.

##### **Limitations of the review**

This literature review had a very specific boundary - to bring forward any analysis and learning from the literature of comparative studies between human rights and patient charters. However, very little comparative work was found.

##### **Defining health as a human right**

Even though the literature review did not find comparative analysis of patient and human rights charters, the material considered did raise other considerations about the potential of patient charters and/or human rights charters to affect health, including healthcare provision.

It is relevant to begin with an overview of definitions.

The UN Committee on Economic, Social and Cultural Rights in 2000 made clear its interpretation of the right to health as not only a right to timely and appropriate healthcare but also to the underlying determinants of health, such as access to safe water, housing and access to health-related education (Committee on Economic Social and Cultural Rights, 2000).

The Special Rapporteur on Health of the Human Rights Commission reinforced these two platforms by defining it as a right to an effective and integrated health system encompassing healthcare **and** the underlying determinants of health (Commission on Human Rights, 2006).

This is an inclusive and encompassing definition of health.

## **The Notion of Patient Rights**

Formalised in 1948, the Universal Declaration of Human Rights recognised "*the inherent dignity*" and the "*equal and unalienable rights of all members of the human family*" (United Nations, 1948). The notion of patient rights emerged from this commitment to human rights and was developed from these overarching definitions of human beings in relation to each other. Patient rights define what is owed to the patient from healthcare providers, health services and the state (World Health Organization, 2008).

## **Patient Charters**

Most discussions about patient rights in the literature were understood and developed within a human rights framework.

Countries such as New Zealand, the United Kingdom, Australia, the United States and Norway have seen the introduction of patient bills of rights and responsibilities, or patient charters. These documents recognised patients' rights, defined healthcare objectives, and emphasised the complementary nature of rights and responsibilities between patients and healthcare providers.

*In some of these nations, patients' rights have the force of law; in others, they are statements of health policy. Regardless of the form they take, these initiatives have two goals: to empower patients by providing them with certain rights and entitlements as they interact with healthcare providers and institutions; and to place the patient-healthcare provider relationship on a more equal footing. By outlining what is expected of healthcare providers, institutions and patients, they also serve as important guidelines for the delivery of healthcare services.*

(Margaret Smith, 2002)

In the US, a report revealed that the effectiveness of the patient charter was largely due to state legislation that oversees the process (Wilson Silver, 1997). This indicates a strong limitation of patient charters in other countries that are not legislated, including Australia.

Smith's overview of different patient bills of rights affirmed the potential of patient charters to strengthen the position of the patient in the patient–healthcare provider relationship. However, therein also lies a significant limitation of patient charters. Patient rights and charters only deal with the aspect of health in relation to healthcare services and do not necessarily address the broader, complex underlying determinants of health.

The question for consideration then is:

Do human rights charters have a stronger potential to protect and promote health as a human right, including those rights contextualised within a patient charter?

### **Human Rights Charters**

The United Kingdom has introduced both a Human Rights Act and National Health Services Patient's Charter.

The British Institute of Human Rights (BIHR) conducted a research project in 2007 to see what impact the Human Rights Act had made on the lives of British citizens. The report documented 15 cases where the Human Rights Act was invoked by people to achieve a satisfactory outcome. Six of these cases were in the area of healthcare (BIHR, 2005). The BIHR concluded that the Human Rights Act has the power to make human rights a characteristic feature of every day life (ibid).

In his article on 'Victorian Charter on the Right Path – An assessment of the first 18 months' (Lynch, 2008), Phillip Lynch, Director of the Human Rights Law Resource Centre, explained that a major evaluation of the Human Rights Act in the UK by the Department of Constitutional Affairs concluded that human rights had exerted a "powerful", "positive and beneficial" impact on the development and delivery of public policy and services. It has been found that the UK HRA has "led to a shift away from inflexible or blanket policies towards those which recognize the circumstances and characteristics of individuals".

Another interesting perspective raised the greater potential of human rights to encompass medical ethics:

*Bioethics and medical ethics... are being challenged now by international human rights... Their contemporary significance arise not only because of increased community expectations of transparency and quality and safety in doctor/patient relations, but also from the rapid expansion of, and public respect for the system of international human rights in those very areas.*

(T A Faunce, 2005)

Faunce concluded that by accepting its normative intersections with international human rights, medical ethics may have its credibility improved and may meet current global challenges more effectively (ibid).

However, human rights (and patient rights), run the risk of becoming mere window dressing unless it becomes legislated and is supported by some form of accountability (Human Rights Council, 2007).

### **The challenges of using a human rights framework in health**

#### *The role of healthcare professionals*

In 2007, the Special Rapporteur on Health reporting to the Human Rights Council recognised the pivotal role that health professionals can potentially have in promoting health within a human rights framework (Human Rights Council, 2007). The report stressed that the realisation of the right to the highest attainable standard of health depends upon health professionals enhancing public health, delivering medical care, developing equitable health policies and programs and making key decisions about priorities and resources within government and non-government health sectors.

*In short, there is no chance of operationalizing the right to health without the active engagement of many health professionals.*  
(ibid)

The Rapporteur also found that most health professionals were unaware of human rights frameworks or felt uncomfortable about them, believing that it would put them at risk or place unreasonable demands on them.

This then is a key challenge in using a human rights framework in healthcare services.

#### *Public health vs human rights?*

The literature also revealed conflicting arguments that stated human rights approaches to health can be seen to prioritise the rights of individuals at the expense of interest groups (L London, 2007).

*When it comes to the practice of public health, there appears to be a deep-seated ambivalence around whether human rights are really compatible with effective, efficient and equitable health policies. Human rights, when framed as entitlements, could be seen to impact negatively on resource allocation by favouring individuals over the welfare of the community, to the detriment of equity or contribute to health system inefficiency.* (L London, 2007)

There is another challenge that has arisen more recently in the relationship between public health and human rights. Gruskin, Grodin, Annas and Marks (2005) stated that since September 11, under the umbrella of public health measures, human rights were being limited by government in times of war and epidemics. They also argued that this was a false argument and that most public health concerns could be addressed without any infringement on human rights.

Regardless of these key challenges, the BIHR affirmed from its research that the Human Rights Act was a tool for tackling inequality, disadvantage and achieving social change. (BIHR, 2005).

### **Conclusions for the Victorian context**

This review was not able to identify relevant literature and findings from any comparative analysis between patient charters and human rights legislation.

However, the review did raise relevant considerations and resources for the Victorian context. These include:

- The potential of patient charters to influence relationships within healthcare services between patients and healthcare providers.
- The potential of human rights charters to influence relationships within healthcare services between patients and healthcare providers.
- Rights charters, whether referring to patient rights or human rights, are most effective in their impact when enacted in law. In the Victorian context, it is important to consider that the Public Hospital Patient Charter is not enacted in law whereas Victorian Human Rights Charter of Rights and Responsibilities became fully applicable in law on 1 January 2008.

- The interconnectedness, as well as the tension between health and human rights:
  - health as a human right includes healthcare and social determinants
  - the critical but hesitant role of healthcare providers in promoting a human rights approach to healthcare delivery
  - concerns that there are trade-offs of human rights in the name of public health.
  
- Importance of case studies which illuminate the meaning of human rights for direct service delivery and policy development, such as the report by the British Institute for Human Rights: *The Human Rights Act – Changing Lives*.

## 4. DISCUSSION

In Victoria, the process of development of healthcare rights for consumers is yet to be concluded.

It is clear that the three existing Charters will be need to be considered for further development and implementation.

They are:

- Victorian Public Hospital Patient Charter
- Victorian Charter of Human Rights and Responsibilities (VCHRR was fully enacted in Victorian law on 1 January 2008) and
- Australian Charter of Healthcare Rights (ACHR was endorsed by Australian Health Ministers and announced 22 July 2008)

The literature review and the two consultation workshops held in collaboration with Ballarat Health Services (BHS) and Victorian Equal Opportunity and Human Rights Commission were carried out before the announcement of the ACHR.

The findings from the consultation were based on the direct comparison and feedback between the Victorian Patient Charter and the VCHRR.

However, HIC strongly believes that the feedback and contributions gained from the consultation continue to be highly relevant on two key levels:

- For the ongoing development and implementation of healthcare rights within a Victorian context with health services on one hand, and consumers, carers and community members.
- For consideration in how to engage and make meaningful the VCHRR for health services and health consumers.

Critical feedback and ideas about the content of a revised Victorian Patient Charter were made during the consultation. Feedback by BHS staff and Ballarat consumers and community members has been fully documented in Appendix 1 of the paper.

Findings within these two broad areas will be highlighted with discussion presented after each finding. Recommendations have been presented in Section 1.2 of the paper.

### 4.1 Development and implementation of healthcare rights within a Victorian context

#### Finding

##### 4.1.1 Healthcare rights need to be situated within a broader context of human rights, especially in Victoria

During the consultation with BHS managers raised an important matter: the apparent defensiveness by some staff across BHS in response to the promotion of the Patient Charter. Staff cited and claimed their own rights as workers in contrast to patient rights. The promotion of the Patient Charter tended to open up an 'us' and 'them' stance by these staff.

However, HIC's observation during the consultation process with BHS managers and staff was their openness to be engaged with the VCHRR and their careful consideration during the dialogue on the meaning of the rights encoded. The VCHRR opened up a discourse about everyone as rights-holders in relation to each other. It was not adversarial and seemed to open up a discussion on the standard people want to set for their treatment of each other, wherever that interaction was taking place.

The UN Special Rapporteur on Human Rights and Health identified health professionals as being pivotal in reinforcing people's human rights, but he also identified that they were mostly unaware of or uncomfortable about using a human rights framework in their practice (Human Rights Council, 2007).

In the consultation it became apparent that the VCHRR had the potential to be an effective beginning point in the process of learning and practice change in relation to healthcare rights in the Victorian context.

### Finding

#### **4.1.2 Communication of healthcare rights need to be part of a broader process by health services in building relationships with consumers and communities**

This was one view common to both BHS staff and Ballarat consumers during the consultation.

From the point of view of BHS staff, consumers and community members will better understand healthcare rights when the issue forms part of a dialogue between health services and consumers; where mutual responsibilities and service limitations can be openly discussed.

The consumers also affirmed that people are better learners in a direct face-to-face exchange, at a time when they are not under stress (i.e. when they are not ill) and when they are part of a process which takes into consideration people's diverse language and learning capacities.

### Finding

#### **4.1.3 There is a need for provision of training and professional development on healthcare rights as well as human rights in healthcare for both consumers and healthcare providers**

**Specific consideration should be given to:**

- **participatory learning as the core methodology**
- **integrating complexities of human rights and healthcare rights to the process of learning**
- **use practical case studies relevant to each right**

These findings arose from the direct feedback from the consultation and also reflected the processes used by VEOHRC and HIC in the consultation workshops.

The consultation involved a multi-faceted process which included guided information to make sense of the actual content of both the VCHRR and the Patient Charter, open discussion, and relevant case studies that opened up issues of competing rights. The actual 'consultation' comparing the Victorian Patient Charter

and the VCHRR was only possible and took place only after this process of learning and dialogue.

First, feedback on the process from both BHS staff and consumers was very positive. Second, it was clear from the consultation process that a discussion on human rights and patient/consumer rights in healthcare opened up significant moral questions about power and the complexity involved in balancing the different rights between different people. These are noted in Part 3 of the table detailing the Comparative analysis of the Victorian Public Hospital Charter with the VCHRR (Appendix 1).

As an example, two very different questions were posed during the consultation by BHS staff:

- 'How do we balance the rights of different patients using the same service; for example, rights to freedom of expression versus right of privacy?'
- 'How do health services implement their own rights; for example, the rights of health service to expect people to attend their appointments?'

It was clear from the questions they posed to each other and to the facilitators that BHS staff and consumers were using their experiences to deepen their understanding of potential contexts and circumstances in which such rights would be played out.

The participatory learning process not only allowed the complexities to be raised, it also guided their elaboration and discussion without creating a moral imposition. It allowed the complexities of human and healthcare rights to be explored by peers in a safe *and* challenging learning environment.

Third, and importantly, BHS staff and consumers were clear about the need for direct examples that gave practical meaning to the application of rights in a health service context. These included not only examples of complaints derived from complaints processes or legal proceedings but where services and consumers used healthcare rights and/or human rights to develop or advocate for improved service delivery and better treatment.

It is interesting to note that the report 'The Human Rights Act – Changing lives', (British Institute of Human Rights, 2007) cites 15 case studies which demonstrate the rich variety of ways in which the Human Rights Act has been used by service providers and /or groups and individuals to challenge poor treatment, and, through this, to improve their own and others' quality of life.

## Finding

### **4.1.4 General healthcare rights need to be defined within a local context and be made clear to inform organisational policy development and day-to-day service delivery**

BHS staff were concerned that the general statements on patient rights in the existing Patient Charter were not helpful in informing practical service delivery by healthcare staff. Consumers recommended that accompanying statements of responsibilities for both healthcare providers and consumers in relation to each right could help clarify the implementation of rights.

As an example, BHS staff feedback on the section in the Patient Charter on 'Treatment and care in a safe environment' indicated that the information on the Patient Representative should not be included as not all health services had such a role and it undermined the role of nurses as advocates for their patient. The consultation with Ballarat consumers gave a different emphasis, but still with the overall point that things need to be specific and relevant to their local health service. Consumers said they wanted direct details of exactly who and how to contact the Patient Representative. They wanted more direct information about how patients raise concerns and clarification about what type of concerns were included.

Given the above example, and the fact that Ballarat consumers asked for clarification and detail on at least ten other rights in the Patient Charter, it is evident that both health services and consumers and communities need an explanation of rights as they pertain directly to their health service.

This poses a potential challenge to the application of ACHR, which includes seven global statements of rights. It needs to become clearer to health services and to health consumers what a service that supports the ACHR does, as part of direct day-to-day services.

### Finding

#### **4.1.5 Outstanding issues in relation to the content of the Victorian Public Hospital Patient Charter need to be considered and clarified within any future development of healthcare rights in Victoria**

##### **Some of these issues include:**

- **Second medical opinion**
- **Rights of carers and families**
- **Patient participation in decisions about treatment and choices**

The consultation process included direct comparison and critical reflection on the Victorian Patient Charter. Feedback presented here alerts us to the need for clarity about the ACHR.

#### ***Second medical opinion***

The Patient Charter had a specific section on 'Information about your healthcare and, if you wish, a second medical opinion'. Presumably, in the new ACHR this is subsumed under the 'Communication' right. It is again one of the rights where BHS staff and consumers had differently nuanced perspectives. During the consultation workshops, it became apparent that this 'right' reflected one of the biggest areas of complaints within BHS (and presumably in many other rural health services).

BHS staff made the point that this right generated conflict internally between health workers. They wanted clarification about this right in terms of whether it was the responsibility of the patient or the health service to organise the second opinion. Should it be sought in the same service or should the patient be seeking outside the service? Even though raised as a question, it was evident that they were questioning the viability of an internal second opinion, given its consequences for conflict.

Ballarat consumers also wanted clarification. They were well-aware of the complexity and tension involved in seeking a second opinion. Consumers stressed the importance of this section being very clear and that communication on treatment needed to be explained in ways that consumers fully understand. They wanted to include the availability of support to know how to ask questions about treatment and choices. They also wanted a clear explanation of how a second opinion could be sought locally.

If seeking a second opinion is a complex matter (and according to both BHS staff and consumers it is especially in rural health services), then it is important that due consideration be given to this finding.

### ***Rights of carers and families***

A second key gap identified in the Patient Charter was the rights of carers, families and personal advocates. This was identified by both BHS staff and Ballarat consumers. Through discussion it became clear that the Patient Charter is an individual statement about rights, focusing on the patient/consumer in relation to the health service. But as their discussions developed further—including consideration of the VCHRR—they both separately identified the need to clarify how carers fitted into Patient Rights, especially since Section 17 of the VCHRR included the Protection of families and children. It is important that due consideration be given to this matter in the clarification of healthcare rights within a Victorian context.

### ***Patient participation in decisions about treatment and choices***

The third key area is in relation to patient participation in decisions about treatment and choices. Participation is defined in one section in the ACHR. In the Patient Charter it was included in three separate sections:

- Participate in making decisions about your treatment and care
- Participate in decisions and receive information about your discharge from hospital
- Information about your healthcare and, if you wish, a second medical opinion.

To each of the sections in the Patient Charter, Ballarat consumers gave strong and multi-faceted feedback. Most importantly and consistently, consumers saw participation in decision-making as highly dependent on clear, mutually respectful communication **and** collaboration between healthcare provider and consumer.

The relationship between consumer and healthcare provider underlies participation. Ballarat consumers said they thought it important to be listened to and to not be judged. Healthcare providers need to understand consumers' social and cultural circumstances, which can affect their decisions and give them information that they can understand. Consumer decisions about their healthcare arose from a collaborative relationship.

Importantly, the VCHRR includes (Section 10) a person's right to not be subjected to medical treatment without his or her full and free informed consent; this section gives the right of consumers to participate in decisions about care and treatment a stronger basis encoded in law.

It is critical then that further consideration and clarification of the meaning and process of 'participation' be made in the ongoing work of detailing participation in healthcare rights in the Victorian context.

## 4.2 Making the VCHRR meaningful to health services and health consumers

### Finding

**4.2.1 There is a need for a guiding framework and resources for Victorian healthcare services to understand human rights including the VCHRR, especially in policy development and direct service delivery**

The VCHRR contain 20 civil and political rights. For many healthcare providers and even consumers and communities interested in healthcare, at first sight, civil and political rights may seem removed from their area of practice and concern.

In his article 'Victorian Charter on the Right Path – An assessment of the first 18 months', Phillip Lynch, Director of the Human Rights Law Resource Centre, observed that organisations such as homelessness services and community legal centres in Victoria were beginning to use the VCHRR to ensure that their services were flexible, responsive, respectful and that they promote human dignity (Lynch, 2008).

He went on to explain that this was consistent with experience in the UK under their *Human Rights Act (HRA)*, where a major evaluation of that legislation by the Department of Constitutional Affairs concluded that human rights had exerted a "powerful" and "positive and beneficial" impact on the development and delivery of public policy and services. It has been found that the UK HRA has "led to a shift away from inflexible or blanket policies towards those which recognise the circumstances and characteristics of individuals" (ibid).

The experience in the UK indicates the potential of the VCHRR to impact on Victorian health services. However, to meet this potential, there is a need for a framework and methodology for making the VCHRR directly accessible and meaningful to healthcare services and consumers.

The central point is that the VCHRR should be made integral to the development and dissemination of healthcare rights in Victoria or vice versa. Healthcare rights for consumers and human rights are interlinked. It seems opportune to link them in the process of dialogue and dissemination to healthcare providers and to consumers and communities. Importantly, the VCHRR is encoded in law in Victoria. Even though not consistently transparent there are rights defined in the VCHRR that strengthen (at least legally) the responsibility for implementation of the rights by healthcare services.

### Finding

**4.2.2 Human rights including the VCHRR need to be made transparent to health and the healthcare context**

**Specific consideration needs to be included:**

- **Need to develop appropriate information and resources about the VCHRR as it directly relates to health and healthcare services**
- **Collation and development of case studies within Victorian healthcare services of use of the VCHRR**

### ***Making the VCHRR transparent to healthcare***

The strongest point expressed by BHS staff was the importance of making the VCHRR meaningful to practice in a health setting. During the consultation what became apparent to BHS staff was the direct relevance—if not always in a transparent and straightforward manner—of many of the sections of the VCHRR to healthcare access, service delivery and development.

BHS staff identified two ‘hidden’ civil and political rights that pertain very directly to health (See part 5 of the Comparative Table in Appendix 1).

First, Section 10 of the VCHRR, Protection from torture and cruel, inhuman or degrading treatment or punishment is explained the following way: *A person must not be: a) subjected to torture; or b) treated or punished in a cruel, inhuman or degrading way; or c) subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent* (Victorian Equal Opportunity and Human Rights Commission, 2008).

This section of the VCHRR reflects a sliding scale of ‘bad’ treatment. It is not a Section that sits comfortably for consideration by health services; and certainly the extremes of treatment covered, including torture, is even more distancing for healthcare services. However, within the definition of that section is the part that clearly states that people should not receive **medical treatment without his or her full, free and informed consent**.

This part is clearly relevant and HIC would say central to healthcare practice. It has been a right clearly expressed in the Patient Charter and is reiterated as one of the rights in the ACHR. However, it is hidden within Section 10, which encodes protection against bad treatment. The relevance to healthcare services and consumers needs to be made transparent.

BHS staff also made a similar critical comment about Section 15 of the VCHRR—Freedom of Expression. This section is defined in the following way:

- 1) *Every person had the right to hold an opinion without interference.*
- 2) *Every person has the right to freedom of expression which includes the **freedom to seek and receive and impart information and ideas of all kinds*** (Victorian Equal Opportunity and Human Rights Commission, 2008).

While the whole definition of this section is not included here comments made by BHS staff as they discussed and interpreted this section was that this section forms the basis of informed decision-making and consent— and where people’s rights to the use of interpreters is covered. However, this was not readily apparent.

These are only two examples but the same feedback and need for transparency can be said of other sections in the VCHRR, including Section 8, Recognition and Equality before the law and Section 9, Right to life; all need to be made transparent and relevant to healthcare services and consumers.

### *Victorian case studies*

Case studies within health will contribute to this process of transparency and applicability across the health sector.

Importantly, VEOHRC during the course of this consultation published a helpful resource, *Civil and political rights explained* (Victorian Equal Opportunity and Human Rights Commission, 2008), which defines each section of the VCHRR in clear language and cites legal and service case studies from both Victorian and international cases relevant to the interpretation of the section within Victoria. This

type of resource will help inform a human rights dialogue with healthcare providers and consumers.

The report '*The Human Rights Act – Changing lives*' (The British Institute of Human Rights, 2007) gives clear meaning to rights through 15 case studies. Six of the case studies involved health services. These case studies have been used widely and repeatedly in Victoria to help service providers across all services and community members to understand practice and service delivery implications of human rights (legislation).

One Victorian 'health' story already exists and comes from the case work carried out by the Human Rights Law Resource Centre (HRLRC). This example is important on two levels. It is a direct example of a case study which relates to access to medical treatment by a Victorian citizen and the use of the VHCRR as an advocacy tool. It shows how civil and political rights do apply to healthcare provision. The HRLRC includes this case of the Provision of Appropriate Medical Services to Elderly Persons outlined in their Bulletin 23. This story also shows the importance for healthcare services, consumers and health advocates for collaborating with a broader network of organisations, including the HRLRC.

Victoria needs its own case studies and examples to help inform and contextualise the understanding of healthcare providers and consumers about the applicability of the VCHRR. It is worth noting the VEOHRC has put out a call for organisations, workers and community members to submit their stories about working and living with the Charter (Victorian Equal Opportunity and Human Rights Commission, 2008). While this is an important initiative, HIC believes it is particularly important that stories be collated and used for reflection, learning and service development and specific to healthcare services.

## APPENDIX 1: CONSULTATION AND WORKSHOP ANALYSIS

The consultation process involved collaboration between HIC, Ballarat Health Services and the Victorian Equal Opportunity and Human Rights Commission. This has been detailed in Section 1.2.3.

The following table was developed to help facilitate the comparative analysis on two levels: first, in the comparison of the Victorian Public Hospital Patient Charter and the VCHRR, and second, in the comparison between feedback and commentary from BHS service managers and staff on one hand, and consumers and community members on the other.

The comments are divided into five parts. The first part focuses on general observations, feedback and ideas in relation to the Victorian Public Hospital Patient Charter. The second part focuses on general observations in relation to the VCHRR. The third part includes observations that are relevant to both the Patient Charter and the VCHRR. The fourth part focuses on the specific rights and sections of the Patient Charter and direct feedback and ideas. It is important to note that not all sections of the Patient Charter has been included as not all of the sections had any further or detailed observations. The fifth part includes specific comments and feedback on some of the specific sections of the VCHRR.

In some cases, either BHS staff or consumers may not have made specific commentary. In other cases, both BHS staff and consumers made similar comments. In other cases, perspectives and contributions were clearly different, reflecting different experiences and perspectives.

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
<b>Part 1 : General observations in relation to the Patient Charter</b>				
		Necessary and relevant to include an explicit reference to the VCHRR in the introduction to the Patient Charter to create a direct link.		
In relation to the Patient Charter – Overall observation	Current Patient Charter seems to include ‘motherhood’ principles - overarching, large statement which are not always meaningful to practice.			There needs to be an accompanying statement about what the responsibilities of the health services and staff are in relation to the rights defined in the Patient Charter. It would also be useful to have a separate section about responsibilities that consumers/community members have to staff and towards each other in public health services.
In relation to the Patient Charter – Overall observation	It seems to be a mixture of rights and protocol/ procedures. (This will be elaborated under specific section of the Patient Charter).			
In relation to the Patient Charter – Overall observation	It is wordy.	Simple, accessible language is required.  Language of Patient Charter needs to be tested appropriately with people (patients/consumers).		The Charter needs to be accessible in its written form but people need to be helped to understand its meaning in face-to-face communication.

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
In relation to the Patient Charter - Overall observation Outreach	It is important that people have access to Patient Charter before they become critically ill.	Outreach education, including in public and community places such as bus stops and groups is necessary.	Is the Patient Charter available to people pre- and post-admission, before treatment begins and for their use afterwards (given that while in treatment people are under stress).	The process of informing people about the Patient Charter needs to recognise that people learn better in a face-to-face exchange in a way that takes into consideration language and people's learning capacity and opens up the opportunity for understanding.
In relation to the Patient Charter - Specific issue unclear Patient restraint	There is a gap in the Patient Charter that does not clarify a patient/person's rights when they require restraint? (i.e. non-psychiatric patients and residents). This is evoked by S22 in the VCHRR Humane treatment when deprived of liberty.			
In relation to the Patient Charter – Specific issue unclear The role of carers	It does not have anything about the role/rights of family/carers/ children. This is evoked by S17 Protection of Families and Children in the VCHRR. This is also very important within the Mental Health Patient Charter.	Important to include in a new Charter the following: 'The right of the individual to have family involved in care and decisions, if he/she gives consent'.		Recognition of the role and support that carers provide is important

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
<p>In relation to the Patient Charter – Specific issues unclear</p> <p>Open Disclosure</p>	<p>There is a gap in the Patient Charter about patient’s right to ‘open disclosure’ and to being informed about other ‘incidents’ that occur in relation to safety and medication.</p> <p>There are many incidents that DHS will not let public know including how many people have suicided while they are in treatment. Such incidents and others including unsafe treatment are recorded on a database but are not necessarily recorded on a patient’s notes. The VCHRR can open up further our transparency directly.</p>	<p>Open disclosure should be included in the Patient Charter and be in line with S15 in the VCHRR.</p> <p>The Patient Charter should therefore also include a statement that reads ‘Information about any unexpected events during your stay in treatment’ similar to the existing section which is</p> <p><b>“Information about which hospital staff will provide your care”</b></p>		
<p>In relation to the Patient Charter - Specific and unclear areas</p> <p>Prevention, self-management</p>			<p>There is a gap in the Patient Charter in relation to education, learning and information in relation to self-management, understanding how the health service works on prevention of illness and promotion of wellness.</p>	

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
<b>Part 2 : General observations in relation to the VCHRR</b>				
In relation to the VCHRR – overall observation  Use in health services	Understand there is a need to embrace the VHRRC; however, the question remains as to how all this translates itself into practice? Policy-makers within health services will use it; however, there is a strong concern as to whether it will be used and integrated at the practice levels.			
In relation to the VCHRR – overall observation  Context of VCHRR		The discussion about our human rights and health should be part of a broader and ongoing relationship with communities and public about the possibilities as well as the limitations of health services.		
<b>Part 3: General observations in relation to the Patient Charter and VCHRR</b>				
	Discussions which raised complex issues in relation to a rights-based approach within health services: How do we achieve the <i>balance</i> between the rights of the individual (patient/consumer) and the rights of the health service providers?			

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
	<p>How do we protect the rights of workers to a safe environment compared with the rights of a consumer to healthcare (who is also behaving aggressively)?</p> <p>How do we balance the right of the patient to discharge themselves with the position of the health service in relation to withdrawing services to that patient (because the health service does not agree and sees discharge as increasing risk)?</p> <p>How do we balance the rights of different patients using the same service; for example, rights to freedom of expression versus right of privacy?</p> <p>How do health services implement their own rights; for example, the rights of health services to expect people to attend their scheduled appointments?</p>			
In relation to the Patient Charter and VCHRR	<p>People know they have a right to something, but because they don't know what and how to use it and how to articulate it, their anger grows. Rights' statements needs to be clear and specific.</p>			

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members of Ballarat</u>	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
<b>Part 4: Specific observations to relevant sections within the Patient Charter</b>				
<p>A wide range of public hospital services</p> <p>Having a wide range of services means that wherever you are in the state, you will have access to high quality and appropriate care</p>	<p>This is the first section of the Patient Charter and essentially refers to the right to healthcare. This makes it stronger than the VCHRR (which does not include right to services and covers only civil and political rights).</p>	<p>There were three points made in relation to this section of the Patient Charter:</p> <p>i) Transfer or referral to a different hospital needs support and coordination with family and carers.</p> <p>ii) Travel is a significant factor that can limit access in rural areas. It is important that travel/ travel support is seen by health services as part of the care and treatment for rural patients/consumers. This section in the Patient Charter should include accommodation and transport information and support to carer and patient. Transport and accommodation should be coordinated by health service – rather than being left to patient/family.</p> <p>ii) What is most appropriate should be clearly discussed and negotiated with the patient/carer.</p> <p>iii) It is important that patients be informed about how medical information will be transferred (with the referral or transfer) and that each patient transferred will be provided with a care plan and liaison contacts within the new location.</p>		
<p>Treatment based on clinical need regardless of your ability to pay your health insurance status</p>	<p>This is a strong section which recognises economic disadvantage as a factor limiting access. This makes the Patient Charter stronger than the VCHRR.</p>	<p>There were two points raised in relation to this section:</p> <p>i) What about people on temporary protection visas and asylum seekers? Is their treatment also based on clinical need? Need to clarify who are we referring to?</p> <p>ii) Does treatment also include medication? This also needs to be made clear.</p>		
<p>Choose whether you wish to have treatment as a public or private patient</p>	<p>Is it appropriate to have this included as a right at all, especially when most of the explanation is more a protocol matter for the patient? It seems more of an effort to try and explain a complicated system.</p>	<p>There were three points made in relation to this section:</p> <p>i) It should also be made clear that if you are private patient that the fees you pay, you pay up front.</p> <p>ii) The part that reads ...<b>“If you are a private patient, you or your health insurer will be charged for some services”</b> is misleading and should read ...‘you are responsible for cost of treatment’.</p> <p>iii) The part that reads <b>“Your ability to choose your treating doctor will differ depending on whether you are a private or public hospital patient.”</b> is unclear and even implies that there is a choice for public patients as well.</p>		

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members of Ballarat</u>	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
Treatment and care in a safe environment	The part in this section which reads ... <b>and to request assistance from the Patient Representative</b> should be deleted. Who is the Patient Representative anyway? Not all health services have such a role. It also undermines the role of the nurse to be advocate for the 'patient'.		There were four points made in relation to this section: i) The part that reads, " <b>You have the right to raise concerns...</b> " is not helpful. How does a patient do this? It needs to be explained. What type of concerns? This needs to be explained so that people know. ii) Who do they raise their concerns with – contact needs to be made clear on the Charter. iii) Carer/or next of kin (as defined and agreed by the patient) also should be able to raise concerns on behalf of the patient. iv) What does safe mean? Does it also include safety from people outside the health service; for example, abusive family member? The part that is written " <b>feel safe</b> " should be stated as "be safe".	
Participate in making decisions about your treatment and care	The part in this section that reads " <b>If you are a patient capable of giving informed consent you also have the right to refuse treatment.</b> " This part makes the whole statement invalid and even ridiculous – who is reading it? ...and what if the person who is reading the Patient Charter is not capable of giving informed consent.		There were three key points raised in this section: i) What does " <b>if you are a patient capable of giving informed consent...</b> " mean? Who decides? How is it established? What about the role of carer/or NOK in this process? ii) Is it the duty of medical staff to disclose all medical matters to the patient, even in circumstances when next of kin requests that patient not be informed; for example, terminal illness? iii) Communication between health workers and patient is the key to making this section meaningful for patients/consumers. It is important that information provided to patients/consumers can be understood and that people can ask questions without being judged. It is important that consumers/patients feel they are listened to (consumers and patients know when they are not listened to).	
Participate in decisions and receive information about your discharge from hospital	There is an obligation for the health service to deliver information but there is no obligation to ensure that the information is understood. For example, is the information presented in an accessible way? Is the information presented in a way that is culturally appropriate? Is the information presented in a way that recognises and respects people's varying abilities?		There are three points made in relation to this section: i) It is important that health services recognise that many people fall through the gap after discharge. Health services need to ask about people's preparedness for leaving. And it is not just about being given information about available services, but health services actually doing follow-up with people after discharge. This should be included in this statement. ii) There should be more here about collaborative decision-making between health worker/service and patient.	

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
			<p>iii) The last statement in this section has a negative, blaming tone. It reads <b><i>“You may discharge yourself against your doctor’s advice, however, you may be asked to sign a form accepting responsibility for your decisions”</i></b>. There may be many complex and social reasons for people to have to discharge themselves –and it is important that the health service show that it understands these complexities. Rather than the word ‘however’, it may be more appropriate to use ‘although’.</p>	
Information about which hospital staff will provide your care			<p>It is very important to give a sense to patients about the continuity of care that is taking place across the changes/handover of staff. It is important that staff introduce themselves constantly as part of the handover and care for patients. It is important to include: ‘ongoing’ and re-assurance of continuity of care inside this explanation. The statement could include “in hospital there will be a number of people looking after you”.</p>	
Information about your healthcare and, if you wish, a second medical opinion	This section raises many complexities in a public hospital setting. It raises conflict internally between health workers; in a rural health service, it is not consistently possible. Who is responsible for organising that second opinion? Is it the health service or the patient? Should it be sought in the same service or should the patient be seeking it outside the service?		<p>There are five points raised in relation to this section:</p> <p>i) This is very complex, especially in a rural hospital setting. One of the community members explained that she sought a second opinion and to do this she had to go off the waiting list, seek her opinion separately and then be put on the waiting list again.</p> <p>ii) Health staff (especially doctors) do not like second opinions being sought.</p> <p>iii) It is very important that this section is explained in very clear, layman’s terms. Information about treatment should be presented in a way that consumers can fully understand. It should also be given in a way that takes into consideration people’s cultural identity.</p> <p>iv) It should also include: “You will be supported to know what questions to ask”.</p> <p>v) There needs to be a clear explanation of <b>how</b> a second opinion can be sought locally. Whose responsibility is it? Is it the patient’s or is it the health services’ responsibility to help the patient find a second opinion? Can the health service support this process and be objective?</p> <p>vi) <b>“You should be given enough time to ask questions, get more information and talk to family and friends before making any decisions”</b>. This all reads well and is appreciated; however, it is also important that this decision be part of the collaboration between consumers, carers and health services. It is about shared decision-making.</p>	

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members of Ballarat</u>	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
Access to your health records and confidentiality for your personal information			There are three points raised in relation to this section: i) It sounds 'paranoid.' One way of writing it may be: "You are able to access your health records at any time". ii) It is too detailed and needs to be written in layman's terms. iii) It should not be a generic response but each health service should clearly include who the direct contact person is when a patient/community member wants to take this up.	
Treatment with respect, dignity and consideration for privacy	The part that reads " <b>You are also expected to treat hospital staff with respect and consideration</b> " is 'hidden'. It should be clearer.		There are four points raised in relation to this section: i) It feels that the treatment with respect and dignity is confined to only in relation to matters of 'privacy'. ii) The two themes should be separated out – respect and dignity should have its own section and 'privacy' should have its own. iii) It is perhaps better worded in the following way: "You have the right to be treated with dignity, respect and sensitivity (or compassion) at all times and in your contact and communication with all staff at the health service". iv) The last line, the responsibility which the patient/community member has: " <b>You are also expected to treat the hospital staff with respect</b> ".....sounds authoritarian.	
If necessary, to have access to an accredited interpreter	The section seems to only focus on interpreters for people from non-English speaking backgrounds. It does not seem to include interpreters for people with disabilities; for example, those who have a hearing impairment who could not access an interpreter via telephone.			
Information on steps the hospital takes to improve the quality of care	The whole of the second a paragraph in this section can be deleted. It doesn't really mean anything to the individual.			

Comparative analysis of Victorian Public Hospital Patient Charter with VCHRR	Reflections, feedback and ideas from <u>health service managers and staff</u> at Ballarat Health Services		Reflections, feedback and ideas from <u>health consumers and carers of BHS and community members</u> of Ballarat	
	Feedback	Ideas for action and change	Feedback	Ideas for action and change
<b>Part 5: Specific observations relevant to sections within the VCHRR</b>				
S10 Protection from torture and cruel, inhuman or degrading treatment or punishment	<p><b>“...A person must not be subjected to medical or scientific experimentation or treatment without his or her full, free and informed consent.”</b></p> <p>This section reflects a sliding scale of ‘bad’ treatment. However, there is a feeling that in relation to healthcare ‘informed consent’ and decision-making gets lost in the vastness of this section.</p>			
S13 Privacy and Reputation	<p>This is fraught and complicated in a public health/hospital setting; for example, in-patients having to discuss their condition/treatment etc. with health workers in a ‘public’ open ward. It is also fraught in relation to coordination between services and workers within the one health system.</p>			
S15 Freedom of expression	<p><b>“...People have the right to seek out, receive and pass on information and ideas</b> of all kinds whether orally, in writing, in print, by way ....”</p> <p>This is where informed decision-making by consumers in healthcare can be placed. This is where people’s rights to the use of interpreters are covered. However, this is not an obvious place. It is hidden.</p> <p>On the other hand, it opens up the discussion and rights of patients for open disclosure and for there not to be any form ‘censorship’ both at the hospital level and at the level of DHS.</p>			

## APPENDIX 2: PROGRAM OF CONSULTATION WORKSHOPS

The way the two consultation workshops were conducted differed.

### **Consultation with Ballarat Health Services managers and staff**

The workshop with BHS managers and staff involved the following:

- Information/ reflective learning/case studies and application of VCHRR. This was presented by the Victorian Equal Opportunity and Human Rights Commission.
- Small-group discussion looking at the specific rights in the Patient Charter and analysing how they fit or don't with the specific sections of the VCHRR. The following questions were asked:
  - *How and where does each patient right reflect the VCHRR? (specific rights within the VCHRR and overall)*
  - *What are the gaps?*
  - *Is there anything within the VCHRR that should be included within the Patient Charter? Is there anything in the Patient Charter that isn't in the VCHRR and should be maintained/ strengthened? How?*
- Whole-group discussion about issues identified.

### **Consultation with diverse consumers and community members from Ballarat**

Workshop with consumers and community members involved the following:

- Information/ reflective learning/case studies and application of VCHRR. This was presented by the Victorian Equal Opportunity and Human Rights Commission.
- Presentation: How Ballarat Health Services uses the Public Hospital Patient Charter and why?
- Whole-group discussion 'What is important to patients/community members when accessing or receiving healthcare/hospital care?'
- In small groups, keeping the Human Rights Charter as a framework, and looking at specific sections within the Patient Charter, discuss:
  - *How can the Patient Charter be strengthened to make it a more useful tool for consumers and community members using health services?*
  - *What could/should be left out? What could/should be put in?*
  - *What could be explained more clearly? How?*

## REFERENCES

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