

# Consumer and Carer Reference Group Communiqué June 2018

This update highlights key discussions and considerations from the fourth, fifth and sixth meetings of the Sustainable Health Review (SHR) Consumer and Carer Reference Group held on 20 March, 17 April and 15 May 2018 respectively, as well as a joint meeting with the SHR Consumer and Carer Reference Group held on 22 May 2018.

## Key Topics for 2018

The Reference Group Chair accepted a list of key topics from the SHR Panel which may be used to guide to inform their advice to the Panel for 2018. Key topics for the Consumer and Carer Reference Group are:

- Consumer involvement/engagement;
- End of Life Care;
- Narrative and vision for the Final Report;
- Changing mindsets;
- Elective Surgery Factory;
- Telehealth; and
- Health literacy

## Engagement

The Reference Group members are currently actively involved in a number of targeted engagement activities under the guidance of the Reference Group Chair. This work is directly connected with the second phase of the Panel's consumer engagement program. This stage will include engagement specifically targeting priority consumer groups including indigenous; culturally and linguistically diverse; the aged; consumers with disabilities and their carers; those with lived experience of mental health conditions and their carers; alcohol and other drug consumers and youth.

## Feedback on Interim Report

The Reference Group provided the Panel with extensive feedback on the SHR Interim Report from a consumer viewpoint. Key comments included:

- The need to strongly articulate a vision, including outcomes, measuring progress and implementation plans.
- Include stronger public discourse on value / outcomes / spend in health – this has impacts for all consumers.
- Not enough recognition of the not-for-profit provider contributions to primary care.
- Members shared views on the language used and suggested more emphasis on person-centred care.
- More regional and remote outreach was needed. Community Resource Centres (CRCs) were supported as a key mechanism for reaching regional consumers.

## Consumer involvement/engagement discussion

The Reference Group was invited to provide advice to the Panel on contemporary consumer involvement/engagement mechanisms and how to develop enduring ways that consumers can be involved in decision making including principles, types and location of services, care goals, funding etc.

Key points from the discussion:

- '*Embedding Consumers in the Health System*' by Tony Addiscott.

- The definition of the health system is often limited to tertiary hospitals. Before we can achieve effective consumer involvement we need to look at the high level structures and ensure they include all organisations that deliver health services.
- Performance Indicators are needed to encourage and deliver progress in the health system.
- More research is required to determine the value of consumer engagement.
- Whole of Government approach needs to be strongly emphasised, particularly in relation to Direction One from the Interim Report. Effective change cannot happen unless all areas of government are accountable and working towards healthy communities.
- Patient Opinion needs to be expanded to include all human services.
- All consumers have a responsibility to make their feedback known.

## End of Life Care discussion

A Joint Reference Group was held in May 2018 with the key topic being end of life care. The Panel invited members to identify opportunities and risks to improving end of life care in Western Australia, through two key areas;

1. End of life care community initiatives; and
2. A range of clinician focused end of life care programs.

Members were asked to provide high level implementation advice and asked to consider an extensive range of resources, models and other related work being done in this area.

Key points and advice from their discussion include:

- **Develop a whole of community, place-based approach to palliative and end of life care**  
The members supported a broad communication/implementation initiative for implementing Compassionate Communities on an industrial scale, recognising the importance of a community response. Also discussed WAPHA partnerships for outreach programs, education and spaces for community level engagement, and much greater involvement of local government to gain traction in every community.
- **Strengthen the relationship between hospitals and residential aged care facilities**  
Embrace Residential Aged Care Facility (RACF) staff and provide specialist palliative care for complex cases at no charge, in return for holistic end of life care for the majority of the residents. Develop a specific communication plan between hospital staff and RACF staff, adapt the funding approach to support reporting to shared outcomes, and develop KPIs for advance care plans and specific outcomes in aged care.
- **Address structural changes**  
Members discussed the need for a Medicare Benefit Schedule (MBS) item for GPs to support consumers to develop advance care plans. The MBS item for advance care planning can be expanded to Nurse Practitioners and Practice Nurses, and greater use of pharmacies to deliver advance care planning (with Nurse Practitioners). Also Community Connectors are a key strategy to consider implementing. Use My Health Record as the central point of storage of advance care planning and as a constant prompt.
- **Implement process changes**  
Implement process changes, such as: require advanced care planning as a condition of admission to the Residential Aged Care Facility; build advance care planning into the aged care assessment process; and consider starting early with linkage to driver's licenses. Approach advance care planning as a prevention initiative and target primary, secondary and tertiary prevention stages or consider develop social enterprise to provide the service.
- **Establish clinical alerts for advance care planning in St John and RFDS systems**

## Next Meeting

Meetings for the Consumer and Carer Reference Group will be scheduled monthly.

## Further information

Email: [SHR@health.wa.gov.au](mailto:SHR@health.wa.gov.au)

Website: <http://ww2.health.wa.gov.au/Improving-WA-Health/Sustainable-health-review>