

A whole-of-journey approach with rural consumers who travel for health care: a report on a resource kit for health services that care for rural consumers who travel for health care

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Michael Janssen is CEO of Health Issues Centre, Victoria's peak health consumer body and Australia's leading consumer research and education organisation. Michael's roles have included CEO of the Australian Diabetes Professional Organisations, Deputy CEO of the Continence Foundation of Australia, Principal Adviser for the Australian Divisions of General Practice, Patient Advocate at The Royal Melbourne Hospital, and Community Relation Manager for Diabetes Australia—Victoria. Michael holds a Masters of Applied Science, a Bachelor of Theology, and recently completed a PHCRED Fellowship with the Department of General Practice, University of Melbourne. Michael brings broad experience and passion that integrates consumer, provider, researcher and funder perspectives in health care. He has been instrumental in a number of rural health programs, including the Chronic Disease Self-Management in Remote Australia Program. Under Michael's leadership Health Issues Centre has developed key initiatives including: the nationally recognised qualifications of the Course in Consumer Leadership and the Graduate Certificate in Consumer Engagement; the inaugural international conference on community engagement in health care titled 'Consumers Reforming Health 2011'; and, initiation of Health CIRCLE—a collaborative venture of university, industry and consumer organisations to establish a national Consumer Issues Research Centre for Learning and Engagement. While having lived in rural areas such as Ballarat, Sale, and Mt Isa, Michael's experience of consumers who travel for health care comes most directly from his time as patient advocate for a large Melbourne hospital where he worked with disadvantaged and disgruntled rural patients on a regular basis.

Background

In 2008 and following concerns expressed by several metropolitan hospitals' Community Advisory Committees, Health Issues Centre prepared a Discussion Paper on 'The needs of rural consumers who travel to Melbourne Hospitals'.

The heart of the paper was the stories shared by 16 rural consumers mostly from the Loddon Mallee region of Victoria of complex and poignant experiences. Very clear strategies for change were identified by the consumers and were reinforced by the literature review undertaken in this work. A consumer-strong reference group developed priorities for recommendations.

With ongoing support from the Victorian Department of Health, Health Issues Centre explored initiatives by Government and health services both in rural and metropolitan areas of Victoria, of enhancing the journey for consumers and carers.

Health Issues Centre coordinated two regional roundtables one each in Gippsland, December 2008 and Loddon Mallee, April 2009. The roundtables brought together rural consumers and carers; regional representatives of the Department of Human Services, primary health services including Divisions of General Practice, community health and primary care partnerships; public health services including metropolitan, regional, district and rural health and community based transport providers.

The consistent theme that emerged was that, because of fragmentation of care due to jurisdictional and communication silos across the health system, it is critical that the journey of the rural consumer be seen as a 'whole', from the moment their rural GP refers them 'away' to specialist services in regional or metropolitan hospitals, through their experience as outpatients and inpatients and to their return home after treatment and needing local care.

The resource kit "A Whole-of-Journey Approach"¹ compiles 18 initiatives by health services that address the priority areas identified by this preliminary work. The kit and its Consumer Checklists² are intended to inform, inspire and connect health services at all levels—primary, acute, rural, regional and city—in their efforts to provide care to rural consumers and their families who travel for health care.

Priority areas

As stated, the conclusion from the collaborative investigation lead by Health Issues Centre is that a whole-of-journey approach is necessary for consistent, coordinated and supportive care to rural consumers who have to travel. This means the journeys of rural consumers and their families need to be understood as a continuum from the point of referral, through travel to access care, and back to the return home after treatment and use of local care and support. To take a whole-of-journey approach, eight priority areas of policy and practice change and development have been identified.

The kit is divided into eight sections, one for each of the priority areas. Each section includes a brief explanation of the priority followed in most cases by one or more current initiatives that address and support rural consumers and families. Sections that do not have initiatives may represent either an identified gap which needs to be addressed or that the call for initiatives did not reach all appropriate stakeholders. The priority areas are:

1. Identifying rural consumers at all points along the journey of health care
2. Developing rural GP practices as the first point of information and coordination
3. Placing staff who can inform, support, coordinate and advocate for rural consumers
4. Developing and providing transport and accommodation information
5. Providing better transport and accommodation support and options
6. Rethinking discharge to 'transfer of care'
7. Reducing the need for rural consumers to travel
8. Policies and programs for a 'whole-of-journey' approach

Priority 1: Identifying rural consumers at all points along the journey of health care

The first priority is the development of a way to consistently identify rural consumers travelling within and between all health services.

A mechanism for consistently identifying rural consumers within all health services could activate higher awareness and a more coordinated response to the needs of rural consumers as they access distant health services. The earlier in the rural consumer's journey this mechanism for identifying rural consumers is activated the better.

Some methods for identifying rural consumers are:

- When the hospital is booking the outpatient appointment with people, asking the question 'Will you have to travel more than ~100kms to reach this service?'
- Placing a rural flag on consumer/patient files.
- Integrating 'rural' identifiers into the templates such as in Victoria, the Service Coordination Tools Template (or SCoTT) developed by the Department of Health for service coordination between primary and acute services.
- Placing maps of patient's rural location over her/his bed or on a ward's patient board.

Example: The example included in the kit is the Outpatient Alert System—Country patients used by the Royal Victorian Eye and Ear Hospital.

Priority 2: Developing rural GP practices as the first point of information and coordination

Rural GP practices are one of the key initial points for information for rural consumers when they are referred to specialist treatment at a distant location. The GP practice manager or practice nurse may be the most

appropriate person to directly provide critical information about travel support, including transport and accommodation services and options.

Responding to this priority will require further development of the role of practice managers and nurses as the starting point of information. For rural GP practice managers and nurses to be effective as information providers to rural consumers, resources and information must be available and easily accessible to them—there is no suggestion that their role should include preparation of information.

Priority 4, which concerns the development and coordination of travel support information including transport and accommodation, will provide useful resources for rural GP practice managers and nurses in their role of information support and coordination to rural consumers.

Example: No examples of the development of this role are included in the resource kit.

Priority 3: Placing staff who can inform, support, coordinate and advocate for rural consumers

It is important that rural consumers and their local health services know that a key point of contact for them exists in their treating hospital.

In some hospitals in Victoria this position is integrated into social work positions. In other hospitals, dedicated positions are created to provide transport or accommodation support. In South Australia, there are rural liaison nurse positions.

These points of contact can provide relevant information about travel support before rural consumers leave their home and while they are in hospital. This role can help coordinate care within and between health services, including taking travel into consideration when making appointments. They can also facilitate a transfer-of-care approach between the treating hospital and more localised health services who will continue the care once the rural consumer has returned home.

Examples:

- Women's Social Support Service (WSSS) at the Royal Women's Hospital, Melbourne, Victoria
- Aboriginal Women's Health Business Unit, Royal Women's Hospital, Melbourne, Victoria
- Transport and Accommodation Coordinator, Social Work Department, Royal Victorian Eye and Ear Hospital, Melbourne, Victoria
- Accommodation Liaison Officer, St Vincent's Hospital, Melbourne, Victoria
- The role of Rural Liaison Nurses and Patient Liaison Positions within the Patient Journey Initiative of Country Health South Australia

Priority 4: Developing and providing transport and accommodation information

There are two connected issues regarding information about travel support for rural consumers and families who have to travel for health care:

- Development of information by health services or other relevant services, including transport services or community organisations.
- Consistent provision of this information at key points along the consumer's journey for health care.

There is a need for the development of accessible, relevant and regularly updated web- and paper-based information about the transport, accommodation and health services available to consumers who travel for medical services. This information must be made available directly to consumers and be accessible to hospital and health service staff, social support agencies, emergency relief networks and at other service providers.

There is a need for the consistent provision of information at all stages of a patient's journey. It is important to identify the positions at health services that are responsible for providing this information and determining their roles and responsibilities. The provision of information is clearly linked to the roles identified in key priority areas 2 and 3.

Examples:

- Let's GET Connected Transport Assistance Information Brochures: East Gippsland and Wellington Shire Councils
- South West Community Transport Program; Western District Health Service
- Victorian Patient Transport Assistance Scheme (VPTAS):
- *Inner Melbourne Hospital Map and Guide*, Department of Transport with Transport Connections
- Accommodation guides by St Vincent's Hospital and the Royal Women's Hospital

Priority 5: Providing better transport and accommodation support and options

This priority area is about strengthening and diversifying transport and accommodation services and options for rural consumers. Recommendations have been made elsewhere³ (Health Issues Centre 2009) about strengthening transport services and support. The issues addressed here are:

- petrol and accommodation subsidies
- demand for community transport
- public transport for intra-regional travel and for travel to Melbourne
- transport support for rural consumers and families who are returning home after treatment in hospitals.

Examples:

- Travellers Aid Australia
- Family Accommodation Service, Royal Women's Hospital
- Gippsland Rotary Centenary House Inc.

Priority 6: Rethinking discharge to 'transfer of care'

Returning home from hospital has its own complexities for rural consumers and their families. Often consumers are left with unanswered questions such as how will they get home, what medication they will need, what services will they need when they return home and will their local GP and other appropriate local services have been informed. Many consumers are unclear about what they should be doing and who they should be contacting for their ongoing care after returning home.

The concept and language of 'transfer of care' seem more appropriate than 'discharge'. It implies an ongoing responsibility by the treating hospital for a safe and supported journey by rural consumers when they return home. It implies communication and relationships with appropriate local rural services.

Some key considerations and features of a 'transfer of care' model include:

- Early planning with the rural consumer and their family.
- Holistic assessment including an understanding of what support mechanisms are available locally.
- Communication that is linked back to the locally based care services, including the GP, rural hospital, community health service, allied health workers, post-acute care coordinators or other appropriate health services.

- Travel support that matches the health needs and financial circumstances of rural consumers and wHealth Issues Centre is coordinated with local transport service providers.
- Medication availability from the treating hospital, wHealth Issues Centre takes into consideration travel and local access difficulties and unavailability.
- Using accessible language and providing culturally appropriate information and support to rural consumers and their families about self-care.

Example:

- Building blocks for discharge communication and resources: General Practice Victoria and General Practice liaison units

Priority 7: Reducing the need for rural consumers to travel

This priority area considers the importance of developing more health care initiatives and services in rural communities, reducing the need for travel—particularly for specialised health care. This is part of the ‘whole-of-journey’ approach because it could reduce the distance travelled for health care or even the need to travel at all. This priority area may be covered by some reforms being considered and introduced as part of the national reform agenda for health and health care in Australia.

It is worth noting that two of the three examples included here involve relationships and initiatives between Melbourne and regional health services.

Examples:

- Specialist Speech Pathology and Nutrition Care mentoring for cancer professionals in regional Victoria. St Vincent’s Hospital, Melbourne
- Virtual Ophthalmology Support—A service agreement between the South West Alliance of Rural Health and the Royal Victorian Eye and Ear Hospital.
- Bendigo Health Transition Care Program. Regional outreach services

Priority 8: Policies and programs for a ‘whole-of-journey’ approach

The many initiatives from various health, transport and community services in the seven key priorities detailed above have been developed in direct response to the needs of rural consumers and families. Health services have recognised gaps at service and systemic levels.

Some health services have used their resources in creative ways to respond to the needs of rural consumers who have to travel for health care, including the creation of specific positions and services. Others have recognised that it is more cost-effective to respond to the priorities of rural consumers outside the hospitals. And others have worked to strengthen communication and coordination between city, regional and rural services to better support rural consumers at different points in their journey.

The priorities of rural consumers who travel for health care are not only centred on transport. But transport is often where the discussion and the action gets stuck. Affordable and accessible transport options, adequate transport support and consistent provision of transport information to rural consumers are all essential. However, transport is only one of the priorities that need to be coordinated and acted on for a ‘whole-of-journey’ approach.

The ‘whole-of-journey’ approach requires a policy framework. It also requires coordinating roles within government health departments.

Implementation: checklists and spin-offs

To assist implementation by health services and providers of better support of consumers who travel for health care, Health Issues Centre developed a number of resources for consumers. Under the main title of

“Key questions to ask if you have to travel for health care”, three checklists were developed (Victorian Government, 2010b) with the subtitles:

- Before you leave home
- At the hospital
- Going home

In addition a “Handy travel and support contacts” sheet was also produced.

Since the publication of the kit and the checklists Health Issues Centre has received a number of communications regarding spin-off projects aimed at addressing one or more of the eight identified priority areas. The most concrete project resulting from the kit to date is being run by North Eastern Metropolitan Integrated Cancer Service (NEMICS) and Austin Health of a ‘travelling patient’ checklist and planning tool regarding patients who travel to access Positron Emission Tomography (PET) scanning. The consumer information resource developed for this project addresses in one document booking, clinical, cost, travel and accommodation issues. Health Issues Centre staff are assisting in the evaluation of this project. This project is an example of the intention of the “A Whole-of-Journey Approach” to “to inform, inspire and connect health services at all levels—primary, acute, rural, regional and city”.

Conclusion

The eighteen initiatives in the resource kit show what can be done when the complex experiences and journeys of rural consumers and their families who have travelled for health care are integrated into policy and service provision. The kit represents a contribution to the long ‘journey’ of addressing health consumer travel issues, which is an ongoing process. Accordingly, this paper has suggested two recommendations for further work on this issue within the current context of health reform:

1. Rural Medicare Locals should consider developing a ‘whole-of-journey’ approach to rural health consumer travel and seek to identify and share resources that improve the support within general practice of consumers who travel for health care
2. Regional and metropolitan Local Hospital Networks (LHNs) will develop linkages with catchment rural Medicare Locals and this should include addressing consumer travel issues. Regional and Metropolitan LHNs receiving and discharging rural patients should consider placing staff capacity to inform, support, coordinate and advocate for rural consumers who travel for health care.

In applying a “A Whole-of-Journey Approach’ within a health service to consumers who travel for health care the eight priority areas identified in the kit become a template or checklist for action.

- Identify patients who travel
- Build point-of-contact capacity
- Build coordination capacity
- Provide consumer information
- Increase travel support
- Transfer care, not patients
- Reduce travel demand/need
- Develop policies

Travel for health care will always occur. There is an increasing focus by government on providing services closer to rural consumers and using virtual services technology to improve communication. This is essential. But this will be a medium- to long-term process and people living in remote parts of Victoria will still need to

travel to their regional services for specialist care. When rural consumers and their families do need to travel for health care, a 'whole-of-journey' approach addresses the complexity of this experience in a coordinated, consistent and supportive way. Policies that address and implement this approach and coordination from government at the state and federal levels are essential.

References

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