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**Title:** Indicators of injury recovery identified by patients, family members and clinicians

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**Key Words**

Trauma, outcome assessment, health priorities, patient-centred care, patient reported outcomes, recovery

## ABSTRACT

**Introduction:** A focus on what is important to patients has been recognized as an essential pillar in care to ensure safe patient care that focuses on outcomes identified as important by patients. Despite this, asking trauma patients and their families what they consider should be the priorities of care and recovery has been neglected.

**Methods:** Adult trauma patients admitted to two centers in Australia for  $\geq 24$  hours for the treatment of physical injury, and family members of injured patients and clinicians caring for injured patients were invited to participate. Individual interviews were conducted with the patient and family members prior to hospital discharge, and again one and three months post discharge. Individual interviews or focus groups were conducted with clinicians at one point in time. Content analysis of all transcripts was undertaken to determine the indicators of successful recovery over time.

**Results:** Participants in the three stakeholder groups were enrolled (patients – 33; family members – 22; clinicians – 95). Indicators of recovery focused on five main categories including *returning to work, resuming family roles, achieving independence, recapturing normality* and *achieving comfort*. Other categories that were less frequently identified included *maintaining one's household, restoring emotional stability, cosmetic considerations and appearance, realignment of life goals, psychological recovery and development of self*. Indicators of recovery after physical injury were similar across the three stakeholder groups, although with greater detail identified by patients. In addition, indicators evolved over time with increasing recognition of the importance of the overall impact of the injury in general and on activities of daily living and an unfolding appreciation that life could not be taken for granted.

**Conclusions:** Description of the indicators of recovery after traumatic injury that matter to patients, family members and clinicians enable an understanding of similarities and differences. Further testing in a broader cohort of participants is essential to identify patient reported outcome measures that might be used in trauma care and associated research.

## Introduction

Patients' perceptions of the indicators of successful recovery should inform the organization and provision of trauma care<sup>1</sup>. Indeed, a focus on what is important to patients is recognized by multiple organizations worldwide as an essential pillar of person centred care to ensure safe patient care that focuses on outcomes considered important by patients. Central to person centred care is our ability to measure the outcomes of that care from the patient's perspective; these are often referred to as patient reported outcome measures<sup>2-4</sup>. Incorporation of a partnership among consumers, family and healthcare providers is vital to promote person centred care and ensure quality care, however to date in trauma care, and most other fields of acute hospital care, patients and their families have not been asked what indicators they consider should be the priorities of care and recovery, or to determine if these indicators mirror those areas of care that clinicians consider important.

Injury is estimated to account for 6.5% of the burden of disease in Australia and accounted for more than 5% of all hospitalizations in 2009-2010<sup>5</sup>. Although the global burden that occurs as a result of injury has reduced in the past 20 years it remains significant, with injuries representing 12 of the top 65 causes of disability worldwide<sup>6</sup>. Outcome measures have been identified for use in specific patient groups such as those with lower limb injuries with some, but not all, of these measures being developed with patients<sup>7</sup>, but patient reported outcome measures that apply to broad groups of trauma patients have not been developed.

The determination of optimal recovery for patients hospitalized with traumatic injury is usually based on aspects of care identified by clinicians, or supported and promoted by the health care system<sup>8</sup>. Yet, recovery is a subjective, personal and multi-dimensional process

that changes as each person progresses through the journey and extends from days to years depending on the severity and type of traumatic injury, as well as personal and contextual factors<sup>9, 10</sup>. There are a few examples of groups consulting with patients or their families to determine what aspects of recovery are a priority or should be measured to indicate success, as well as to identify concerns in recovery<sup>8</sup>. When examined, significant differences in recovery preferences and perceptions have been identified, with patients placing greater value on activities of daily living such as eating, bathing and toileting while clinicians valued cognitive activities such as expression, comprehension and memory<sup>11</sup> or with patients and relatives perceiving greater compromise than clinicians<sup>12</sup>. Further, there is evidence that indicators of successful recovery change over time with the number of concerns being greatest 1 to 4 weeks after hospital discharge, and focusing on practical issues at this time<sup>13, 14</sup>.

Although sometimes consulted on an individual basis, recipients of care – both patients and their families – are rarely asked to identify the indicators of successful recovery to inform activity at the healthcare system or national level<sup>1, 11, 13</sup> or to determine the salient outcomes included in research studies to test newly developed interventions and therefore influence improvements in healthcare. The scant evidence outlined above suggests that prioritization of care and assessment of recovery based on clinician preference may not meet the most pressing needs of patients and their families. These findings also suggest the need to explore perceptions of recovery at multiple time points during and after hospitalization.

The purpose of this study was, therefore, to determine what patients, family members and clinicians considered to be the indicators of successful recovery from an acute hospitalization



after traumatic injury and to highlight if these indicators differed between these groups of stakeholders or changed over time, from during hospitalization to 3 months post discharge.

## **Methods**

Participants were recruited from trauma departments in two Australian teaching hospitals.

The first center, located in Darwin, Northern Territory, provides tertiary level care to approximately 650 trauma admissions per year. The population of the Northern Territory is approximately one third Aboriginal (indigenous) and this is reflected in the patients cared for in this hospital. The second study center is located in an area of Brisbane, Queensland where more than a quarter of the residents are from a different cultural or language group and provides tertiary level care to more than 4000 trauma admissions per year.

### ***Participants***

Participants were recruited from three stakeholder groups consisting of trauma patients, family members and clinicians working in the field of trauma. Patients were invited to participate if they were an adult ( $\geq 18$  years), had an acute admission to hospital for  $\geq 24$  hours for the treatment of physical injury and were able to communicate in English. Patients were excluded if their primary reason for admission was traumatic brain injury with a Glasgow Coma Score  $< 15$  at hospital discharge or spinal cord injury with motor or sensory loss at hospital discharge as these patients were considered to experience a different recovery pathway.

Family members invited to participate in the study included any person that the patient identified as a family member, including partners and relatives, providing the family member

lived with the patient or had frequent in-person contact (at least 3 times per week on average) and was able to communicate in English. Family members were able to participate in the study independent of participation of their relative who was a patient; this was because the study did not match responses from both members of the dyad, but built a body of knowledge from each of the three cohorts of participants.

Clinicians invited to participate in the study were multi-disciplinary team members, including nurses, medical officers and allied health practitioners (specifically physiotherapists, occupational therapists and social workers) involved in the ongoing acute care of traumatic injury patients. These clinicians generally practiced in trauma wards, high dependency units and intensive care units. Clinicians who typically only had exposure to patients on a single occasion such as those practicing in the emergency department or operating room were excluded.

Ethical approval was obtained from the Human Research Ethics Committees of participating hospitals (Metro South: HREC/11/QPAH/424; Menzies School of Health Research: HREC-2011-1628) and university (Griffith University: NRS/35/11/HREC) prior to commencement of the study. Written informed consent was obtained from all participants prior to study involvement and reconfirmed verbally at the time of any subsequent data collection. Where quotes are provided in this paper, pseudonyms obtained from a random name generator are used.

### ***Data Collection***

Trauma service personnel in each site identified all patients who potentially met the inclusion criteria and confirmed their willingness to speak with study personnel who then reviewed

eligibility criteria and provided detailed information regarding the study to the patient and/or the family members. All clinicians who practised in relevant work areas received an invitation to participate (via email and/or during meetings). Stakeholders who provided written consent to study involvement participated in individual interviews (patients, family members and clinicians) or focus groups (clinicians) to determine their priorities in recovery. The interviews with patients and family members were conducted at three different time points – prior to hospital discharge in face-to-face format and at one month and three month post discharge via telephone. Interviews were conducted by a Research Nurse in one site and a Research Assistant with experience in health research in the other site; neither interviewer interacted with the study participants during routine daily activities and neither had experience as a trauma clinician. Clinicians participated in one interview or focus group in face-to-face format and were asked to reflect on expected changes in priorities of recovery over time from prior to hospital discharge to three months later. Focus groups were multidisciplinary and included 4 – 8 participants. All interviews and focus groups lasted for 30 – 60 minutes and were audio recorded and transcribed verbatim.

Interviews with patients and family members were conducted in hospital and commenced with some contextual questions regarding the type of injuries sustained, the effect these injuries might have on returning to normal activities and the type of home environment to which the patient was returning. Participants were then asked the broad question: ‘what do you think will be important to you/your family member about recovery from your/your family member’s injury when you go home? Examples might include returning to work, being able to play sport, look after family, be back within the community etc.’ The same questions were posed at the one and three month follow-up, although with the wording changed to reflect ‘what was important about recovery from injury since returning home’ or

‘since the last time we spoke’. Follow-up questions were then tailored to probe for more information about each of the individual responses. Summary questions included ‘how will you know when you have successfully recovered / got better?’ and ‘of these indicators you have described [which were summarised at this point for the participant] are some more important to you than others? If so, which ones are most important?’

Interviews with clinicians were slightly different given they did not relate to a specific patient and were conducted at one point in time. Responses were elicited using the following questions:

1. What are the indicators of successful recovery after traumatic injury?
2. What aspects of recovery do you believe are most important to patients and family members after traumatic injury?
3. Do the indicators of successful recovery differ from just prior to hospital discharge to 1 or 3 months post hospital discharge? If so, how do they differ?

Brief review of the transcripts was undertaken by two team members as interviews were occurring to determine when no new priorities or issues were emerging in the interviews. Detailed analysis was not undertaken until after all interviews were completed. Transcripts were analysed using content analysis by two team members working independently. The transcripts were first read in entirety to obtain familiarity, then all components of the transcript that related to indicators of recovery were identified. Content related to indicators was grouped into categories and sub-categories using an inductive approach. Comparison of the categories and sub-categories identified by the two team members was conducted, with discussion of differences until agreement was reached. Discussion then occurred with a third team member to identify overlap and inconsistencies and refine the final category structure.

Analysis was conducted within each participant group, and then across groups to identify similarities and differences. To examine temporal changes in identified indicators of recovery, patterns were reviewed within participant groups across time (in hospital, 1 month, 3 months).

## **Results**

Ninety-five participants in the three stakeholder groups across the two sites were recruited into the study. Patients were predominantly male, with family members who participated being predominantly female (Table 1). Patients who participated were younger on average than family members. Family members were predominantly spouses (n=17) with 3 mothers and 2 fathers of trauma patients also participating. No Aboriginal family members and only one Aboriginal patient consented to participation in the study however the one patient was lost to follow-up at both one and three month time points. Within the clinician group there was wide representation of the multi-disciplinary team involved in trauma care, with 27 registered nurses, 5 medical officers, 4 physiotherapists, 3 occupational therapists and 1 social worker participating. We limited the data we collected from clinicians to profession, and did not collect other demographic details (e.g. age, gender) to maximise anonymity and encourage open conversations. Where names are used in the presentation of results they represent pseudonyms obtained from a random name generator.

Indicators of recovery identified by stakeholders focused on five main categories including *returning to work*, *resuming family roles*, *achieving independence*, *recapturing normality* and *achieving comfort*. These five categories were identified by participants in all stakeholder groups, with most of the related sub-categories also described by all groups of participants (Table 2). Other categories included *maintaining one's household*, *restoring emotional*

*stability, cosmetic considerations and appearance, realignment of life goals, psychological recovery and development of self* and were less consistently identified by the three groups of participants (Figure 1).

Although most of the categories and sub-categories were identified as indicators of recovery by all three groups of stakeholders (Table 3), the level of detail and sense of understanding that was expressed varied among the groups with patients typically articulating much greater detail than the other stakeholder groups.

*Returning to work* was identified as an important indicator of recovery by all three groups of stakeholders, however there were differences in why work was important. In the initial stages work was often seen only as a simple activity primarily focused on earning capacity or income to provide *financial security*. In later stages, however, work was seen more as a broad indicator of recovery, in other words return to work signified recovery. Participants in all three stakeholder groups noted the relationship between work, income and self-esteem or a *sense of worth*.

*Resuming family roles* was an important indicator identified by patient participants. Two different aspects were clearly expressed including a *functional role*, often related to the activities of being a mother, father or sibling and an *emotional role* that related to who the patient was within the family and how he or she felt about their role and self within the family. This emotional aspect of the role within the family was less frequently expressed by family members and not identified by clinicians.

*Achieving independence* was identified as an indicator of recovery by all three groups of stakeholders. Patients described in detail the components of *physical function*, such as mobilising, using all limbs and regaining strength; *taking care of self* and the desire to not rely on others for bathing, dressing, eating etc; and *moving about the community*, particularly in regard to driving and the opportunities and freedom that driving afforded. Family members echoed these sub-categories, although the need for *taking care of self* was recognised by only a few and in limited detail. Clinicians used different language, referring to ‘returning to premorbid state’ and a ‘reasonable amount of function’, often making a distinction between ‘full’ and ‘partial’ recovery. The clinicians’ focus was on *physical function*, with limited recognition of the need for *taking care of self* or *moving about the community*.

*Recapturing normality* was comprised of four elements including *leisure activities*, *fitness*, *social interaction* and *community involvement*. Again, patient stakeholders expressed significant granularity in the elements of recovery that were important, while family and clinician stakeholders provided less detail. Desired *leisure activities* covered a full range of pursuits with some involving very physically strenuous sports and travelling while others required very specific or fine motor abilities such as sewing. Significant levels of *fitness* were important to some participants who had previously had high levels of fitness, for example triathletes, and this was recognised by both the patients and family members as an important indicator of recovery. *Social interaction* was often dependent on other elements of recovery such as the ability to drive and was recognised as important by both patients and family members, but was not identified by clinicians. Similarly, the ability to return to *community activities*, which was related to both socialising and contributing back to the community, was an indicator of recovery for some patients, noted by one family member and not identified by clinicians.

*Achieving comfort* was the final category identified by all stakeholder groups and was largely related to being pain-free, although patients and family members also considered it in the context of not needing to take medication. Patients expressed a broader view of comfort that extended well beyond being pain-free. They focused on the importance of physical comfort on other aspects of their life, such as ability to rest or sleep.

*Maintaining one's household*, for example carrying out household chores, maintaining the garden and looking after pets, was identified as an important component of recovery by both patients and family members, but not by clinicians. A link was frequently made between the ability to carry out these household activities and self-sufficiency or independence and the self-esteem that resulted.

*Restoring emotional stability* was considered important by both patients and family members and focused on confidence, mental healthiness, not having to be cautious (driven by fear of re-injury), and being positive and happy in life. In contrast, clinicians focused on psychological recovery from a pathological perspective and talked about the importance of having no depression, PTSD, flashbacks or suicidal thoughts.

### ***Cultural influence***

One of the study sites was located in a city with a significant cultural mix including indigenous Aboriginal Australians. Although no patient or family member participants were Aboriginal, clinician participants interviewed in this site frequently identified culture as an important factor that affected patients' perceptions and goals related to recovery. Clinicians noted the importance of reconnecting with the land, with indigenous patients often choosing



to return home even when their health was at risk. This often resulted in a need to balance full recovery, as perceived by clinicians, and the patient's desire to return to the land and community, as described by one clinician:

The value for him was he wanted to be - he didn't want to lose his other foot. That was at risk. He wanted to go home with his other foot because he wanted to be able to stand on his country with two feet. He didn't have two feet, but at least one was better than none. He used to talk about feeling the water at his feet, and different things. That was very important to him.

Clinicians also noted the influence of perceptions by members of the Aboriginal community, often portrayed as shame, as illustrated here:

The indigenous cultural factor of shame is a big problem up here, that if someone's a little bit different or unwell or amputation or scarring or something and it's different, or they have to do breathing exercises, any exercises even, that can be seen as shame and they might get laughed at when at home or put out the back and neglected.

### ***Changes over time***

Perceptions of indicators of injury recovery changed for some participants over the three months post-discharge. These changes fell into three broad groups: 1) increasing recognition that activities of daily living were important; 2) increasing realisation of the impact of the injury; and 3) unfolding appreciation that life could not be taken for granted.

In hospital, participants often noted the desire to be able to care for themselves. The practical implications of their physical limitations however, did not fully reveal themselves until after discharge. Instead the ripple effects of limitations became increasingly apparent within the

first month of being at home. During that time participants recognized the effects of physical limitations on carrying out the most basic activities such as not being able to shower or dress themselves or achieve a full range of movement of limbs. Samuel clearly described this:

So simple things like being able to go to the toilet on my own, get in and out of bed on my own, brush my teeth, comb my hair, get dressed. Basically just become a little bit more self-sufficient. Make a sandwich or butter a piece of toast, get a drink of water; so try and do all those things without needing to get help.

The impact of injury on various aspects of life also became clearer after discharge. For example, Liam initially saw cycling and driving as important indicators of recovery simply because they brought the ability to get to work. One month after discharge Liam continued to consider cycling important but for additional and more complex reasons:

Cycling [is important to get back to] because it [the injury] happened at cycling. It's sort of like getting back on a horse... the 20 other riders that I was coaching that morning saw - they didn't see me but they saw the state I was in after the accident. A lot of those have stopped cycling so I want to get back on the horse to get those people back on the bike again. So it's had a knock-on effect with other people that I ride with so it's pretty important I get back on the bike again for me and for them and work, of course.

However three months after hospital discharge Liam expressed yet a more nuanced perspective about cycling within the broader context of his life:

Cycling is important but not to the extent that it was when I had the accident. But you know when you have time to think you think about what is really important. Is cycling - yes cycling is important but is it as important as family and being with family and interacting with family?

Finally, a growing appreciation that some aspects of life could not be taken for granted emerged over the three months post-injury. While Emma was in hospital she considered:

“They're sending me home with painkillers so I don't think that [pain] will be [an issue]”

However by one month after discharge Emma noted:

“When I can sort of - just back to no pain, you know, I can walk around, I can bend, [I will know I am recovered]”

This evolved over the following two months:

“Yeah, just to be active and - yeah, just to do be able to do things without having the pain” and “when I can sort of just know that I can get out of bed without having to limp or ache - that would be good.”

## **Discussion**

This is one of the first studies to examine priorities in recovery identified by three groups of stakeholders: patients, family members and clinicians over time. The most commonly identified priorities included *returning to work*, *resuming family roles*, *achieving independence*, *recapturing normality* and *achieving comfort*. Although identified priorities were similar, differing levels of detail were provided by the stakeholder groups and priorities changed over time. While there has been some development of instruments to measure quality of care after injury<sup>15</sup>, we could find only one example of exploration of issues or outcomes identified as important by patients<sup>16</sup> and this was specific to people with ankle fractures. Further exploration of recovery priorities using quantitative techniques is required

to determine relevance to a broad cross-section of trauma patients and to develop an appropriate set of outcome measures that patients consider to be important.

Although some differences between stakeholder groups have been identified here, similarities and differences need to be tested further in larger groups. Differences in the meaning of disability and optimal recovery have been identified between patients with acute onset activity limitations and clinicians<sup>11</sup>, and between care recipients, relatives and nurses in relation to the quality of care of older people<sup>17</sup>. In a related area, patients and caregivers considered different factors than clinicians when making decisions about the most appropriate procedure for treatment of abdominal aneurysms<sup>18</sup>. Understanding of different perceptions in relation to outcomes is particularly important in trauma where patients may not be able to participate in decision making for some of their hospitalisation.

Returning to work after injury is consistently reported as a challenge, with up to half of injured cohorts not returning to work in 4 – 24 months after injury<sup>19-22</sup>. Return to work has been recognised as an important outcome after major injury in the United Kingdom where a consensus meeting was held to identify appropriate outcome measurements in major injury patients<sup>23</sup>. Despite recognition of the importance, it was also noted that easy measurement of return to work (e.g. through linked data) is not currently possible in most settings.

Considerations such as resuming family roles and recapturing normality during recovery from injury were frequently identified by patients, and to a lesser extent family members and clinicians. Although we could find no trauma specific instrument that incorporated these characteristics they are reflected in the recently developed Spinal Cord Injury – Quality of Life (SCI-QOL) Positive Affect and Well-being items<sup>24</sup>, and the generic Sickness Impact

Profile (SIP)<sup>25</sup>. The SCI-QOL items were developed through initial interviews and focus groups with patients and clinicians followed by expert item review prior to validation in a larger cohort of spinal cord injured patients<sup>24</sup>. The SIP was developed with input from a range of stakeholders, including patients, and is a comprehensive instrument that has been used to measure health status in the injured population and incorporates 12 categories including ambulation, mobility, eating, communication, emotional behavior, social interaction, sleep/rest, work, home management, recreation and pastimes, body care and movement, and alertness behavior. In the current study, aspects of life such as resuming family roles and achieving normality contributed to who the person was, in addition to what they could do, which in turn is likely to promote a general sense of satisfaction and well-being and therefore warrant consideration in measurement of recovery.

Functional ability and independence is related to, and important for, resuming other roles in life. In an early study of multi-trauma patients vocational and leisure disability were identified as important determinants of life satisfaction<sup>26</sup>. Participants in the current study frequently described the need to be able to undertake activities of daily living such as dressing and feeding themselves, as well as travel using public transport or driving, as important pre-requisites to be able to work, socialise and resume family roles such as collecting children from school which in turn were rated as priorities of recovery.

That emotional recovery is equally important as physical recovery after traumatic injury has received increasing recognition among clinicians<sup>27</sup>, in part because of the contribution of psychological responses to post-injury disability<sup>28</sup>. Clinicians approach emotional recovery from a more pathological lens, speaking of PTSD and depression, and this is consistent with the preponderance of the current literature<sup>29, 30</sup>. Importantly, stakeholder groups differed in

their perspectives of *recovering emotional stability*. This indicates there is a significant opportunity to re-focus on working with patients to enhance their positive growth and to encourage confidence in their abilities to resume their previous activities and lives.

The passage of time and the process of experiencing recovery influenced the priorities and expectations described by participants, particularly the patients, in some of the categories. These changes over time were particularly evident in relation to *achieving independence* and *recapturing normality*. This echoes one element of findings by Clay and colleagues<sup>31</sup> where more severely injured workers changed their expectations about their recovery timeframe; as well as the finding by Zatzick and colleagues that patient concerns gradually reduced over time<sup>14</sup>. Changes in priorities and expectations over time has implications for the provision of both education and support, with these needing to be available and relevant at different phases in the recovery trajectory. As patients and family members change their expectations over time, appropriate care needs to be made available across the care continuum.

Changes in perceptions of recovery over time also affect what are perceived as facilitators and barriers to that recovery. Until patients and family members recognize the challenges they face and the trajectory of their recovery, it is difficult to adequately match resources, services and activities to facilitate that recovery. This is particularly challenging in health care systems that tend to treat illness and injury in a more episodic and specialized manner.<sup>9</sup>

The extremely limited participation of indigenous patients and family members enrolled in this study is a limitation. All comments related to differing priorities in recovery for indigenous patients have come from the trauma clinicians. The inability to recruit indigenous participants is not unexpected given the poor compatibility between the Western health

system and traditional Aboriginal health beliefs,<sup>32, 33</sup> but it is concerning. Given the differences in stakeholders' identification of indicators of recovery, the report of cultural differences provided by clinicians must be taken with caution. Nonetheless, it does emphasize the importance of considering culture in the care we deliver. Although it is not always possible to know another culture in depth, or to know values and beliefs based on people's ethnicities<sup>34</sup>, it is important to explore what is important with each individual and to ensure recovery and rehabilitation systems are developed in a manner that is culturally sensitive<sup>35</sup>. Some of the ways that culture might influence recovery include perceptions of what recovery is acceptable, involvement of family, appropriateness of care and processes and expectations for community reintegration<sup>36</sup>.

## **Conclusion**

A rich description of the priorities of recovery identified by the patient, family members and clinicians has been described. The categories borne out through content analysis were similar across the three stakeholder groups. There was an overlap in these categories identified in the patient and family experience across the continuum of in-hospital to three months. It is envisaged this understanding of what matters to patients and family members will empower patients to be active participants in the healthcare process and will underpin development of the patient reported outcomes that should be used in practice and research in trauma care. This information will also inform future trauma outcome research to ensure these priority areas are appropriate for a broader range of participants

## **CONFLICT OF INTEREST STATEMENT**

No authors have any financial or personal conflict of interest that might bias this work.

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## References

1. Bayley KB, London MR, Grunkemeier GL, Lansky DJ. Measuring the success of treatment in patient terms. *Med Care* 1995;33(4 Suppl):AS226-35.
2. Australian Commission on Safety and Quality in Health Care (ACSQHC). Australian Safety and Quality Framework for Health Care Canberra 2010 [cited 2010 29 November 2011]. Available from: [http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs\\_NSQF-con](http://www.safetyandquality.gov.au/internet/safety/publishing.nsf/Content/com-pubs_NSQF-con).
3. Berwick DM. What 'patient-centered' should mean: confessions of an extremist. *Health Aff (Millwood)* 2009;28(4):w555-65.
4. Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346:f167.
5. Australian Institute of Health and Welfare. *Australia's health 2014. Australia's health series no. 14. Cat. no. AUS 178*. Canberra: AIHW, 2014.
6. Global Burden of Disease Study 2013 Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013. *Lancet* 2015;386(9995):743-800.
7. Ashford S, Brown S, Turner-Stokes L. Systematic review of patient-reported outcome measures for functional performance in the lower limb. *J Rehabil Med* 2015;47(1):9-17.
8. Hausman AJ, Hohl B, Hanlon AL, Becker J, Branas CC, Hayden UT, et al. Translating community-specified indicators of program success into measurable outcomes. *J Public Health Manag Pract* 2009;15(6):E22-30.
9. Richmond TS, Thompson HJ, Deatrick JA, Kauder DR. Journey towards recovery following physical trauma. *J Adv Nurs* 2000;32(6):1341-7.
10. Richmond TS, Aitken LM. A model to advance nursing science in trauma practice and injury outcomes research. *J Adv Nurs* 2011;67(12):2741 - 53.
11. Stineman MG, Rist PM, Kurichi JE, Maislin G. Disability meanings according to patients and clinicians: imagined recovery choice pathways. *Qual Life Res* 2009;18(3):389-98.
12. Buchanan KM, Elias LJ, Goplen GB. Differing perspectives on outcome after subarachnoid hemorrhage: the patient, the relative, the neurosurgeon. *Neurosurgery* 2000;46(4):831-8; discussion 8-40.
13. Rastogi R, Chesworth BM, Davis AM. Change in patient concerns following total knee arthroplasty described with the International Classification of Functioning, Disability and Health: a repeated measures design. *Health Qual Life Outcomes* 2008;6:112.
14. Zatzick DF, Kang SM, Hinton WL, Kelly RH, Hilty DM, Franz CE, et al. Posttraumatic concerns: a patient-centered approach to outcome assessment after traumatic physical injury. *Med Care* 2001;39(4):327-39.
15. Bobrovitz N, Santana MJ, Kline T, Kortbeek J, Widder S, Martin K, et al. Multicenter validation of the Quality of Trauma Care Patient-Reported Experience Measure (QTAC-PREM). *J Trauma Acute Care Surg* 2016;80(1):111-8.
16. McPhail SM, Dunstan J, Canning J, Haines TP. Life impact of ankle fractures: qualitative analysis of patient and clinician experiences. *BMC musculoskeletal disorders* 2012;13:224.
17. Hasson H, Arnetz JE. A comparative study of nursing staff, care recipients' and their relatives' perceptions of quality of older people care. *International journal of older people nursing* 2010;5(1):5-15.
18. Faggioli G, Scalone L, Mantovani LG, Borghetti F, Stella A. Preferences of patients, their family caregivers and vascular surgeons in the choice of abdominal aortic aneurysms treatment options: the PREFER study. *Eur J Vasc Endovasc Surg* 2011;42(1):26-34.

19. Kendrick D, Vinogradova Y, Coupland C, Christie N, Lyons RA, Towner EL. Getting back to work after injury: the UK Burden of Injury multicentre longitudinal study. *BMC Public Health* 2012;12:584.
20. Bocci MG, Grieco DL, Lochi S, Minguell Del Lungo L, Pintaudi G, Caricato A, et al. Defining needs and goals of post-ICU care for trauma patients: preliminary study. *Minerva Anestesiol* 2016;82(1):22-9.
21. Hou WH, Sheu CF, Liang HW, Hsieh CL, Lee Y, Chuang HY, et al. Trajectories and predictors of return to work after traumatic limb injury--a 2-year follow-up study. *Scand J Work Environ Health* 2012;38(5):456-66.
22. Holtslag HR, van Beeck EF, Lindeman E, Leenen LPH. Determinants of Long-Term Functional Consequences After Major Trauma. *J Trauma* 2007;62(Number 4):919-27.
23. Ardolino A, Sleat G, Willett K. Outcome measurements in major trauma--results of a consensus meeting. *Injury* 2012;43(10):1662-6.
24. Bertisch H, Kalpakjian CZ, Kisala PA, Tulskey DS. Measuring positive affect and well-being after spinal cord injury: Development and psychometric characteristics of the SCI-QOL Positive Affect and Well-being bank and short form. *J Spinal Cord Med* 2015;38(3):356-65.
25. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The sickness impact profile: Development and final revision of a health status measure. *Med Care* 1981;19:787-805.
26. Anke AG, Fugl-Meyer AR. Life satisfaction several years after severe multiple trauma--a retrospective investigation. *Clin Rehabil* 2003;17(4):431-42.
27. Richmond TS. Commentary on "Determinants of quality of life and role-related disability after injury: Impact of acute psychological responses". *J Trauma* 2005;59:1335.
28. O'Donnell ML, Holmes AC, Creamer MC, Ellen S, Judson R, McFarlane AC, et al. The role of post-traumatic stress disorder and depression in predicting disability after injury. *Med J Aust* 2009;190(7 Suppl):S71-4.
29. Richmond TS, Amsterdam JD, Guo W, Ackerson T, Gracias V, Robinson KM, et al. The effect of post-injury depression on return to pre-injury function: a prospective cohort study. *Psychol Med* 2009;39(10):1709-20.
30. Davydow DS, Zatzick DF, Rivara FP, Jurkovich GJ, Wang J, Roy-Byrne PP, et al. Predictors of posttraumatic stress disorder and return to usual major activity in traumatically injured intensive care unit survivors. *Gen Hosp Psychiatry* 2009;31(5):428-35.
31. Clay FJ, Devlin A, Kerr E. Exploring the distribution and determinants of a change in recovery expectations following traumatic injury to Victorian workers. *J Occup Rehabil* 2013;23(3):318-28.
32. Maher P. A review of 'traditional' aboriginal health beliefs. *Aust J Rural Health* 1999;7(4):229-36.
33. Morgan DL, Slade MD, Morgan CM. Aboriginal philosophy and its impact on health care outcomes. *Aust N Z J Public Health* 1997;21(6):597-601.
34. Costigan CL, Bardina P, Cauce AM, Kim GK, Latendresse SJ. Inter- and intra-group variability in perceptions of behavior among Asian Americans and European Americans. *Cultur Divers Ethnic Minor Psychol* 2006;12(4):710-24.
35. Niemeier JP, Burnett DM, Whitaker DA. Cultural competence in the multidisciplinary rehabilitation setting: are we falling short of meeting needs? *Arch Phys Med Rehabil* 2003;84(8):1240-5.
36. Lequerica A, Krch D. Issues of cultural diversity in acquired brain injury (ABI) rehabilitation. *NeuroRehabilitation* 2014;34(4):645-53.

**Table 1: Patient and family member participant's characteristics**

	Patients (n = 33)	Family members (n = 22)
Gender – female: n	9	17
Age in years: mean $\pm$ SD (range)	43 $\pm$ 16 (33 – 57)	50 $\pm$ 14 (33 – 79)
Injury Severity Score: mean $\pm$ SD (range)	15.6 $\pm$ 8.0 (3 – 38)	n/a

**Table 2: Indicators of recovery identified by stakeholder groups**

Priorities	Patients	Families	Clinicians
Returning to work			
Financial security	✓	✓	✓
Sense of worth	✓	✓	✓
Resuming family roles			
Functional role	✓	✓	✓
Emotional role	✓	✓	✗
Achieving independence			
Physical function	✓	✓	✓
Taking care of self	✓	✓	✓
Moving about community	✓	✓	✓
Recapturing normality			
Leisure activities	✓	✓	✓
Fitness	✓	✓	✓
Social interaction	✓	✓	✗
Community involvement	✓	✓	✗
Achieving comfort	✓	✓	✓
Maintaining one's household	✓	✓	✗
Restoring emotional stability	✓	✓	✗
Cosmetic considerations/appearance	✓	✗	✓
Development of self	✓	✗	✗
Realignment of life goals	✗	✗	✓
Psychological recovery	✗	✗	✓

Note: ✗ denotes indicators that were not raised by this stakeholder group

**Table 3 Participants' descriptions of indicators of recovery**

<b>Priorities</b>	<b>Patients</b>	<b>Family members</b>	<b>Clinicians</b>
<b><i>Returning to work</i></b>			
Financial security	Probably work because it's the thing I derive my income [from] .... for the next 15 or 20 years .... work is the main thing (ih)	He shares the rent and the food and he's not working, so I've had to pick it all up and he's got no savings because he's a young man (1m)	Things like work, family, driving, earning some form of a living, back at what they were doing
Sense of worth	Something with purpose like work or whatever. I'm looking forward to that because it has a purpose (1m)	Being able to get back into the classroom teaching is not essential from a financial point of view but it's important for Jo's wellbeing and morale (1m)	There are people who enjoy their work and they get a lot of satisfaction out of their work and there's also a lot of self-esteem and purpose in life associated with work
<b><i>Resuming family roles</i></b>			
Functional role	I can't pick my kids up. I can't bend down and wash them.... our young one - only five months old - she needs to be picked up .... I can't bend down with them or anything. So it's making it really hard on my misses, because she's doing the whole lot (1m)	To be able to run around with the kids and just be dad (ih)	I think the family dynamics really impact on that; the person's role in the family; how much they can go back into that role
Emotional role	Yeah, the quality time that we used to have (with the family) (3m)	Being part of the family again ....it [having meals together in hospital] is not the same as being at home and being at the family dinner ....he doesn't	-

		really get to feed her [baby daughter] .... that was their bonding time. I think yes, she misses him and he misses her (ih)	
<b><i>Achieving independence</i></b>			
Physical function	How easily I can walk up and down my back steps.... being mobile because it's about 20 steps or something from the bottom to the top step at my house (ih)	Get back to being physically active again. I think that's really important that she's not lying around too long... back to her walks and eventually a bike (ih)	Return to the pre-morbid function level and returning to work and daily activities; Whether they require gait aids and progression of gait aids would actually be an example
Taking care of self	Even doing up my fly or brushing my teeth or cleaning my ears or, you know, getting something out of my eye or anything that I used to just take for granted that I can't do now (1m)	She needs aid to dress. I mean, she can't do her own bra up because she can't get her arm round her back (1m)	Being able to live independently if he lived independently before
Moving about community	So getting back to driving is important because I can then see my extended family (1m)	It's very frustrating because she can't get around, she can't do a lot of things (1m)	I think just driving down to the shops now that they have to rely on maybe the daughter or someone to go shopping for them
<b><i>Recapturing normality</i></b>			
Leisure activities	Well my main task will be climbing in the boat, that's the most difficult thing at the moment (1m)	She won't be able to dance anymore probably. She used to like dancing (1m)	If they were playing a sport, getting back to playing at that level of sport I would see as being fully recovered
Fitness	Physically, I'll know I'm successfully recovered when I	He'd like to get back to more of his physical recreation, like	Some of them get their injuries through the sport, and they're

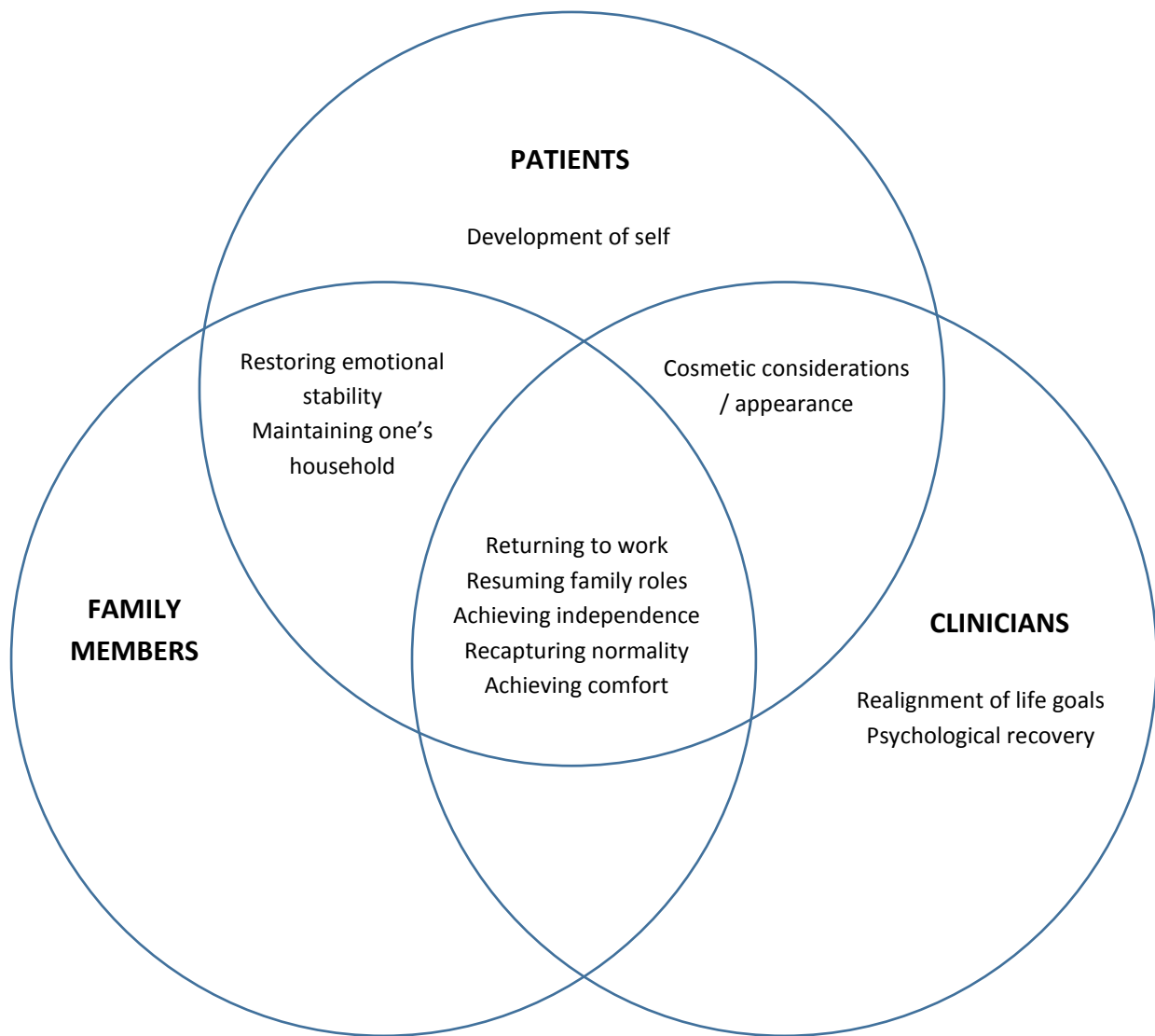
Social interaction	<p>can do the 3 Peaks bike ride in the same time I did it before the accident - that's 240 kilometres in a day, 5000 metres of climbing, that's a pretty sensible quantum benchmark (1m)</p> <p>I'm back into the Rotary. I've actually enjoyed that, you know, a lot of those guys have been through different sorts of ordeals themselves so it's always good to get out there and mix outside the circle and find out other people's opinions and life experiences (3m)</p>	<p>walking and gym and exercises he does just for himself to keep fit (3m)</p> <p>We've just hired this wheelchair now, so we just throw him in that and off we go, just so that he's out circulating and he's just not sitting here going stale and getting lost in his own thoughts (1m)</p>	<p>quite determined to go back to the sport, even if they might not be able to</p> <p>-</p>
Community involvement	<p>I can't do the flowers at the church anymore because I'm not allowed to lift the vases because they're all brass.... I can't because of the weights that I'm not allowed to carry.... Going to the hospital to visit the veterans. I haven't been able to do that, again because I can't drive (3m)</p>	<p>Because he's very determined that he wants to - yes he's got to recover but he also wants to get back and do those things [Rotary, fire brigade] again (ih)</p>	<p>-</p>
<i>Achieving comfort</i>	<p>I had to sleep in a chair for a while because I couldn't lay flat out with comfort, mainly because of the bruising and such like on my back and the ribs (3m)</p>	<p>I'll know the way he gets around and when he doesn't have to have medication for the pain I'd say (1m)</p> <p>cuddling in bed, he can't do that because he's so uncomfortable because of the pain he's in (3m)</p>	<p>something like pain can be a terrible thing if you've still got problems with it at 24 months, whereas, in hospital it's part and parcel, it's expected, so you just deal with it</p>

<b><i>Maintaining one's household</i></b>	Mowing the lawn, cutting hedges, those type of things.... yes they are important because I can't rely on family members to do it, the girls to do it, nor do I want them to do it (3m)	I know she worries because I have to do everything and she's very independent. She would like to be doing the washing and all this sort of thing. All these things are important for her recovery (3m)	-
<b><i>Restoring emotional stability</i></b>	The most important would be to not have to be cautious all the time and not have to second guess everything (3m)	He was one of these people that never stopped.... To suddenly just be sitting there and nothing to do it's just really doing his head in (1m)	-
<b><i>Development of self</i></b>	I think the uni [university] and getting back onto the path and the progress I was making before the accident.... uni was personal - like a bit of life progress that I was making (1m)	-	-
<b><i>Cosmetic considerations / appearance</i></b>	It's mainly cosmetic wise, I know that I'm going - I'll be walking normally again soon-ish and I'll be able to do stuff, but certainly the cosmetic aspect of it you know, I'm 26 years old and I'm not going to be able to wear a pair of shorts for a very long time (1m)	-	Initially they might worry about the scars or how their arm looks or this looks, but they're more worried about the function.... if it doesn't look as nice as it used to but if it works well I think most people are happy with that
<b><i>Realignment of life goals</i></b>	-	-	Then they completely change their lives and go off and do all those things that they'd never really thought about doing



			because they nearly died
<i>Psychological recovery</i>	-	-	encountering depression or nightmares perhaps, difficulty sleeping, panic attacks, anything like that that could be as a result of pain from the trauma or from an ICU stay or any of the combination of the traumatic process

**Timeframe of quotes:** ih – in hospital; 1m – 1 month post discharge; 3m – 3 months post discharge



**Figure 1: Priorities of recovery identified by stakeholders**