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ORIGINAL ARTICLE

Minimum data set to measure rehabilitation needs and health outcome after major trauma: Application of an international framework

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ABSTRACT

BACKGROUND: Measurement of long term health outcome after trauma remains non-standardized and ambiguous which limits national and international comparison of burden of injuries. The World Health Organization (WHO) has recommended the application of the International Classification of Function, Disability and Health (ICF) to measure rehabilitation and health outcome worldwide. No previous poly-trauma studies have applied the ICF comprehensively to evaluate outcome after injury.

AIM: To apply the ICF categorization in patients with traumatic injuries to identify a minimum data set of important rehabilitation and health outcomes to enable national and international comparison of outcome data.

DESIGN: A mixed methods design of patient interviews and an on-line survey.

SETTING: An ethnically diverse urban major trauma center in London.

POPULATION: Adult patients with major traumatic injuries (poly-trauma) and international health care professionals (HCPs) working in acute and post-acute major trauma settings.

METHODS: Mixed methods investigated patients and health care professionals (HCPs) perspectives of important rehabilitation and health outcomes. Qualitative patient data and quantitative HCP data were linked to ICF categories. Combined data were refined to identify a minimum data set of important rehabilitation and health outcome categories.

RESULTS: Transcribed patient interview data (N.=32) were linked to 234 (64%) second level ICF categories. Two hundred and fourteen HCPs identified 121 from a possible 140 second level ICF categories (86%) as relevant and important. Patients and HCPs strongly agreed on ICF body structures and body functions categories which include temperament, energy and drive, memory, emotions, pain and repair function of the skin. Conversely, patients prioritised domestic tasks, recreation and work compared to HCP priorities of self-care and mobility. Twenty six environmental factors were identified. Patient and HCP data were refined to recommend a 109 possible ICF categories for a minimum data set.

CONCLUSIONS: The comprehensive measurement of health outcomes after trauma is important for patients, health professionals and trauma systems. An internationally applied ICF minimum data set will standardize the language used and concepts measured after major trauma to enable national and international comparison of outcome data.

CLINICAL REHABILITATION IMPACT: A minimum ICF data set for trauma will standardize rehabilitation language and provide a minimum dataset to capture outcome in trauma systems to enable comparison and service improvement.

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Key words: Rehabilitation - Multiple trauma - Outcomes assessment (Health Care).

Major trauma involving multiple injuries is a leading contributor to the global burden of disease and mortality for working aged adults.[1] However, as survival from injury improves with modern trauma care, so does the importance of the rehabilitation and health outcomes for these patients.[2, 3] Many severely injured trau-

ma patient will experience prolonged periods in critical care which often leads to additional non-injury related morbidity.[4, 5] The accurate and comprehensive assessment of health outcomes, which includes physical, psychological and social wellbeing,[6, 7] as well as the impact on the family and society is fundamental to inform future efforts to improve lives after injury.[8] However existing generic outcome measures only assess a small proportion of the overall burden experienced by trauma patients.[9, 10] Moreover, the lack of validated trauma specific outcome measures has caused uncertainty amongst experienced trauma clinicians regarding which key domains should be measured as part of a minimum data set.[11-13] As a consequence, little is known about the multidimensional effects that major traumatic injury has on outcomes important to patients.[14, 15] Many measures fail to evaluate the patients' perception of their health outcome and recovery, and consequently there may be little agreement between patient priorities and goals set by rehabilitation professionals.[16] Moreover, the patients' performance within their social context needs to be considered as part of the rehabilitation process, as support and systems can either hinder or help recovery.[17] This improved knowledge would inform rehabilitation priorities to support patient recovery and facilitate cost effective trauma service delivery and resource utilization.[11] Outcomes derived from a minimum data set would enable assessment of trauma system performance while patients return to health after injury.[18, 19]

Recent developments of trauma systems in the United Kingdom and Europe necessitate a robust, patient centered data set to measure health outcome after trauma. Not only are prehospital and in-hospital outcomes important, factors such as the impact of critical care, secondary complications and population burden after discharge need to be considered.[8] In line with current methodology, new health measures should be developed within an internationally recognized framework,[20] involving patients and health care professionals to ensure wide acceptance and validity. The International Classification of Function, Disability and Health (ICF) [21] is a hierarchically organized framework consisting of approximately 1400 health categories. The World Health Organisation (WHO) has recommended its application in all health outcome studies.[22] ICF Core Sets have been applied in many rehabilitation settings and health conditions including traumatic brain injury [23] and spinal cord injury.[24] However, patients with multiple traumatic injuries have additional, potentially more complex needs to those with isolated brain or spinal injury. Recent publications have called for the development of core sets specifically for use in trauma outcome evaluation and rehabilitation.[25-27] The ICF health categories most applicable for multiply injured patients are yet to be reported.

The primary aim of this study was to identify important ICF health and rehabilitation categories from the perspective of patients and health care professionals (HCPs). We aimed to investigate patient and HCP perspectives of important health outcomes following trauma with the ICF framework as a reference to identify a minimum data set of important rehabilitation and health outcomes to enable national and international comparison of outcome data. Secondly we wished to evaluate to what degree components of body functions, body structures and activities and participation are affected by trauma in relation to contextual issues such as the environmental and personal factors.

Materials and methods

ICF definitions

The ICF is a comprehensive and international framework that considers human functioning as a whole. Part one captures health and disability in terms of how body functions (b), body structures(s) and activities and participation (d) are affected. Part two comprises of contextual factors and includes environmental (e) and personal factors (Figure 1). All aforementioned components, except personal factors, consist of several chapters which contain hierarchically organized categories including second and third level sub-categories. Each category contains specific health issues and becomes more detailed in second and third level sub-categories, similar to ICD-10 categories. For example: b1 Mental functions' (first level category), b114 Orientation functions' (second level category), b1142 Orientation to person (third level category).

Study design

Mixed methods were used to investigate important health outcomes after trauma. We conducted qualitative semi-structured, face-to-face interviews with patients. Health care professionals (HCPs) participated in an international on-line questionnaire to identify important

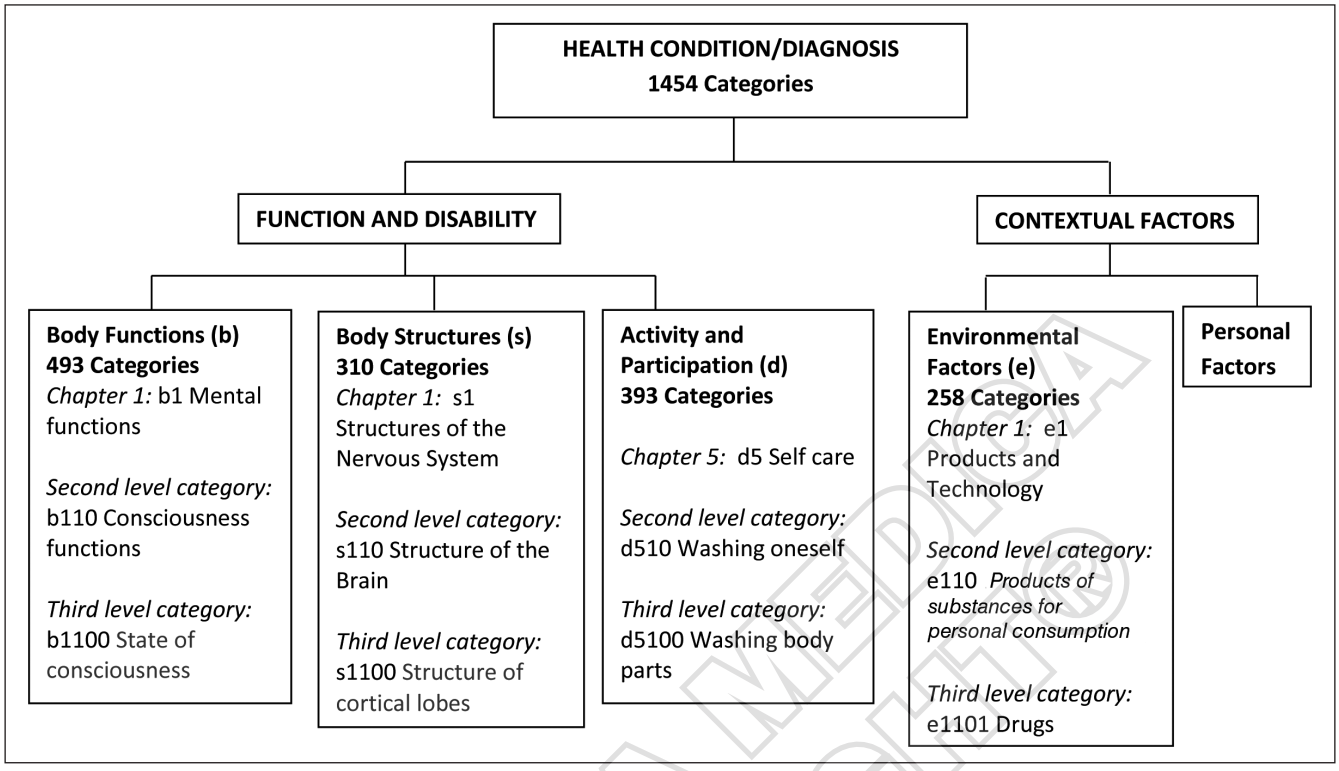

Figure 1.—ICF framework illustrating four different components body function (b), body structure(s), activity and participation (d) and environmental factors (e). Personal factors currently do not have categories and codes. Numbers indicate total number of second, third and fourth level categories in each component.

health issues after trauma. Ethical approval was gained from an NHS Research Ethics Committee.

Qualitative patient interviews

Study population

Participants were recruited from an urban major trauma centre in London that admits on average 1800 patients with multiple traumatic injuries each year. Discharged adult patients (≥18 years of age) were invited to participate via a postal invitation, which was followed up by a telephone call. A convenience sample of patients with varying ages, genders, time since injury, injury mechanisms, and injury severity were recruited. The severity of injury was categorised using the Injury Severity Score (ISS).[28] We aimed to capture all potential problems rather than which problems occur at specific timeframes, therefore patients were approached at a variety of time frames since injury as health problems and the prevalence of symptoms may change over time. This form of purposive sampling was used to obtain a wide-ranging sample of this heterogeneous patient population and has been used successfully in previous studies.[29] A sample size of 40-45 participants was chosen whilst aiming for a 50% recruitment rate to ensure sufficient interview data. Previous qualitative studies suggest that data saturation can be reached with 20-30 interviews.[30] Data saturation is the point at which no new data is generated by participant interviews in an effort to reduce bias and increase trustworthiness.

Data collection

Where possible, interviews were scheduled to coincide with other hospital appointments to reduce patient burden. Written consent was obtained prior to all interviews. Semi-structured interviews were conducted by one researcher (Karen Hoffman, KH) over a three month period using an interview guide containing six questions based on the components of the ICF and rehabilitation priorities. These questions related to body functions,

body structures, carrying out usual activities, participating in meaningful tasks and issues related to environmental barriers or facilitators and personal factors. A final question allowed for any other comments. Interviews were digitally recorded and transcribed verbatim.

On-line questionnaire for health care professionals

Inclusion criteria

Any HCP registered with a professional body with at least five years' experience of working in trauma and able to read and write English were able to participate. A health care professional was defined as a doctor, nurse, physiotherapist, occupational therapist, psychologist, social worker, dietician and speech and language therapist (non-exhaustive list). It was not the intention to get the view of specific HCPs, but rather to obtain an overview of important rehabilitation categories as identified by trauma experts. This would facilitate application of a minimum data set for trauma rehabilitation in multidisciplinary team settings.

Sample size and recruitment

Previous ICF studies recruited between 21 and 126 HCPs to develop condition specific ICF Core Sets.[31-33] Their recruitment rate varied between 50%-70% and completion rate between 36-50%.[31-33] In order to ensure sufficient representation from an international trauma community we aimed to recruit 70% of invited participants with a completion rate of 50%. We invited two groups of HCPs to participate. Group one was a purposively selected cohort known to be experts in trauma care and were invited to participate via email. The trauma experts were from international settings with representation from five of the World Health regions and were identified via peer review publications, trauma organizations and societies. The second group of trauma HCPs were recruited through web based invitations posted on profession specific or special interest group websites.

Data collection

Consent to participate was obtained at the start of the online questionnaire, using Survey Monkey® online web platform.[34] Rather than presenting all 1400 detailed ICF categories for the online questionnaire, researchers identified 140 ICF categories from the Acute and Post-acute Comprehensive ICF Core Sets,[35-37] previously developed by experts working in orthopedic, neurological and cardio-vascular settings using a Delphi process. These specific core sets were selected for their similarities to the early stages and post-acute injury rehabilitation, scientific rigor used to develop them and to reduce respondent burden. During the online questionnaire HCPs were asked to rate the prevalence and importance of ICF categories for trauma patients. Some health issues may not be very prevalent (common) but could have a significant impact on rehabilitation and outcome and should be given greater importance.

Data analysis for patient interviews and on-line questionnaire

Transcribed interviews were analyzed using the meaning condensation procedure, typically used during ICF core set development.[38] Transcribed text was reviewed and grouped into meaningful units or themes. In a second step, health and rehabilitation concepts contained in the meaningful units were identified. A meaningful unit can contain more than one concept, *e.g*. "I get tired when walking*"*. This contains concepts related to mobility (walking) and energy levels (fatigue). In a final step, each identified concept was systematically linked to ICF categories according to published ICF linking rules.[39, 40] Detailed third level categories were converted into less detailed second level categories to enable comparison with HCP data which included only second level ICF categories. Absolute and relative frequencies were calculated. Relative frequency aims to establish prevalence, and refers to the number of patients who mentioned a specific category, thus the category was recorded only once per interview despite possibly being mentioned several times. Absolute frequency was used to capture the magnitude or total number of times a category was mentioned, where some patients may mention the same category or concept more than once. For example, many patients mentioned *pain* several times during the interview. Once ICF categories were identified, a process of member checking, sometimes referred to a respondent validation,[29] was completed in an effort to ensure all aspects important for patients were captured. Member checking helps to validate data accuracy and reduce bias and patients returned summaries of tran-

scribed data, confirming important categories. In line with previous ICF patient perspective studies, categories with a relative frequency between ≥5% and <10% were reported and regarded as low to moderate frequency categories.[41, 42] Categories with a frequency ≥15% were considered as high frequency categories[42] and relevant for comparison with categories identified by HCPs.

HCP questionnaire data were analyzed using descriptive statistics. Each of the 140 ICF categories contained two response options. One captured how prevalent or common a category was (not common, common or very common) and the other how important a category was (not important, important, very important). The average for both options are presented as a percentage, representing how many HCPs regarded a specific ICF category as common (prevalent) or important.

Previous consensus conference cut off points of ≥50% were used to indicate low to moderate HCP agreement.[43] Categories with a combined frequency (prevalence and importance) of ≥70% were regarded as high frequency categories [42] and relevant for comparison with categories identified by patients.

Finally, moderate to high frequency ICF categories identified by patients and HCPs were compared and condensed. All categories which had a patient identified relative frequency of ≥15% and all HCP categories with a combined frequency (prevalence and importance) of ≥70% were included in the final minimum data set representing moderate to high frequencies of relevant ICF categories. Consensus between HCP reported data was set at 70% to ensure adequate level of agreement.[33, 44]

Results

Patients

Forty four patients were invited to participate and 35 (80%) consented to be interviewed (Table I). Participants that did not provide written consent (N.=9) were younger males (30 years), more recently injured (3-9 month post injury) and more severely injured (ISS: 25). Of these, six did not attend their out-patient clinic appointment after providing verbal telephone consent, two opted not to participate as they were too busy and one patient could not be reached after he was included in the sample. Health concepts captured from three of the interviews were excluded as they related to non-trauma chronic medical issues. The majority of patient participants were male (87%, N.=27) with an average age of 37 years (range 18-75). Participants with blunt injuries were older (42 years *vs.* 25 years) compared to participants with penetrating trauma, but similar severity of injury (ISS: 20 *vs.* ISS 22) (Table I). Finally, those who had suffered blunt trauma had longer timeframes since injury (9 months *vs.* 4 months) in comparison to penetrating injuries.

A total of 2742 health concepts were extracted from the interviews. These were linked to 388 second and third level ICF categories. Third level categories were converted to a total of 234 second level ICF categories. Of these, 146 (62%) had a relative frequency of ≥5% and were identified by two or more patients (Tables II-V). Due to the high level of categories identified by less than two patients (38%), data saturation was inferred. Fifty five concepts were too general to be linked or related to personal factors which currently do not have ICF categories. An average of 86 ICF categories were identified per patient (range: 15 to 182 categories).

Health care professionals

Three hundred and twenty nine HCPs consented to participate and 214 completed the questionnaire (65%), (Table VI). From the 210 invited trauma experts in group one, 179 agreed to participate and 128 (72%) completed the questionnaire. Group two, had 179 participants with a completion rate of 48% (N.=86).

TABLE I.—*Demographic information for patients invited to participate in interviews.*

	All	Blunt	Penetrating	ISS<16*	ISS≥16
Total n (%)	32 (100%)	28 (88%)	4 (13%)	9 (28%)	23 (72%)
Age^	37 (19-75)	42 (19-75)	25 (21-29)	53 (27-68)	31 (19-75)
Male (%)	27 (84%)	22 (69%)	4 (16%)	6 (67%)	21 (91%)
Injury Severity Score -ISS^	20 (4-45)	20 (4-45)	22 (16-30)	9 (4-14)	25 (16-45)
Length of stay (days)^	14 (2-86)	14 (3-82)	23 (2-62)	11 (2-35)	14 (2-82)
Time since injury (months)^	5 (1-36)	9 (0-36)	4 (3-12)	6 (1-36)	5 (1-24)

Forty-four patients were invited to participate and 35 (80%) consented to be interviewed. Data from 32 patients were used as three patients had ongoing medical issues not related to their traumatic injury. Data is presented as n (%) or ^median with range. *No penetrating trauma in this group.

TABLE II.—*Low to moderate frequency body function categories identified by 5% of patients and 50 % of health care professionals.*

Body functions	Patient		HCP	
	RF	AF	COM	IMP
Chapter 1: Mental functions				
b110 Consciousness	9%	25%	71%	87%
b114 Orientation	16%	25%	83%	86%
b126 Temperament	88%	431%	78%	87%
b130 Energy and drive	81%	228%	87%	87%
b134 Sleep	47%	131%	83%	83%
b140 Attention	34%	59%	83%	84%
b144 Memory	56%	163%	85%	90%
b147 Psychomotor	9%	13%	75%	83%
b152 Emotional	81%	372%	86%	86%
b156 Perceptual	9%	19%	63%	76%
b160 Thoughts	34%	72%	71%	75%
b164 Higher-level cognition	28%	100%	77%	86%
b167 Recognising & using signs/symbols in language	13%	38%	47%	67%
b176 Sequencing movements	0%	0%	60%	74%
b180 Self awareness	56%	172%	69%	75%
Chapter 2: Sensory functions and pain				
b210 Seeing/vision	13%	38%	47%	74%
b230 Hearing	6%	13%	30%	57%
b235 Vestibular control	13%	28%	44%	71%
b260 Proprioception	3%	3%	50%	73%
b265 Touch sensation	16%	22%	47%	65%
b270 Sensation of temperature	13%	13%	40%	54%
b279 Additional sensory functions	6%	6%	NI	NI
b280 Pain	81%	275%	93%	96%
b298 Sensory other	9%	9%	NI	NI
Chapter 3: Voice and speech functions				
b310 Voice	6%	6%	42%	56%
b320 Articulation	6%	6%	51%	69%
b330 Fluency of speech	6%	9%	NI	NI
Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory systems				
b420 Blood pressure	3%	3%	69%	75%
b430 Haematological	13%	19%	52%	64%
b435 Immune system	16%	34%	35%	61%
b440 Respiration functions	13%	22%	67%	78%
b445 Respiratory muscle functions	0%	0%	51%	72%
b450 Additional respiratory functions	9%	13%	40%	49%
b455 Exercise tolerance	41%	91%	84%	80%
b460 Cardiac and respiratory	6%	6%	45%	59%
Chapter 5: Functions of the digestive, metabolic and endocrine systems				
b510 Ingestion	9%	25%	63%	72%
b515 Digestion	6%	6%	38%	51%
b525 Defecation	13%	13%	61%	67%
b530 Weight maintenance	25%	28%	66%	67%
b535 Sensations associated with the digestive system	6%	6%	38%	38%
b545 Water, mineral and electrolyte balance	0%	0%	51%	62%
b550 Thermoregulations	6%	13%	NI	NI
Chapter 6: Genitourinary and reproductive functions				
b610 Urinary excretory functions	3%	6%	48%	59%
b620 Urination	16%	19%	60%	68%
Chapter 7: Neuro musculoskeletal and movement-related functions				
b710 Joint mobility	13%	38%	88%	92%
b715 Joint stability	3%	6%	77%	84%
b720 Mobility of bone functions	6%	13%	NI	NI
b730 Muscle power	28%	38%	91%	92%
b735 Muscle tone	19%	22%	74%	82%
b740 Muscle endurance	13%	13%	82%	78%
b755 Involuntary movement	0%	0%	43%	60%
b760 Voluntary movement	9%	13%	67%	78%
b770 Gait pattern	9%	19%	82%	85%
b780 Sensations related to muscles and movement	6%	9%	61%	70%
Chapter 8: Functions of the skin and related structures				
b810 Protective functions of the skin	9%	9%	41%	57%
b820 Repair functions of the skin	56%	138%	64%	75%
b840 Sensation related to the skin	13%	13%	NI	NI

The table presents 57 *body function* categories identified by 5% of patients and 50% of Health Care Professionals (HCPs).
NI: category not included in HCP questionnaire; RF: relative frequency; AF: absolute frequency; COM: common categories identified by HPCs; IMP: important categories identified by HPCs.

TABLE III.—*Low to moderate frequency body structure categories identified by 5% of patients and 50% of health care professionals.*

Body structures	Patient categories		HCP categories	
	Relative frequency	Absolute frequency	Common	Important
Chapter 1: Structures of the nervous system				
s110 Structures of brain	19%	50%	84%	94%
s120 Spinal cord and related structures	9%	13%	67%	92%
s130 Structures of meninges	0%	0%	40%	73%
Chapter 2: The eye, ear and related structures				
s220 Structure of eyeball	6%	13%	NI	NI
s230 Structures around eye	6%	16%	NI	NI
Chapter 3: Structures involved in voice and speech				
s320 Structure of the mouth	9%	16%	NI	NI
Chapter 4: Structures of the cardiovascular, immunological and respiratory systems				
s410 Structures of cardiovascular system	0%	0%	53%	77%
s420 Structure of immune system	6%	6%	NI	NI
s430 Structures of respiratory system	22%	59%	69%	79%
Chapter 5: Structures related to the digestive, metabolic and endocrine systems				
s530 Structures of stomach	16%	25%	30%	54%
s560 Structure of liver	6%	9%	NI	NI
Chapter 6: Structures related to genitourinary and reproductive systems				
s610 Structure of urinary system	9%	16%	NI	NI
Chapter 7: Structures related to movement				
s710 Structures of head and neck region	31%	66%	74%	85%
s720 Structures of shoulder region	13%	25%	72%	82%
s730 Structures of upper extremity	28%	50%	84%	87%
s740 Structures of pelvic region	16%	28%	70%	88%
s750 Structures of lower extremity	63%	159%	84%	91%
s760 Structures of trunk	25%	34%	74%	85%
s770 Additional musculoskeletal structures	6%	16%	NI	NI
Chapter 8: Skin and related structures				
s810 Structures of areas of skin	6%	9%	68%	73%
s820 Structure of skin glands	6%	6%	NI	NI

The table presents twenty-one *body structure* categories identified by 5% of patients and 50% of HCPs.
NI: Category not included in HCP questionnaire; RF: relative frequency; AF: absolute frequency; COM: common categories identified by HPCs; IMP: important categories identified by HPCs.

The majority of HCPs who commenced the questionnaire (N.=256; 78%) had more than eight years' trauma experience (Table VI), and 66% were based in an acute care setting (N.=216). Nineteen percent (N.=61) of participants worked in both the acute and post-acute setting. The majority of respondents (N.=224; 68%) were allied health professionals (AHPs) including therapists and nurses. Participating doctors (N.=105; 32%) were from emergency medicine, general surgery, traumatology, critical care, anesthesia, vascular and orthopedic surgery and rehabilitation settings. Of the 140 ICF categories presented to the HCPs 86% were regarded as relevant for trauma patients (≥50 % common and important).

Comparison of patient and HCP responses

Low to moderate frequency categories of patient (≥5%) and HCP (≥50%) data were combined resulting in 192 categories with a frequency above 5% for patient data and 50% for HCP. Patients identified some ICF categories which were not included (NI) in the HCP questionnaire and vice versa (Tables II-V). The greatest overlap of categories between patients and HCP was seen in the body functions (b) and body structures(s) component. There was a high level of agreement for 7 body function categories which were temperament and personality functions (b126), energy and drive functions (b130), memory functions (b144), emotional functions (b152), experience of self and time functions (b180), sensation of pain (b280) and repair function of the skin (b820) (Table II). Seven body functions were considered important by HCPs, but not by patients. These were level of consciousness (b110), psychomotor problems (b147), perceptual problems (b156), blood pressure (b420), respiratory functions (b440), muscle endurance (b740) and gait pattern (b770). In terms of *body structures*, patient identified an additional eight structures (Table III). Very few patients discussed issues related to body structures during the interviews and lower extremity (s750) was mentioned the most frequently (63%).

TABLE IV.—*Low to moderate frequency activity and participation categories identified by 5% of patients and 50% of health care professionals.*

Activity & participation	Patient categories		HCP categories	
	RF	AF	COM	IMP
Chapter 1: Learning and applying knowledge				
d110 Watching	3%	3%	44%	64%
d115 Listening	0%	0%	55%	73%
d120 Other sensing	0%	0%	37%	56%
d130 Copying gestures	0%	0%	40%	58%
d135 Rehearsing	0%	0%	48%	61%
d155 Acquiring skills	0%	0%	66%	80%
d160 Focusing attention	9%	9%	79%	87%
d163 Thinking	9%	9%	NI	NI
d166 Reading	9%	9%	58%	70%
d170 Writing	6%	6%	61%	73%
d175 Problem solving	0%	0%	74%	85%
d177 Making decisions	3%	3%	77%	86%
Chapter 2: General tasks and demands				
d210 Single task	22%	25%	NI	NI
d220 Multiple tasks	13%	16%	NI	NI
d230 Daily routine	25%	53%	84%	88%
d240 Handling stress	44%	200%	82%	89%
Chapter 3: Communication				
d310 Communication verbal	3%	3%	63%	79%
d315 Communication nonverbal	0%	0%	64%	75%
d330 Speaking	13%	25%	54%	74%
d335 Producing nonverbal messages	0%	0%	40%	64%
d350 Conversation	0%	0%	59%	70%
d360 Using communication devices	0%	0%	48%	66%
d398 Communication, other specified	6%	9%	NI	NI
Chapter 4: Mobility				
d410 Changing basic body position	56%	191%	78%	87%
d415 Maintaining a body position	22%	31%	73%	85%
d420 Transferring oneself	19%	41%	80%	89%
d430 Lifting and carrying objects	34%	78%	84%	85%
d440 Fine hand use	16%	25%	77%	88%
d445 Hand and arm use	16%	28%	69%	87%
d450 Walking	69%	153%	88%	93%
d455 Moving around	56%	109%	NI	NI
Chapter 4: Mobility				
d460 Moving around in different locations	41%	66%	84%	88%
d465 Moving around using equipment	28%	41%	77%	87%
d470 Using transportation	53%	94%	NI	NI
d475 Driving	50%	84%	NI	NI
Chapter 5: Self-care				
d510 Washing and drying oneself	50%	69%	84%	88%
d520 Caring for body parts	6%	6%	80%	84%
d530 Toileting	0%	0%	78%	92%
d540 Dressing	25%	32%	83%	89%
d550 Eating	22%	34%	72%	90%
d560 Drinking	6%	6%	70%	88%
d570 Looking after one`s health	72%	247%	80%	85%
Chapter 6: Domestic life				
d610 Acquiring a place to live	9%	13%	NI	NI
d620 Acquisition of goods and services	25%	50%	NI	NI
d630 Preparing meals	28%	28%	NI	NI
d640 Doing housework	31%	38%	NI	NI
d650 Caring for household objects	6%	9%	NI	NI
d660 Assisting others	41%	97%	NI	NI
Chapter 7: Interpersonal interactions and relationships				
d710 Basic interpersonal interactions	25%	28%	NI	NI
d720 Complex interpersonal interactions	16%	31%	NI	NI
d730 Relating with strangers	6%	9%	NI	NI
d740 Formal relationships	9%	9%	NI	NI
d750 Informal Social relationships	19%	34%	NI	NI
d760 Problems with family relationships	59%	184%	83%	91%
d770 Intimate relationships	41%	63%	NI	NI
Chapter 8: Major life areas				
d845 Acquiring/keeping a job	19%	31%	NI	NI
d850 Remunerative employment	84%	222%	NI	NI
d855 Non-remunerative employment	6%	6%	NI	NI
d859 Employment, other unspecified	6%	9%	NI	NI
d870 Economic self-sufficiency	38%	100%	82%	84%
d898 Major life areas, other specified	6%	6%	NI	NI

(To be continued)

TABLE IV.—*Low to moderate frequency activity and participation categories identified by 5% of patients and 50% of health care professionals (Continues).*

Activity & participation	Patient categories		HCP categories	
	RF	AF	COM	IMP
Chapter 9: Community, social and civic life				
d910 Engaging in community	9%	9%	81%	83%
d920 Recreation and leisure	75%	231%	NI	NI
d930 Religion and spirituality	3%	3%	44%	58%
d940 Human rights	0%	0%	47%	64%
d998 Community, social life	6%	6%	NI	NI

The table presents 76 activity and participation categories identified by 5% of patients and 50% of HCPs.
NI: categories not included in HCP questionnaire.

TABLE V.—*Low to moderate frequency environmental barriers and facilitators identified by 5% of patients and 50% of health care professionals.*

Environmental barriers and facilitators	Barriers			Facilitators		
	PRF	PAF	HCP	PRF	PAF	HCP
Chapter 1: Products and technology						
e110 Products for personal consumption and ingestion (food, drink and drugs)	28%	50%	32%	44%	75%	68%
e115 Products and technology for personal use in daily living (walking stick, bath board)	25%	47%	11%	34%	66%	89%
e120 Products and technology for personal indoor and outdoor mobility	19%	16%	22%	31%	50%	78%
e125 Products and technology for communication (computers, mobile phones)	0%	0%	26%	3%	3%	74%
e150 Design, construction and technology of building for public use	28%	44%	57%	9%	9%	43%
e155 Design, construction and technology of building for private use	13%	22%	63%	6%	9%	38%
Chapter 2: Natural environment and human-made changes to the environment						
e210 Physical geography	3%	3%	NI	6%	6%	NI
e225 Climate	13%	13%	60%	0%	0%	40%
e235 Human-caused events	9%	13%	NI	NI	NI	NI
e240 Light (sunlight, candles, oil or paraffin lamps, fires and electricity)	0%	0%	36%	0%	0%	64%
e250 Sound (e.g. banging, ringing, buzzing, in any volume that is useful/distracting)	3%	6%	87%	0%	0%	13%
Chapter 3 Support and relationships						
e310 Immediate family (by birth or marriage)	13%	16%	22%	44%	66%	78%
e315 Extended family (uncles, aunts, nieces)	3%	3%	21%	0%	0%	79%
e320 Friends	19%	19%	18%	50%	69%	82%
e325 Acquaintances, peers, colleagues, neighbours and community members	0%	0%	NI	6%	6%	NI
e330 People in position of authority	0%	0%	NI	22%	22%	NI
e340 Service providers that enable work, education etc (nanny, cleaners)	3%	3%	16%	13%	13%	84%
e355 Health professionals (doctors, nurses, therapists)	56%	138%	11%	75%	209%	89%
e360 Health related professionals (lawyers, social workers, teachers, architects)	3%	3%	16%	3%	3%	84%
e398 Support and relationships, other specified	9%	9%	NI	6%	9%	NI
Chapter 4 Attitudes						
e410 Attitudes of immediate family members that influence individual behaviour	6%	6%	39%	22%	22%	61%
e415 Attitudes of extended family members that influence behaviour or actions	0%	0%	40%	6%	6%	60%
e420 Attitudes of friends (specific opinions that that influence behaviour or actions)	9%	9%	34%	31%	38%	66%
e430 Attitudes of people in positions of authority that influence behaviour or actions	0%	0%	46%	3%	9%	54%
e440 Attitudes of personal care providers and personal assistants	0%	0%	29%	0%	0%	71%
e445 Individual attitudes of strangers	6%	13%	NI	0%	0%	NI
e450 Attitudes of health professionals	22%	50%	25%	22%	50%	75%
e455 Attitudes of other professionals	3%	3%	31%	3%	9%	69%
e460 Societal attitudes	6%	6%	NI	3%	3%	NI
e465 Social norms, practices and ideologies (moral and religious behaviour or etiquette)	3%	3%	53%	0%	0%	47%
Chapter 5 Services, systems and policies						
e535 Communication services, systems and policies	3%	3%	NI	6%	6%	NI
e545 Civil protection services, systems and policies	0%	0%	NI	9%	9%	NI
e550 Legal services, systems and policies (legislation and other law of a country)	9%	9%	52%	0%	0%	48%
e555 Associations, memberships and organizational services (e.g. charities)	0%	0%	14%	0%	0%	86%
e570 Social security, services, systems & policies	41%	69%	45%	19%	25%	55%
e575 General social support services	9%	13%	29%	9%	19%	71%
e580 Health services, systems and policies	56%	197%	27%	81%	247%	73%
e590 Labour and employment services, systems and policies	19%	28%	NI	16%	22%	NI

The table presents 38 *environmental factors* identified by 5% of patients and 50% of HCPs.
NI: category not included in HCP questionnaire; PRF: patient Relative frequency; PAF: patient Absolute frequency; HPC: health care professional.

TABLE VI.—*Demographics of health care professionals that commenced the online questionnaire.*

All HCPs	N.	%
Total questionnaire commenced	329	100%
Male	131	40%
Allied Health Professionals (AHPs) including trauma managers	224	68%
Medical Practitioners	105	32%
5 to 8 years' experience	73	22%
More than 8 years' experience	256	78%
Acute setting	216‡	66%
Major Trauma Centre (Specialist acute hospital)	137	63%
Trauma Unit (General acute hospital)	61	28%
Hospital (Undefined)	18	8%
Postacute setting	173‡	53%
Generic in-patient rehabilitation	30	17%
Specialist in-patient rehabilitation	63	36%
Skilled Nursing Facility	9	5%
Forensic unit	2	1%
Community rehabilitation team	38	22%
Out patients	26	15%
Other	5	3%

Demographic data for 329 HCPs that commenced the on-line questionnaire and 214 HCPs completed the questionnaire. ‡ 61 HCPs worked in both acute and postacute settings. The majority of participants worked in acute settings and had more than eight years' experience.

The biggest discrepancy was seen for structures of the brain (s110), spinal cord (s120), the shoulder region (s720) and areas of skin (s810) (Table III).

There was less agreement between patients and HCPs in areas of activities and participation (d) (Table IV). Fifteen categories identified by patients were not included in the HCP questionnaire. In contrast, four categories within the *Learning and applying Knowledge* (d1) chapter were identified as important by clinicians but were rarely reported by patients. Patients prioritized tasks such as housework, shopping and helping others as part of *domestic life* (chapter 6) compared to HCPs that prioritised items of self-care (chapter 5). Both patients and HCPs agreed on the importance of walking (d450), looking after one's health (d570) and handling stress and other psychological demands (d240). They also agreed on family relationships (d760). Patients identified additional relationships such as social (d750) and intimate relationships (d770). Remunerative employment (d850) does not occur in the comprehensive ICF core set and was not included in the HCP questionnaire, although economic self-sufficiency (d870) is, and this was regarded as very important by HCPs. Similarly recreation and leisure (d920) was very important for patients, whereas problems with engaging in community life (d910) were identified in the HCP questionnaire.

There were also discrepancies in the environmental factors (e) component (Table V). Environmental categories, which refer to contextual factors, are coded as barriers or facilitators to functioning. The most important environmental facilitators identified by both patients and HCPs were support and attitudes of immediate family members (e310, e410), support from and attitudes of health care professionals (e355, e450) and health services, systems and policies (e580). Many patients (41%) described social security, systems and policies (e570) as a barrier to recovery where HCPs reported these as facilitators. The third level category *drugs* (e1101) or medication was aggregated to the second level category substances for personal consumption (e110) which was seen as both a barrier and a facilitator for patients. HCPs identified 742 personal factors which could either help or hinder recovery such as age, education and attitude. Personal factors in patient interviews related to dealing with death of a relative involved in the incident, the impact of injuries on retirement, attitudes towards recovery and the content of nightmares.

Table VII presents the final list combined of ICF categories important for rehabilitation and health outcome as frequently identified by patients and HCPs. These are the combined categories with a relative frequency of ≥15% for patient data and/or a frequency of ≥70% for HCPs categories. The final list consists of 109 categories comprising of 29 body functions, 11 body structures, 41 activity and participation categories and 28 environmental factors. There was 100% agreement for body function and body structure categories. Patients identified 39 (93%) of the activity and participation categories compared to 27 (62%) identified by HCPs. Environmental factors had an 88% overlap between HCPs and patients.

Discussion

This mixed methods study describes the breadth and importance of rehabilitation and health outcomes after severe injury, using an internationally accepted framework of function and disability. We demonstrate that it is possible to engage both trauma patients and HCPs in rehabilitation research using the ICF as a reference with acceptable levels of recruitment and participation, well above our expected threshold of 50%. Both patients and health care practitioners identify a broad range of categories, the majority of which are not captured by indi-

TABLE VII.—*Moderate to high frequency categories identified by ≥15% of patients or ≥70% of HCPs summarising a proposed for minimum data set (N.=109 categories).*

Body functions (N.=29)

- b110 Level of consciousness
- b114 Orientation functions
- b126 Temperament and personality functions
- b130 Energy and drive functions
- b134 Sleep functions
- b140 Attention functions
- b144 Memory functions
- b147 Psychomotor problems
- b152 Emotional functions
- b156 Perceptual problems
- b160 Thought functions
- b164 Higher-level cognitive functions
- b180 Experience of self and time functions
- b265 Touch function
- b280 Sensation of pain
- b420 Blood pressure functions
- b435 Immunological system functions
- b440 Problems with respiration functions
- b455 Exercise tolerance functions
- b530 Weight maintenance functions
- b620 Urination functions
- b710 Mobility of joint functions
- b715 Stability of joint functions
- b730 Muscle Power Functions
- b735 Muscle tone function
- b740 Muscle endurance functions
- b760 Control of voluntary movement functions
- b770 Gait pattern functions
- b820 Repair function of the skin

Body structures (N.=11)

- s110 Structures of brain
- s120 Spinal cord and related structures
- s430 Structures of respiratory system
- s530 Structures of stomach
- s710 Structures of head and neck region
- s720 Structures of shoulder region
- s730 Structures of upper extremity
- s740 Structures of pelvic region
- s750 Structures of lower extremity
- s760 Structures of trunk
- s810 Structures of areas of skin

Activity and participation (N.=41)

- d155 Acquiring skills
- d160 Focusing attention
- d175 Solving problems
- d177 Making decisions
- d210 Undertaking a single task
- d230 Carrying out daily routine
- d240 Handling stress
- vd310 Communicating
- d410 Changing basic body position
- d415 Maintaining a body position
- d420 Transferring oneself
- d430 Lifting and carrying objects
- d440 Fine hand use
- d445 Hand and arm use
- d450 Walking
- d455 Moving around
- d460 Moving around in different locations
- d465 Moving around using equipment
- vd470 Using transportation
- d475 Driving
- d510 Washing oneself
- d520 Caring for body parts
- d530 Toileting
- d540 Dressing
- d550 Eating
- d560 Drinking
- d570 Looking after one's health
- d620 Acquisition of goods and services
- d630 Preparing meals
- d640 Doing housework
- d660 Assisting others
- d710 Basic interpersonal interactions
- d720 Complex interpersonal interactions
- d750 Informal Social relationships
- d760 Family relationships
- d770 Intimate relationships
- d845 Acquiring, keeping and terminating a job
- d850 Remunerative employment
- d870 Economic self-sufficiency
- d910 Community life
- d920 Recreation and leisure

(To be continued)

TABLE VII.—*Moderate to high frequency categories identified by ≥15% of patients or ≥70% of HCPs summarising a proposed for minimum data set (N.=109 categories) (Continues).*

Environmental barriers and facilitators (N.=26)	
e110 Products for personal consumption	e410 Attitudes of immediate family members
e115 Products/technology for personal use	e415 Attitudes of extended family members
e120 Products/technology for mobility (in/out doors)	e420 Attitudes of friends
e125 Products and technology for communication	e430 Attitudes of people in positions of authority
e150 Design/construction of building-public use	e440 Attitudes of personal care providers
e155 Design/construction of building for private use	e450 Attitudes of health professionals
e310 Immediate family - support and relationships	e455 Attitudes of other professionals
e315 Extended family - support and relationships	e465 Social norms, practices and ideologies
e320 Friends - support and relationships	e550 Legal services, systems and policies
e330 People in position of authority	e570 Social security, services, systems & policies
e340 Service providers that enable work &education	e575 General social support services
e355 Health professionals	e580 Health services, systems and policies
e360 Health related professionals	e590 Labour and employment services & systems

vidual outcome measures.[9] There was substantial agreement between patients and HCPs in areas related to body structure and body function. However within the activity, participation and environmental components there were categories which patients deemed important but were not considered significant or prevailing by HCPs. Conversely some areas considered important by HCPs were not frequently recognized by patients. There was disagreement in some contextual factors of the environment as to whether particular factors were more likely to be barriers or facilitators to recovery. One previous study used the ICF to as a conceptual framework to develop a list of all deficits (LOAD) to capture the overall burden of traumatic injuries.[8] Population burden was calculated using a combination of 20 domains consisting of individual, family and societal deficits. The purpose of the Injury LOAD framework was to list all deficits and highlight the importance of each factor to prompt the scientific community to recognize the wider impact of injury and to develop population metrics.[8] Whilst this work is complementary to our study it has a strong emphasis on cost burden, presented as population burden which is not the focus of our work. Rather, the application of a minimum data set will improve standardized data collection to enable comparison and description of rehabilitations needs, input and outcomes of trauma populations, where after burden can be accurately evaluated.

Measuring health outcome of major trauma is complex, particularly due to varied injury patterns and heterogeneous patient populations. By dividing patient and HCP data into high and low frequency categories in our study we defined common and important problems faced by trauma patients. This methodology, frequently used in ICF studies, appears to provide useful insights into trauma patients' recovery priorities. For example, trauma outcomes research has historically used clinician rated dependency measures such as the Barthel Index [45] or disability measures such as the Functional Independence Measure.[46] These are most often applied in sub-acute and primary rehabilitation settings, whereas other outcome studies measured longer term function using health related quality of life (HRQL) measures thus not capturing all aspects of health outcome. Safety and independence in self-care is often a discharge requirement [47] and HCPs may spend some time getting patients independent or provide equipment to reduce risk prior to discharge.[3] This focus may not be important for patients' during or after acute hospitalization. Our data demonstrate that work, finance and domestic tasks were of greater importance to patients than self-care activities. Others have reported a discrepancy between rehabilitation goals described by trauma patients' and their rehabilitation professionals with only a 40% agreement related to work or education and 19% agreement for recreation and leisure.[16] The combined data, and proposed data set provides a comprehensive set of key domains which should be considered for trauma outcomes assessment. This may focus rehabilitation priorities on patients-driven outcomes and increase engagement between patients and HCPs.[16] It will also direct and facilitate health service delivery and research.[48]

Existing outcome measures individually capture only a fraction of the health outcomes identified in this study. In a recent systematic review,[9] we found that commonly used measures collectively assessed a maximum of 29 ICF categories (8% of the total 2nd level categories and 2% of overall ICF). The majority of these measures were developed with a narrow scope based on chronic disease models,[49] and not specifically for trauma.[50] Only one measure, the Trauma Outcomes Profile (TOP) [51] used in one study, captured 61 ICF categories (17% second level categories). However, 14 of these related to pain in different body structures, thus only 47 (13%) unique ICF categories. Furthermore, less than 2% of all environmental factors were captured with these outcome measures [9] despite evidence of the impact of education, access to medical insurance, trauma systems and support services has on outcome after injury.[52] Thus, there is a real concern that studies using existing measures of health outcomes after trauma do not comprehensively reflect the greater impact of injury on patients' lives.

As an example, post-traumatic stress disorder (PTSD) is not evaluated by existing generic outcome measures [53] although PTSD scales are used intermittently in specific patient populations such as the military [54] and critical care.[5] In our study patients did not diagnose themselves with PTSD but rather described factors that impact on their ability to manage stress after trauma. These included stress management (d240) which was the third most limiting factor in activity and participation. Patients also reported difficulty in managing temperament (b126); struggling to look after their own health (d570); and loss of productivity in terms of remunerative employment (d850). Similarly, environmental factors such as limited access to health care services, health care professional attitudes and lack of support systems or service are known to affect the recovery burden.[52] Assessment of these factors are of importance and should be considered during rehabilitation and outcome assessment, especially given the discrepancy between patient and HCP in relation to which environmental factors are barriers or facilitators to recovery. The importance of family support and relationships (d760 and e310) has been highlighted in traumatic brain injury rehabilitation.[55] It was identified by more than half of the patients and nearly 90% of HCPs despite a lack of research on the impact of family support and relationships in major trauma.

Finally, work (d850) and leisure (d970) were the most important activity and participation categories identified by patients but are not routinely measured in trauma outcome studies despite the evidence that emphasizes the importance of these aspects.[56] Productivity losses, due to traumatic injuries, are estimated to be billions of pounds each year due to the demographic make-up of trauma patients, such as age, education and compensation status,[57, 58] The benefit of sport and leisure activities was demonstrated in survivors of spinal cord injury.[59] Our data demonstrate that outcomes that are not captured by existing measures are non-trivial despite widespread recognition of their important impact on recovery.

The ICF framework shows clear potential in its ability to capture rehabilitation and health outcomes of trauma patients. Our methodology has produced a potential minimum data set of 109 ICF categories that may be used to measure rehabilitation priorities and health outcome of injured patients in the future. It also prompts clinicians to consider contextual issues such as environmental factors as these will impact recovery and access to services. The coded categories derived from this study will enable national and international comparison of rehabilitation and health outcome after injury using a standardized language.

There are a number of limitations to this study. Patient interviews were conducted on a small sample from only one trauma center albeit in an ethnically diverse major city. Secondly, patients were at home and this possibly reflects the prioritization of domestic tasks over self-care or other tasks. Moreover, people of different age groups may have different perceptions and attitudes to functional limitations and older people may report no difficulty in a task despite changes in the way they used to perform the task.[60] These differences and perceptions were not analyzed or captured during the interviews but will add important depth to understanding the degree of difficulty experienced by some. HPCs identified health issues related to body functions which were not identified by patients and were excluded from the final data set due to low frequencies. This could be attributed to the fact that the majority of HCPs were based in acute services and had knowledge of acute problems, rather than community services. HPCs are also knowledgeable about specific body functions such as consciousness (b110) and psychomotor problems (b147) which is not necessarily problematic for patients in the community.

Other issues to consider are the impact of missing data in terms of patients consented to participate (N.=32 from 44 patients invited; 73%) and completion rate of the on-line questionnaire (N.=214 from 329 HCP's invited; 65%). Although a sample size of 32 participants are acceptable to ensure data saturation in qualitative interviews,[61] it need to be recognized that the patients that declined to participate were younger and more severely injured. They have similar characteristics to those described as "lost to follow-up" in other trauma studies,[62, 63] and may have different problems and priorities from the sample interviewed. We therefor recognize that more work needs to be done to ensure their needs are captured in ICF categories to enable generalization to all trauma patients. In addition, even though we achieved an above average response- and completion rate for the on-line questionnaire,[64-66] we acknowledge that there are a substantial amount of missing data for non-respondents (N.=115; 35%). A variety of factors contributed to this for which we received feedback. These include the length of the questionnaire, invitations to clinicians that are too busy or HCPs regarding the topic as irrelevant to their area of practice. We did not analyze the characteristic of non-respondents or in-complete questionnaires. As a consequence this may limit generalization and application of results due to an under representation of the views of certain HCPs or the international community. Whilst recognizing this, we aim to address some of these issues at an international consensus conference with appropriate international representation from a variety of health care professionals.

We propose an international consensus conference, which includes patients, patient representatives and professionals, to further debate issues and reach agreement of the principal categories to include in a minimum dataset for trauma. The final categories can also be grouped in terms of setting. Acute and post-acute settings may have different priorities, resulting in some body structure categories being made redundant. This will warrant wide application and international acceptance to ensure implementation and adherence to allow comparison of rehabilitation and outcome after trauma.

Conclusions

We have used the internationally recognized ICF framework to describe the range and complexity of health outcomes after injury. The comprehensive assessment of on-going health issues of injured patients is important for individuals, institutions, regional trauma systems, science and society. The strong consensus between an international group of trauma experts and patients presents an opportune prospect for the application of a trauma framework to collect international trauma outcome data. We present the candidate categories for an ICF-based minimum data set for the development of modern health outcome assessment in trauma care.

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