

Perspectives of patients with long term health conditions

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Annex 10 To SHN Work Package 3 Deliverable D3.3

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² ICF Research Branch in cooperation with the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI); Swiss Paraplegic Research; Nottwil, Switzerland

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	understanding of patients' experiences of long term health problems				
	(i.c. Heart failure) and their interactions with healthcare systems and				
	providers. An exploration was made of the suitability of the				
	International Classification of Functioning (WHO-ICF) to represent				
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Note:

This annex was commissioned by Prof. Dr. Dipak Kalra, Project Leader, and Prof. R. Vander Stichele, Workpackage Leader of SemanticHealth Net WP3, to Paul Rastall, Health Informatics Unit, Royal College of Physicians, London

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1. Introduction

Patient care is supported by clinical record systems capable of recording and sharing appropriate clinical information. Clinical experts are able to accurately define the data elements, patient information and investigation results required to deliver multi-disciplinary evidence based care. The evolution of record systems with semantic interoperability further supports this endeavour.

Clinical care, however, is evolving and we aspire to provide personalised care that not only applies best clinical evidence but also takes account of a patient's individual circumstances, the impact ill health has on them and reflects their personal goals and priorities. Delivery of this personalised care requires patients to be informed and engaged in their healthcare management, cultural change from clinicians and the greater evolution of shared decision making in routine clinical practice. Information is key to this process and future electronic record systems will need to facilitate the capture, sharing and use of richer patient focussed information. The National Information Board has identified this as a target in their report 'Personalised Health and Care 2020' (HM Government 2014) and The Royal College of General Practitioners identifies the need for professional change in 'An Inquiry into Patient Centred Care in the 21st Century' (RCGP 2014).

Previous pilot work was carried out to look at patients' perspectives on their health and care when living with heart failure¹. This highlighted that detailed information about the impact of disease on patients' functional ability was often absent from record system datasets, as well as being variable within clinical practice. The capturing of broader patient perspectives was also identified to be sub-optimal and led to the further investigation detailed in this report.

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 $^{^{\}rm 1}$ Rastall P, Carpenter I, Hoogewerf J. Patient Perspectives in Heart Failure. Annex to SHN Deliverable 3.2

Our work has been designed to explore and gain a greater understanding of patients' experiences of long term health problems and their interactions with healthcare systems and providers. Our focus has been to try to identify the key information areas, identified as important by patients and their carers, which adequately represent patient perspectives. We believe the creation and future use of appropriate patient experience focussed record headings may facilitate improvements in patient care and support the delivery of personalised care planning.

Multiple general quality of life and disease specific assessment tools exist. Typically they allow the calculation of a score or grading category that can then prompt or assist in care delivery, can be used to demonstrate change over time and can be a powerful tool when aggregated and used in population health analysis. By their design these tools rely on quantifiable responses to set questions without the opportunity for the capture of more detailed information. What this project has addressed is the impact of a person's illness on specific aspects of their lives that they consider important. Patients clearly would like their clinicians to know these matters, as treatment options may improve pathology or physiology in relation to illness but have a negative impact on aspects of their lives that they consider important. Understanding these factors will assist both clinicians and patients in choosing treatment and care options to best meet the patients' desired goals.

Classification systems such as The International Classification of Functioning, Disability and Health (ICF) are powerful tools traditionally used in population health work as well as in monitoring the impact of interventions at both an individual and population level. Although ways of using the ICF in individual patient care are still developing, the potential for the contribution it can make is recognised. Their primary role is in the categorisation of functional ability and the practicalities of how this is assessed are not specified. Whilst this work uses ICF categories as its starting point for exploration of patient perspectives it is not the intention of this report to demonstrate operationalization of ICF; however this is discussed in Annex 11 of the SemanticHealthNet Deliverable D3.3.

2. Methods

We used a process of iterative development and incremental refinement to develop the proposed patient perspective headings, engaging with patients, carers and professionals in three stages as summarised in the flow chart below. Development was consensus based with internal review by the project team.



Diagram 1; Methodology used in development of patient perspective domains.

30 ICF headings, made up of the ICF Generic set (7) and ICF Disability set (23)², are believed to be the most relevant across clinical populations through the continuum of care (Prodinger et al). These were reviewed and used as the starting point for our consultations.

ICF Code	Title
b130	Energy and drive functions (G)
b134	Sleep functions
b152	Emotional functions (G)
b280	Sensation of pain (G)
b455	Exercise tolerance functions
b620	Urination functions
b640	Sexual functions
b710	Mobility of joint functions
b730	Muscle power functions
d230	Carrying out daily routine (G)
d240	Handling stress and other psychological demands
d410	Changing basic body position
d415	Maintaining a body position
d420	Transferring oneself
d450	Walking (G)
d455	Moving around (G)
d465	Moving around using equipment
d470	Using transportation
d510	Washing oneself
d520	Caring for body parts

 $^{^2}$ For a comprehensive description of functioning it is recommended to complement this list of b and d categories with a list of 10 environmental factor categories. We only drew upon the 30 categories from the ICF Disability Set as a starting point for this project.

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d530	Toileting
d540	Dressing
d550	Eating
d570	Looking after one's health
d640	Doing housework
d660	Assisting others
d710	Basic interpersonal interactions
d770	Intimate relationships
d850	Remunerative employment (G)
d920	Recreation and leisure

(G) indicates categories of ICF Generic Set

Table 1; Prodinger, Bickenbach, Stucki, & Cieza, 2014 (See Appendix 1 for associated ICF descriptions).

A half day workshop was held at the Royal College of Physicians London on 13 November 2014 and patients, or carers of patients with long term health conditions, were invited. 8 people attended and represented people with varied health conditions including cardiac disease, diabetes, congenital disorders, chronic kidney disease and musculoskeletal problems. The first half of the meeting was a group discussion, facilitated by Dr Paul Rastall, to explore patients' priorities, concerns and perspectives regarding life with a long term health condition. The remainder of the workshop was spent with group activity to consider the 30 ICF categories culminating in group feedback and discussion.

Detailed notes were taken during the meeting and thematic analysis was carried out by the research team. A draft set of patient perspective headings with associated descriptors was created and formed the basis for an online survey.

The survey was live for 5 weeks from 12 December 2014 until 17 January 2015 and was completed by 250 respondents. Patients and carers were invited to respond through established links with patient representative groups and via a social media communication strategy. Respondents were asked questions about their background, health problems and the impact they felt they had on their lives. For each draft heading they were asked to judge whether the heading and descriptor made sense, whether the issues described were relevant to them personally and to provide comments or any additional feedback.

Following closure of the survey, thematic analysis was undertaken by the project team and this informed a further re-draft of the proposed domains/headings. The Health Informatics Unit at the Royal College of Physicians, London has well established contacts with a wide range of professional and patient organisations.

The second draft of the headings was circulated amongst this network for consultation between 20 February 2015 and 9 March 2015 and feedback was provided. Analysis of all comments received was considered by the research team and led to the final version of the headings.

3. Results

3.1 Workshop

Thematic analysis of the output of the facilitated small group discussions revealed the following key themes that patients and carers felt were important in representing their perspectives and planning their care:

- Service delivery issues
 - o The ability to see their records and contribute to them
 - Desire to be involved in shared decision making regarding their health
- Information/content related
 - Ability to state and prioritise symptoms important to patients
 - Being able to make clinicians aware of their personal and family background
 - Sharing lifestyle information
 - Input from carers regarding care planning
 - The ability to share opinions about future plans and prioritise elements of care
 - Provide feedback about treatment/medications (including interactions, side-effects)
 - o The ability to make a personal statement about their care
 - Detailing of their language/communication needs

During the second half of the workshop the 30 ICF headings were reviewed and lively group discussion ensued. The consensus was that whilst all the headings were potentially important in many cases they were too specific or narrowly focused. There was consensus that the headings did, however, represent broad key domains which they felt were potentially important to a wide range of people with long term health conditions.

Based on work carried out in the workshop and subsequent analysis of the discussions we were able to draft 11 potential record headings with associated descriptors to capture patient perspectives (Table 2).

Heading	Description
Emotions and mood	How your mood and emotions affect your daily life or your ability to deal with other health issues. Eg depression, worry, stress etc.
Energy and drive	How your levels of motivation, drive and energy affect your daily life or your ability to deal with other health issues. Eg fatigue, restlessness etc.
Sleep	How problems you have with going to sleep, disturbed sleep patterns, early wakening or daytime sleepiness affect your daily life
Symptoms that affect daily living	How symptoms or issues that you have affect your daily life. Also include and changes over time. Eg. Pain, itchiness, cough
Self care	How problems you have caring for yourself affect your daily life. Eg washing yourself, using the toilet, eating and drinking etc. Include details of any help or equipment you need or use.
Mobility and movement	How problems you have in moving around, both inside and outside, affect your daily life. Include details of any help or equipment you need or use. Eg moving from a bed to a chair, walking, jogging etc.
Social life	How your ability to engage in your social life, with friends, relatives or colleagues impacts on your daily life. This can include intimate relationships with a partner or spouse.
Work and leisure	How problems you encounter in undertaking paid or voluntary work and leisure activities, affect your daily life. This includes housework, managing your finances, shopping etc.
Understanding of your health issues and treatment	How well you understand your health problems, treatment and care. Include any particular concerns or questions you may have.
Individual needs	Information you think it is important that people involved in your care know. Eg accessibility or communication requirements.
Care priorities and goals	Your current and future care priorities and goals. Include any information relevant to your care plan.

Table 2 – draft headings based on RCP workshop

3.2 Survey

250 people responded to the survey (57% female, 43% male, median age 49, range 1-95 years). 56% were patients, 32% carers, 8% both patient and carer and 4% other (mainly health professionals). Almost all respondents were from the UK with 2 from Belgium, and 1 each from Italy and Ireland. 7% described themselves as coming from a black or minority ethnic group. Respondents reported a wide range of long term conditions including heart and respiratory disease, diabetes, forms of arthritis and other musculoskeletal disorders, Multiple Sclerosis and other neurological problems, mood disorders and other psychiatric illnesses, HIV as well as a number of rarer

conditions and paediatric illnesses. Self reported impact of their long term conditions was generally high with 92% rating it as moderate or worse and 31% reporting very high impact. Table 3 provides a breakdown of responses to the questions about the 11 draft headings.

	This heading makes sense to me		This heading is relevant to me		This description is easy to understand			This description covers issues relevant to me				
	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know	Yes	No	Don't know
Emotions and mood	93%	4%	3%	87%	11%	2%	90%	7%	3%	87%	10%	3%
Energy and drive	96%	3%	1%	90%	5%	5%	88%	7%	5%	88%	7%	5%
Sleep	95%	4%	1%	83%	16%	1%	94%	5%	1%	82%	17%	1%
Symptoms that affect daily living	92%	6%	2%	90%	8%	2%	86%	11%	3%	86%	10%	4%
Self care	93%	6%	1%	64%	34%	2%	93%	6%	1%	64%	35%	1%
Mobility and movement	94%	5%	1%	69%	30%	1%	93%	6%	1%	67%	31%	2%
Social life	97%	2%	1%	83%	16%	1%	95%	4%	1%	82%	16%	2%
Work and leisure	96%	3%	1%	83%	17%	0%	92%	6%	2%	79%	19%	2%
Understanding of your health issues and treatment	97%	2%	1%	92%	7%	1%	95%	4%	1%	92%	6%	2%
Individual needs	88%	8%	3%	78%	19%	3%	92%	7%	1%	75%	21%	4%
Care priorities and goals	87%	8%	5%	76%	14%	10%	85%	11%	4%	74%	16%	10%

Table 3 – summary of survey responses

The headings and descriptors were generally understood by most respondents (>87% and 85% respectively). Headings reported as less relevant included self care (64% considered the heading relevant), mobility and movement (69%), individual needs (78%) and care priorities and goals (76%).

Thematic analysis and review by the research group identified the following important factors that led to the second draft of the headings:

- Energy and drive were frequently identified as separate issues with energy being seen as a physical function and drive being more of an emotional or psychological one.
- It was highlighted that symptoms are often not physical and the wording was adjusted to reflect this.
- Self care was seen to be confusing and often interpreted as self management of health rather than provision of personal care.
- Driving and the ability to use public transport were highlighted as important issues and were added to the mobility and movement descriptor.

- Social life was felt to be too trivial or flippant and was changed to social activities to reflect impact of function on social life.
- Education and training was highlighted as relevant and added to the work and leisure descriptor.
- Issues with finance were frequently identified and an additional heading was added.
- Issues related to treatment or medication were commonly reported and a new heading was added.
- The individual needs heading was commonly misunderstood and significant feedback was received. This was changed to 'your needs' to highlight that this is designed to capture personal information rated as important for clinicians to know in order to provide individualized care.

The second draft of the headings included 15 unique domains and associated descriptors (Table 4).

Heading	Description			
Emotions, mood and stress	How your mood and emotions affect your daily life or you ability to deal with other health issues. Eg depression, anxiety, worry, stress, anger, frustrations			
Motivation and drive	How your levels of motivation and drive affect your daily life or your ability to deal with health issues.			
Energy	How your energy levels affect your daily life or your ability to deal with health issues.			
Sleep	How problems you have with going to sleep, disturbed sleep patterns, early wakening or daytime sleepiness affect your daily life			
Symptoms that affect your life	How symptoms that you experience affect your life. Include those with the biggest impact on you. Includes physical and non-physical symptoms.			
Pain	How long term or severe pain affects your life. This could include a description of the pain, how you manage it and what it limits or stops you doing.			
Personal care	How problems you have caring for yourself affect your daily life. Eg washing yourself, using the toilet, eating and drinking etc. Include details of any help or equipment you need or use.			
Mobility and movement	How problems you have in moving around, both inside and outside, affect your daily life. Include details of any help or equipment you need or use. Examples include changing position, walking, the ability to drive or use public transport.			

Social activities	How your ability to engage in social activities, with friends, relatives or colleagues impacts on your daily life. This can include intimate relationships with a partner or spouse.
Work and leisure	How problems you encounter in undertaking paid or voluntary work and leisure activities, affect your daily life. This can also include education/training, housework, shopping etc.
Finance	How finance or money issues affect your life. This could include details of costs incurred because of your health problems, problems you experience due to a lack money or any issues you have managing your own financial affairs.
Medication or treatments	How your medication or treatment affects your life. This could include details of any side-effects you experience, problems you have taking the medication or issues with any special monitoring or follow up required.
Understanding of your health issues and treatment	How well you understand your health issues, treatment and care. Give details of any extra help you need to better understand your health issues, concerns or questions you may have.
Individual needs OR Your needs	Information that you want to share with people involved in your care. This could include communication or accessibility requirements.
Care priorities and goals	Your current and future care priorities and goals. This could include details of your personalised care plan.

Table 4 – 2nd draft following survey analysis

3.3 Consultation

We received detailed responses from 18 clinical and patient representative groups (see Appendix 2).

All responses were discussed by the research team and individual replies were sent in response to their comments. The key themes that arose from this consultation were:

- Widespread acknowledgement that this was important work and agreement that patient perspectives were lacking from current systems
- Advise that some of the language used was adjusted to make it more suitable for a patient group
- Identification that this work was synergistic with other work that is ongoing particularly in the fields of rehabilitation medicine and occupational therapy
- Identification that limitations of cognitive function and memory were not included and suggestions of how this may be rectified.
- Advice and input regarding issues associated with future implementation and use of patient perspective headings.

 Feedback form professional groups, particularly GPs regarding the compatibility or potential difficulties of using these headings in traditional consultation settings.

It was identified that the descriptors we had provided to facilitate patients understanding of the headings were in fact easily interpreted as questions and potential assessment tools. This was never the intention of this work and these were therefore re-drafted.

Following detailed discussion and further communication with certain respondents the final draft headings were completed (Table 5).

Heading	Description			
Emotions, mood and stress	Refers to mood and emotions that affect daily life or ability to deal with other health issues. Eg depression, anxiety, worry, stress, anger, frustration.			
Motivation and drive	Refers to levels of motivation and drive that affect daily life or ability to deal with health issues.			
Energy	Refers to energy levels that affect daily life or ability to deal with health issues.			
Sleep	Refers to problems associated with going to sleep, disturbed sleep patterns, early wakening or daytime sleepiness that affect daily life.			
Memory and thoughts	Refers to problems with memory and /or thoughts (including confusion) affecting daily life.			
Symptoms that affect your life	Refers to important or significant symptoms that affect daily life. Eg itchiness, cough, confusion.			
Pain	Refers to long term or severe pain affecting daily life.			
Personal care	Refers to problems with caring for yourself that affect daily life. Eg washing yourself, using the toilet, eating and drinking etc. Also covers help or equipment needed for personal care.			
Mobility and movement	Refers to problems with moving around, both inside and outside, that affect daily life. Also covers help or equipment needed and the ability to drive or use public transport.			
Social activities	Refers to problems engaging socially with friends, relatives or colleagues and romantic or sexual relationships.			
Work, learning and leisure	Refers to problems with paid, voluntary or house work and learning or leisure activities that affect daily life.			

Finance	Refers to finance or money issues that affect daily life.
Medication or treatments	Refers to issues with medication, treatment, side effects or special monitoring that affects daily life.
Understanding of your health issues and treatment	Refers to a person's understanding of health issues, treatment and care. Also includes extra help needed to better understand health issues plus potential concerns or questions.
Your needs	Refers to information that a person may want to share with people involved in their care and could include communication or accessibility requirements.
Care priorities and goals	Refers to a person's current and future care priorities and goals and could include details of a personalised care plan.

Table 5 – Final patient perspective headings

4. Discussion

At all stages of this work feedback from both patients and professionals has highlighted the need for greater patient engagement and an appetite amongst patients and carers to contribute rich information to their clinical records to help direct their subsequent clinical care. It is clear that current clinical practice and use of clinical information frequently omits or fails to take account of the types of information that we have consulted on. The need for change is therefore clear.

It is important to note that our consultation and engagement with patients and carers, whilst wide reaching, cannot capture all possible opinions and experiences. Our survey group was younger than might be typically the case in work of this kind (median age 49) and this is reflected in the comments highlighting issues such as work, leisure, travel and driving. The fact that headings such as self care, mobility and movement, individual needs and care priorities and goals were seen as less relevant also potentially points towards a younger more independent group with less of a disease burden. We propose that this is a strength of our work as we aim to demonstrate domains with relevance across a continuum of life and clinical care. We received a number of comments regarding suitability for paediatric care. We believe that whilst there will be clear overlap with adult care this is an issue which requires much more detailed work and we limit our current scope to adults.

We also note that our methods for engagement favoured a patient and carer group with access to email and social media. Future work will need to consider how to engage with hard to reach groups not included here as well as the challenge of how their perspectives are captured in their routine clinical care.

During the final phase of consultation we received comments from multiple groups agreeing with the motives behind our work but expressing concern regarding the practical use of such headings. They felt that capturing patient focussed information was a key clinical skill and pointed to the training overseen by the Royal College of General Practitioners. We agree that clinical skill and culture is vital to the advancement of personalised care. We however highlight that feedback from our patient engagement has identified that practice is variable and often sub-optimal. Furthermore time constraints and pressures placed upon clinicians mean that practice is often very different to the gold standard that is taught and recommended by professional bodies.

Additionally comments from primary care highlight that their information systems are consultation based, rather than headings based. Future work must look at how the headings can be incorporated into clinical record structures in a way that is workable for both patients and clinicians.

It is our belief that continued development and implementation of the patient perspective headings that we propose, in parallel with evolving clinical practice and culture change, will enhance patient clinical care. The headings we propose are places for recording, reviewing and communicating information in a standard way. It is not the remit of this project to determine how information is gathered, recorded or used, however work must be done to answer some of these vital questions. In their simplest form these headings act as an aide memoire during clinical care however innovative use harnessing new technologies promises much greater benefits. We propose that integrating these record domains into future interoperable, patient centred and accessible record systems paves the way for individualised care. Changes in how we interact with patients including information gathering before traditional consultations, embracing new styles of communicating with patients and allowing patients greater input to their clinical records further add to the richness of clinical information available.

5. Conclusions

The patient perspective headings that we propose provide a structure for the standardised recording, use and sharing of information rated as important by patients with long term health problems. Further challenges exist on how to deal with the way this information is gathered, in what format it is recorded and how it is validated and used. It is essential that patient and professional engagement is part of this ongoing development.

It was not the aim of this work to demonstrate operationalization of ICF categories. However our methodology allows the proposed headings to be mapped to relevant ICF headings. This is both the subset of 30 we used originally and the wider ICF catalogue where appropriate. It is therefore possible that patient information recorded under the structured headings that we propose could be used to derive ICF classification data. Similarly parallel work has been undertaken to look at the feasibility of mapping between ICF categories and the InterRAI assessment tool³. It may therefore be possible to use the same patient reported information to guide clinical care, gain functional classification data and populate functional assessments suitable for individual and population use.

³ Annex 11 of the SemanticHealthNet Deliverable D3.3.

Appendix 1: WHO ICF domains and descriptions

ICF Code	Title	
b130	Energy and drive functions	General mental functions of physiological and psychological mechanisms that cause the individual to move towards satisfying specific needs and general goals in a persistent manner. Inclusions: functions of energy level, motivation, appetite, craving (including craving for substances that can be abused), and impulse control Exclusions: consciousness functions (b110); temperament and personality functions (b126); sleep functions (b134); psychomotor functions (b147); emotional functions (b152)
b134	Sleep functions	General mental functions of periodic, reversible and selective physical and mental disengagement from one's immediate environment accompanied by characteristic physiological changes. Inclusions: functions of amount of sleeping, and onset, maintenance and quality of sleep; functions involving the sleep cycle, such as in insomnia, hypersomnia and narcolepsy Exclusions: consciousness functions (b110); energy and drive functions (b130); attention functions (b140); psychomotor functions (b147)
b152	Emotional functions	Specific mental functions related to the feeling and affective components of the processes of the mind. Inclusions: functions of appropriateness of emotion, regulation and range of emotion; affect; sadness, happiness, love, fear, anger, hate, tension, anxiety, joy, sorrow; lability of emotion; flattening of affect Exclusions: temperament and personality functions (b126); energy and drive functions (b130)
b280	Sensation of pain	Sensation of unpleasant feeling indicating potential or actual damage to some body structure. Inclusions: sensations of generalized or localized pain in one or more body part, pain in a dermatome, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia, analgesia and hyperalgesia
b455	Exercise tolerance functions	Functions related to respiratory and cardiovascular capacity as required for enduring physical exertion. Inclusions: functions of physical endurance, aerobic capacity, stamina and fatiguability Exclusions: functions of the cardiovascular system (b410-b429); haematological system functions (b430); respiration functions (b440); respiratory muscle functions (b445); additional respiratory functions (b450)
b620	Urination functions	Functions of discharge of urine from the urinary bladder. Inclusions: functions of urination, frequency of urination, urinary continence; impairments such as in stress, urge, reflex, overflow, continuous incontinence, dribbling, automatic bladder, polyuria, urinary retention and urinary urgency Exclusions: urinary excretory functions (b610); sensations associated with urinary functions (b630)

		Mental and physical functions related to the sexual act, including the arousal, preparatory, orgasmic and resolution stages.
		Inclusions: functions of the sexual arousal, preparatory, orgasmic
		and resolution phase: functions related to sexual interest, performance, penile erection, clitoral erection, vaginal
b640	Sexual functions	lubrication, ejaculation, orgasm; impairments such as in
		impotence, frigidity, vaginismus, premature ejaculation, priapism
		and delayed ejaculation
		Exclusions: procreation functions (b660); sensations associated
		with genital and reproductive functions (b670)
		Functions of the range and ease of movement of a joint.
		Inclusions: functions of mobility of single or several joints,
	Mobility of joint	vertebral, shoulder, elbow, wrist, hip, knee, ankle, small joints of
b710	functions	hands and feet; mobility of joints generalized; impairments such
	TUTICLIONS	as in hypermobility of joints, frozen joints, frozen shoulder, arthritis
		Exclusions: stability of joint functions (b715); control of voluntary
		movement functions (b760)
		Functions related to the force generated by the contraction of a
		muscle or muscle groups.
		Inclusions: functions associated with the power of specific
	Muscle power functions	muscles and muscle groups, muscles of one limb, one side of the
b730		body, the lower half of the body, all limbs, the trunk and the body as a whole; impairments such as weakness of small muscles in
		feet and hands, muscle paresis, muscle paralysis, monoplegia,
		hemiplegia, paraplegia, quadriplegia and akinetic mutism
		Exclusions: functions of structures adjoining the eye (b215);
		muscle tone functions (b735); muscle endurance functions (b740)
		Carrying out simple or complex and coordinated actions in order
	Carrying out daily routine	to plan, manage and complete the requirements of day-to-day
		procedures or duties, such as budgeting time and making plans
d230		for separate activities throughout the day. Inclusions: managing and completing the daily routine; managing
		one's own activity level
		Exclusion: undertaking multiple tasks (d220)
		Carrying out simple or complex and coordinated actions to
	Handling stress	manage and control the psychological demands required to carry
d240	and other psychological demands	out tasks demanding significant responsibilities and involving
u240		stress, distraction, or crises, such as driving a vehicle during heavy
		traffic or taking care of many children.
		Inclusions: handling responsibilities; handling stress and crisis
		Getting into and out of a body position and moving from one location to another, such as getting up out of a chair to lie down
d410	Changing basic body position	on a bed, and getting into and out of positions of kneeling or
		squatting.
		Inclusion: changing body position from lying down, from
		squatting or kneeling, from sitting or standing, bending and
		shifting the body's centre of gravity
		Exclusion: transferring oneself (d420)
	Maintaining	Staying in the same body position as required, such as remaining
d415	Maintaining a	seated or remaining standing for work or school.
	body position	Inclusions: maintaining a lying, squatting, kneeling, sitting and standing position
		Station & Position

d420	Transferring	Moving from one surface to another, such as sliding along a bench or moving from a bed to a chair, without changing body position.
	oneself	Inclusion: transferring oneself while sitting or lying
		Exclusion: changing basic body position (d410)
		Moving along a surface on foot, step by step, so that one foot is
d450	Walking	always on the ground, such as when strolling, sauntering, walking forwards, backwards, or sideways.
		Inclusions: walking short or long distances; walking on different surfaces; walking around obstacles
		Exclusions: transferring oneself (d420); moving around (d455)
d455	Moving around	Moving the whole body from one place to another by means other than walking, such as climbing over a rock or running down a street, skipping, scampering, jumping, somersaulting or running
		around obstacles.
		Inclusions: crawling, climbing, running, jogging, jumping, and swimming
		Exclusions: transferring oneself (d420); walking (d450)
d465	Moving around using equipment	Moving the whole body from place to place, on any surface or space, by using specific devices designed to facilitate moving or create other ways of moving around, such as with skates, skis, or scuba equipment, or moving down the street in a wheelchair or a walker.
		Exclusions: transferring oneself (d420); walking (d450); moving around (d455); using transportation (d470); driving (d475)
	Using transportation	Using transportation to move around as a passenger, such as being driven in a car or on a bus, rickshaw, jitney, animal-powered vehicle, or private or public taxi, bus, train, tram, subway, boat or aircraft.
d470		Inclusions: using human-powered transportation; using private motorized or public transportation
		Exclusions: moving around using equipment (d465); driving (d475)
d510	Washing oneself	Washing and drying one's whole body, or body parts, using water and appropriate cleaning and drying materials or methods, such as bathing, showering, washing hands and feet, face and hair, and drying with a towel.
		Inclusions: washing body parts, the whole body; and drying oneself
		Exclusions: caring for body parts (d520); toileting (d530)
d520	Caring for body parts	Looking after those parts of the body, such as skin, face, teeth, scalp, nails and genitals, that require more than washing and drying.
		Inclusions: caring for skin, teeth, hair, finger and toe nails
		Exclusions: washing oneself (d510); toileting (d530)
d530	Toileting	Planning and carrying out the elimination of human waste (menstruation, urination and defecation), and cleaning oneself afterwards.
		Inclusions: regulating urination, defecation and menstrual care
		Exclusions: washing oneself (d510); caring for body parts (d520)
d540	Dressing	Carrying out the coordinated actions and tasks of putting on and taking off clothes and footwear in sequence and in keeping with climatic and social conditions, such as by putting on, adjusting and removing shirts, skirts, blouses, pants, undergarments, saris,

		kimono, tights, hats, gloves, coats, shoes, boots, sandals and slippers.
		Inclusions: putting on or taking off clothes and footwear and choosing appropriate clothing
d550	Eating	Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and consuming it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining. Exclusion: drinking (d560)
d570	Looking after one's health	Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.
		Inclusions: ensuring one's physical comfort; managing diet and fitness; maintaining one's health
d640	Doing housework	Managing a household by cleaning the house, washing clothes, using household appliances, storing food and disposing of garbage, such as by sweeping, mopping, washing counters, walls and other surfaces; collecting and disposing of household garbage; tidying rooms, closets and drawers; collecting, washing, drying, folding and ironing clothes; cleaning footwear; using brooms, brushes and vacuum cleaners; using washing machines, driers and irons.
		Inclusions: washing and drying clothes and garments; cleaning cooking area and utensils; cleaning living area; using household appliances, storing daily necessities and disposing of garbage Exclusions: acquiring a place to live (d610); acquisition of goods and services (d620); preparing meals (d630); caring for household objects (d650); caring for others (d660)
d660	Assisting others	Assisting household members and others with their learning, communicating, self-care, movement, within the house or outside; being concerned about the well-being of household members and others. Inclusions: assisting others with self-care, movement, communication, interpersonal relations, nutrition and health maintenance
		Exclusion: remunerative employment (d850)
d710	Basic interpersonal interactions	Interacting with people in a contextually and socially appropriate manner, such as by showing consideration and esteem when appropriate, or responding to the feelings of others. Inclusions: showing respect, warmth, appreciation, and tolerance in relationships; responding to criticism and social cues in relationships; and using appropriate physical contact in
		relationships
d770	Intimate relationships	Creating and maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners.
		Inclusions: romantic, spousal and sexual relationships

d850	Remunerative employment	Engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups.
		Inclusions: self-employment, part-time and full-time employment
d920	Recreation and leisure	Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programmes of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure. Inclusions: play, sports, arts and culture, crafts, hobbies and
		Exclusions: riding animals for transportation (d480); remunerative and non-remunerative work (d850 and d855); religion and spirituality (d930); political life and citizenship (d950)

Appendix 2: Clinical and patient representative groups

Organication	Speciality
Organisation Putting Condinuouslan Society	Speciality
British Cardiovascular Society	Cardiology
British Kidney Patient Association	Patient Representation
British Psychological Society	Psychology
British Society of Rehabilitation	Rehabilitation Medicine
Medicine	
College of Occupational Therapists	Occupational Therapy
Croydon Health Services NHS Trust	Psychology
Lancashire Care NHS Foundation Trust	Psychology
North Derbyshire Clinical	Commissioning
Commissioning Group	
Nottingham University Hospitals NHS	Psychology
Trust	
Renal Association	Renal
Royal College of General Practitioners	General Practice
Royal College of Physicians Patient and	Patient Representation
Carer Network	
Royal Devon and Exeter Foundation	Psychology
NHS Trust	
Royal Free London NHS Foundation	Paediatric, Audiology & Audiovestibular
Trust	Medicine
Sussex Partnership NHS Foundation	Psychology
Trust	
University Hospitals Birmingham NHS	Psychology
Foundation Trust	
Yorkshire & Humber Academic Health	Academic
Science Network	