Documenting Routinely What Matters to People: Standardized Headings for Health Records of Patients with Chronic Health Conditions

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Abstract

Objective   Specifying the content in electronic health records (EHRs) through standardized headings based on international reference classifications will facilitate their semantic interoperability. The objective of this study was to specify potential chapter headings for EHRs aligned with the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) based on the perspectives of people living with chronic health conditions, carers, and professionals.

Methods   A multistage process was established including (1) a patient workshop, (2) an online survey of both patients and carers, and (3) an online consultation with patient and professional bodies. The ICF served as a starting point. Based on the first stage, a first draft of the headings was developed and further refined based on the feedback at each stage. We examined in a fourth step whether items from existing assessment tools support the operationalization of the identified headings. Therefore, we used the WHO Disability Assessment Schedule 2.0 (WHODAS2.0), a patient-reported instrument, and interRAI, a clinician-administered instrument.

Results   The first workshop was attended by eight people, the survey was completed by 250 persons, and the online consultation received detailed feedback by 18 professional bodies. This study resulted in 16 potential chapter headings for EHRs which capture aspects related to the body, such as emotions, motivation, sleep, and memory or thoughts, to being involved in social life, such as mobility, social activities, and finances, as well as to the care process, such as understanding of health issues and treatment or care priorities and goals. When using the WHODAS2.0 and interRAI together, they capture all except one of the proposed headings.

Conclusion   The identified headings provide a high level structure for the standardized recording, use, and sharing of information. Once implemented, these headings have the potential to facilitate the delivery of personalized care planning for patients with long-term health problems.

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Background and Significance

The delivery of high-quality, efficient, and safe clinical care by multidisciplinary teams across various institutions and settings requires person-centered health records capable of capturing and sharing appropriate clinical information. In particular in the care of people with chronic health conditions, moving from a conventional, disease-specific care approach to one that is person-centered, individually tailored, and fully integrated has been promoted to respond best to patients' health and related needs.[1,2] Moving toward a person-centered care approach requires a shift away from assigning the person receiving care with a passive role in the care process and instead empowering them to take greater control of their care with shared responsibility between service users and providers.[3–5] To facilitate this, it is essential that health records capture and facilitate the sharing of information relevant to all aspects of a person's health, functioning, and well-being. Electronic health records (EHRs) enable the recording of clinical information over time and facilitate the sharing of this information between health care professionals and patient in ways not possible with paper records. Ideally, EHRs are designed according to widely agreed standards related to content, structure, and electronic messaging alongside the use of an agreed coding system or terminology, as these all help facilitate semantic interoperability.[6]

Data quality is of pivotal importance in healthcare environments and in particular where information is to be shared. Key to the ability to share information is the need for interoperable health records that ideally build upon nationally and internationally agreed standards for record structure, coding terminologies, and messaging protocols. Standards on structure and content of information add an important dimension to the value of information, provide its context so that the precise meaning of the information is preserved when information is transmitted from one computer to another, and support semantic interoperability.[7–9] Such standards need to be meaningful and relevant to service users for use throughout the care process and should be developed with both clinician and patient input and leadership.[10–12] A fine balance between being able to express the idiosyncrasies of the individual person and a structured format needs to be achieved.[13] In the context of person-centered care, not only medical aspects but also health-related aspects, such as social, functional, and financial status, have been identified as being important for documentation[14] and are essential for supporting people with chronic health conditions in the self-management of their health and related needs.[15,16]

The need for documenting not only disease-specific information but also psychosocial aspects in health has also been expressed by the World Health Organization (WHO) in the conceptualization of functioning in the International Classification of Functioning, Disability, and Health (ICF).[17] Functioning is an umbrella term and refers to the interaction of a health condition and its attributes with what people do in their daily lives. It includes contextual factors, such as availability and access to health services, support of informal and formal caregivers, and personal lifestyle factors and traits.[18,19] The ICF is complementary to the International Classification of Diseases (ICD) and contains an exhaustive and mutually exclusive set of more than 1,450 categories to serve as a unified and consistent standard language of human functioning.

A systematic review has shown that while the ICF is accepted as a conceptual and terminological standard, its implementation into EHRs is still limited.[20] One reason therefore is its complexity and, thus, the need for a reduced, yet agreed upon number of ICF categories. The challenge is that the ICF categories selected for consideration in a routine clinical setting must be as exhaustive as possible and yet remain practical for daily use.[21] In response to this challenge, more than 25 ICF Core Sets have been developed based on a multiphase international consensus process. Each ICF Core Set constitutes a short list of ICF categories most relevant for patients with a particular health condition.[22] Based on empirical data from people aged over 18 years with the respective health conditions of 22 ICF Core Sets, a minimal generic set of seven ICF categories was identified, the ICF Generic Set or ICF Generic-7, which contains most relevant aspects to describe health and functioning across health conditions and the general population.[23] Additional 23 ICF categories have been identified in particular for clinical populations. This extended set of 30 ICF categories is referred to as the ICF Rehabilitation Set or ICF Generic-30[24] and provides a minimum standard set of functioning aspects to describe functioning across various clinical populations and across the continuum from acute to early post-acute and long-term care (►Table 1). As functioning and disability occurs in interaction with the environment, a minimal set of 12 environmental factors has also been identified for use alongside the ICF Rehabilitation Set.[24] These sets can serve as the minimum standard for consistency in recording functioning information. Though the perspective of individuals living with various health conditions has been integrated in the development[22] and validation of single ICF Core Sets,[25–27] it is unknown whether the ICF Rehabilitation Set reflects most adequately of what is most important from the perspective of individuals living with a chronic health condition. Thus, the ICF Rehabilitation Set is a meaningful starting point to identify chapter headings for EHRs of people with chronic health conditions. In this study, a chapter heading is understood as a label that groups a unit of data stored in a field of a EHR. For the acceptance of new innovative systems, such as the exploitation of EHRs to support person-centered care, the properties of a system need to resonate well with all stakeholders concerned.[28–30]

Objective

The objective of this project was to specify potential chapter headings aligned with the ICF for inclusion in future standards for EHRs based on the perspectives of people living

Table 1 ICF categories contained in ICF generic and rehabilitation set

ICF code	ICF category	ICF Generic Set (also ICF Generic-7)	ICF Rehabilitation Set (also ICF Generic-30)
b130	Energy and drive functions	✔	✔
b134	Sleep functions		✔
b152	Emotional functions	✔	✔
b280	Sensation of pain	✔	✔
b455	Exercise tolerance functions		✔
b620	Urination functions		✔
b640	Sexual functions		✔
b710	Mobility of joint functions		✔
b730	Muscle power functions		✔
d230	Carrying out daily routine	✔	✔
d240	Handling stress and other psychological demands		✔
d410	Changing basic body position		✔
d415	Maintaining a body position		✔
d420	Transferring oneself		✔
d450	Walking	✔	✔
d455	Moving around	✔	✔
d465	Moving around using equipment		✔
d470	Using transportation		✔
d510	Washing oneself		✔
d520	Caring for body parts		✔
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	✔	✔
d920	Recreation and leisure		✔

Abbreviation: ICF, International Classification of Functioning, Disability, and Health.

with chronic health conditions, carers, and professionals. More specifically, the aims were as follows:

1. To develop from the perspective of people living with a chronic health condition standardized chapter headings for EHRs which capture their main concerns of and perspectives on daily life which are relevant for continuous routine care by using the ICF Rehabilitation Set as a starting point.
2. To gain feedback from carers and professionals on chapter headings for EHRs identified from the patients' perspective.
3. To examine whether existing assessment tools can capture the most important aspects of functioning identified in the chapter headings for EHRs.

Methods

A multistage, iterative development process was established including a multimethod design. ►Fig. 1 provides an overview of the design. We opted for iterative rounds to allow first for an open and in-depth discussion in a smaller group (first stage: patient workshop) before gaining feedback from a broader group of patients and carers in a more structured way (second stage: online survey). Since patient and professional bodies are highly relevant stakeholders in the implementation of standards for care, we also wanted to gain their perspective on the proposed chapter headings for EHRs (third stage: online consultation). This three-stage process resulted in a final proposal of standardized chapter headings for EHRs. Finally, a fourth stage examined the extent to which existing assessment tools could capture appropriate information to be recorded under the identified headings.

Patient's Workshop

First we invited people living with chronic health conditions to a workshop held in London, UK. We applied convenience sampling by contacting people from the Royal College of Physicians (RCP) Patient Carer Network, an established network of around 65 patients, carers, and members of the public from across the United Kingdom with a wide range of backgrounds,[31] ages, and varying long-term conditions. All 65 members of the network were invited to attend the workshop. The workshop was structured in two parts, each part lasting approximately 45 minutes, and moderated by two members of the research team (D.W., P.R.). D.W. moderated the discussions and was responsible for the overall coordination of the workshop. P.R. provided content input and guided the discussions. A third member (B.P.) observed the workshop and took notes of the plenary discussions following the small group discussions. The structure and content of the workshop was prepared by these three authors and revised based on the feedback of the whole research team. All three authors had experience in conducting and moderating group discussions (e.g., focus groups, workshops, expert panels). P.R. provided a short background to the study and then introduced the different parts. In the first part, participants were divided into smaller groups and a discussion was held to discuss their priorities, concerns,
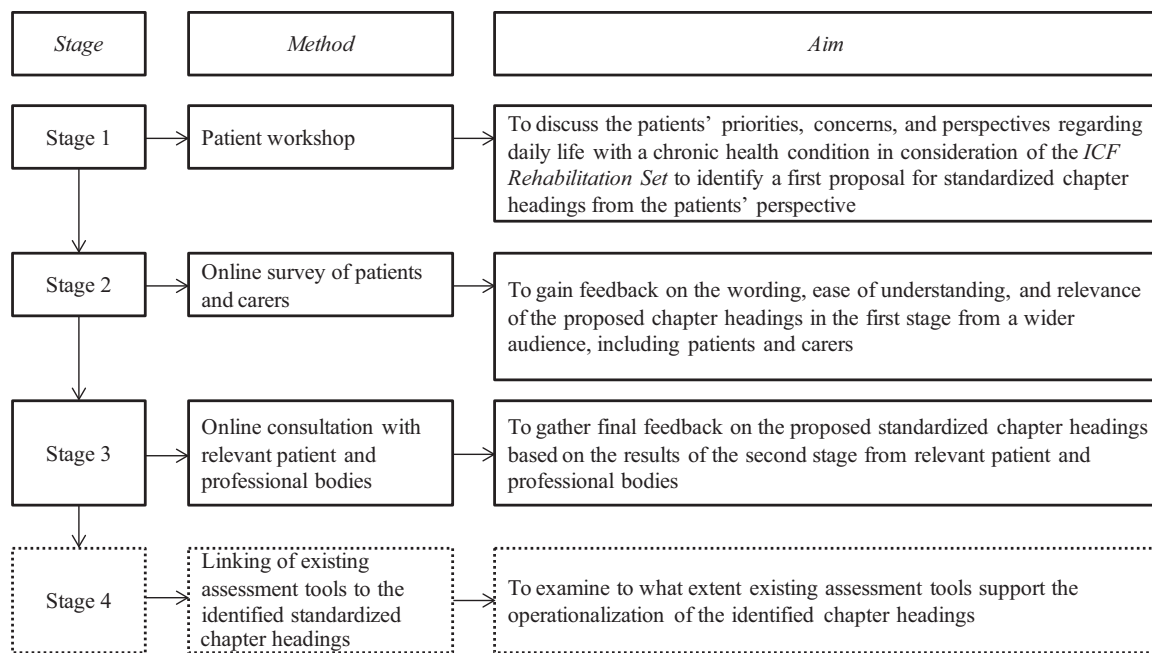
Stage	Method	Aim
Stage 1	Patient workshop	To discuss the patients' priorities, concerns, and perspectives regarding daily life with a chronic health condition in consideration of the *ICF Rehabilitation Set* to identify a first proposal for standardized chapter headings from the patients' perspective
Stage 2	Online survey of patients and carers	To gain feedback on the wording, ease of understanding, and relevance of the proposed chapter headings in the first stage from a wider audience, including patients and carers
Stage 3	Online consultation with relevant patient and professional bodies	To gather final feedback on the proposed standardized chapter headings based on the results of the second stage from relevant patient and professional bodies
Stage 4	Linking of existing assessment tools to the identified standardized chapter headings	To examine to what extent existing assessment tools support the operationalization of the identified chapter headings

Fig. 1 Overview of study design.

and perspectives regarding daily life with chronic health condition. The actual questions are shown in ►**Table 2**. Comments were then fed back to the full group. In the second part, participants were asked to review and

Table 2 Questions asked at each stage of the development process

Stage 1: Patient's workshop
Part 1:
What kind of issues would you like to see recorded in your care records?
What should people know about your abilities/disabilities to tailor your care?
What information would you like to be able to record?
Part 2:
Do the ICF categories cover the domains that matter to you?
Based on your previous discussion, are there any domains missing?
Are there any unnecessary domains?
Is the wording of the headings and descriptions understandable?
Stage 2: Online survey of both patients and carers
Does the heading make sense to you?
Is the description easy to understand?
Does the heading as well as its description cover issues relevant to you?
Please suggest any additional headings, identify duplication or redundancy.
Do you have any general comments?

Abbreviation: ICF, International Classification of Functioning, Disability, and Health.

comment on the functioning aspects proposed in the ICF Rehabilitation Set again in small groups, and to discuss how well these matched with their earlier thoughts. The ICF Rehabilitation Set was chosen as it is supposed to contain the most relevant aspects to describe functioning in people with various health conditions along the continuum of care.[24] The smaller groups were asked to organize themselves with the only request to nominate one person who reports back to the full group. Thematic content analysis was conducted from the detailed notes taken during the workshop and a first draft of proposed chapter headings for EHRs was developed.

Online Survey of Both Patients and Carers

To overcome a potential selection bias introduced through the convenience sampling in the first stage, for example, only people who are already in the RCP Patient Carer Network were invited to the workshop, we conducted a national online survey in the second stage. We recruited potential participants via existing contacts and networks of Health Informatics Unit at the Royal College of Physicians, including the RCP Patient Carer Network, as well as via social media advertising, patient organizations, and contacts of the research team. Patients and carers were invited to complete an online survey via SurveyMonkey which was open for 5 weeks (December 2014 to January 2015). Participants were asked basic sociodemographic questions and to indicate a health condition; only survey responses of persons indicating a health condition were included in the further analysis. Furthermore, they were provided with the first proposal of standardized chapter headings for EHRs as identified in the first stage and asked structured questions to provide feedback on the wording, ease of understanding, and relevance of the proposed headings to them. Each heading was listed and participants were asked to respond

to the questions detailed in ►Table 2. Participants were given three response choices: Yes; No; Don't know. Blank answers were treated as missing values. Descriptive statistics were used to analyze the results of the structured questions, and thematic content analysis for the open questions. Descriptive statistics were calculated in Microsoft Excel, and thematic content analysis was conducted in Microsoft Word. A new item was added if the thematic content analysis revealed a theme based on the feedback of a considerable number of participants. If concepts only appeared sporadically, they were not merged into a theme and, subsequently, did also not translate into an item. Based on the findings of the online survey, a second version of the proposed headings was drafted first by two researchers and then finalized based on the feedback of the whole research team.

Online Consultation with Relevant Patient and Professional Bodies

The revised chapter headings for EHRs, based on the online survey, were sent out in the third and final stage to relevant patients and professional bodies to gather final feedback on the proposed list. Forty-three relevant patients and professional body stakeholder groups were identified from the RCP Health Informatics Unit communications network. These bodies represented doctors, nurses, health and social care professionals, and patient groups from across the United Kingdom. They received the list of proposed chapter headings for EHRs and their descriptions via e-mail and were asked to provide feedback on the comprehensiveness of the proposed headings, their suitability, and value for clinical practice based on open-ended questions. As in the second stage, thematic content analysis was applied for analysis. The feedback was reviewed by the entire multidisciplinary research team and incorporated into the final revision of the headings. The final list of chapter headings for EHRs was then mapped back to the ICF using the latest version of the ICF Linking Rules,[32] a method developed to link systematically existing information to the ICF.

Linking of Existing Data Collection Tools to the Identified Chapter Headings for EHRs

Chapter headings for EHRs specify the high-level information domains for patient records but do not specify where that information should be drawn from or how it should be expressed. We investigated two assessment tools, a patient-reported outcome measure and a clinician-administered assessment instrument, to assess their suitability. We selected both to demonstrate potential methods for populating the headings based on existing models for data collection. As a patient-reported outcome measure, we selected WHODAS 2.0, which is the second version of the WHO Disability Assessment Schedule. It is a generic instrument to be used in both general and clinical populations, and is valid across age groups and cultures.[33,34] As a clinically administered assessment instrument, we opted for interRAI, which is a widely used assessment system for monitoring functioning in people with chronic health conditions over time and across care settings.

The interRAI assessment system consists of item sets for use across populations and care settings, but also specific item sets tailored toward particular clinical populations and care settings to generate data for use in care planning and resource allocation, reimbursement, as well as quality improvement and evaluation.[35] Both WHODAS 2.0 and interRAI have been shown in previous research to capture relevant aspects covered in the ICF.[33,36] The ICF Linking Rules,[32] as in the third stage, were applied to identify items that could assist in the collection of relevant information for the identified chapter headings for EHRs. For WHODAS 2.0, all items were linked initially to the ICF. Subsequently, items were linked to the identified chapter headings for EHRs through the ICF categories specified in the third stage. Since interRAI is an assessment system, the research team consulted with interRAI experts to identify parts of the assessment system that match broadly with the domains identified as being important to people with chronic health conditions. Subsequently, the identified parts of the assessment system were linked to the ICF and checked for concordance with the chapter headings for EHRs using the same method applied for WHODAS 2.0 items. This procedure was considered appropriate by the entire research team as the aim was to identify whether existing tools, WHODAS 2.0 and interRAI, allow operationalization of the identified chapter headings for EHRs and not whether these existing tools can be linked to the ICF in general.

Results

This study identified 16 chapter headings for EHRs that most completely capture the breadth of issues highlighted as being important by people living with a chronic health condition. An overview of the results is presented in ►Fig. 2.

Patient Workshop

Eight people (five women, three men) with varying health conditions (including diabetes, endocrine disorders, kidney disorders, arthritis, thyroid disorders, and ulcerative colitis) participated in this workshop. The key themes that participants named as being important in their care included issues related to organizational aspects related to their care, such as being able to access and contribute to their health record and being involved in shared decision-making processes regarding their health and treatment. With respect to what information should be captured systematically and continuously, personal aspects (i.e., family context, personal care priorities and preferences, and communication needs), health condition–specific aspects (i.e., symptoms most rated as important by patients), and treatment-related aspects (i.e., information about adverse effects of medication and interactions among various drugs) were named. While all of the elements of the ICF Rehabilitation Set were considered as relevant, participants recommended the grouping of some of the categories together into larger information domains. For example, the ICF categories related to walking, moving around, moving around using equipment, and using transportation from the ICF Chapter d4 Mobility were all subsumed under the heading "Mobility
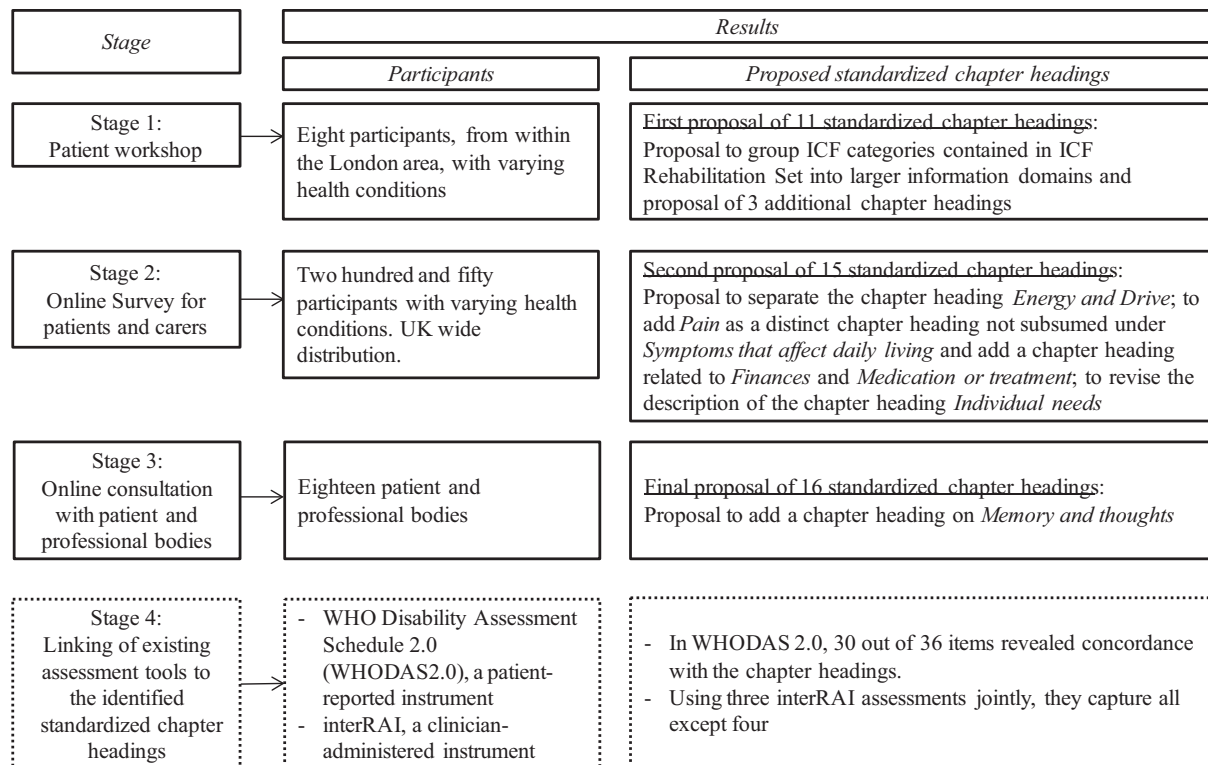
Stage	Results	
	Participants	*Proposed standardized chapter headings*
Stage 1: Patient workshop	Eight participants, from within the London area, with varying health conditions	First proposal of 11 standardized chapter headings: Proposal to group ICF categories contained in ICF Rehabilitation Set into larger information domains and proposal of 3 additional chapter headings
Stage 2: Online Survey for patients and carers	Two hundred and fifty participants with varying health conditions. UK wide distribution.	Second proposal of 15 standardized chapter headings: Proposal to separate the chapter heading *Energy and Drive*; to add *Pain* as a distinct chapter heading not subsumed under *Symptoms that affect daily living* and add a chapter heading related to *Finances* and *Medication or treatment*; to revise the description of the chapter heading *Individual needs*
Stage 3: Online consultation with patient and professional bodies	Eighteen patient and professional bodies	Final proposal of 16 standardized chapter headings: Proposal to add a chapter heading on *Memory and thoughts*
Stage 4: Linking of existing assessment tools to the identified standardized chapter headings	- WHO Disability Assessment Schedule 2.0 (WHODAS2.0), a patient-reported instrument - interRAI, a clinician-administered instrument	- In WHODAS 2.0, 30 out of 36 items revealed concordance with the chapter headings. - Using three interRAI assessments jointly, they capture all except four

Fig. 2 Overview of results.

and movement." They argued that mobility and movement is relevant to most patients with chronic conditions, while more detailed ICF categories separated functioning aspects into a level of detail not relevant across various health conditions. Additional domains were identified, mainly related to the care process. Examples of the additional domains include "Understanding of health issues," "Treatment," and "Care priorities and goals." Based on the themes identified by participants of this workshop, 11 chapter headings for EHRs were included in the first draft as outlined in columns 1 and 2 of ►Table 3.

Online Survey of Both Patients and Carers
The survey was completed by 250 participants with varying health conditions, including diseases of the respiratory system (i.e., asthma, chronic obstructive pulmonary disease, cystic fibrosis), diseases of the circulatory system, endocrine diseases (i.e., diabetes), diseases of organ systems (i.e., liver disease, kidney disease), musculoskeletal disorders (i.e., arthritis), neurological diseases (i.e., multiple sclerosis, Huntington's disease, Parkinson's disease, stroke), neurodevelopmental disorders (i.e., learning disabilities), mental disorders, as well as other conditions (i.e., HIV, skin disorders, and sensory impairments). More than half of the participants (57%) were female; the median age was 49 years (range: 1–95). A small group (7%) was reported to be from a minority ethnic group. Most participants rated the impact of their chronic health condition as moderate to high (92%). Out of the 250 participants, 138 (55%) were patients, 93 (37%) were carers, 19 (8%) considered themselves both patients and carers.

The analysis of the structured questions revealed that most headings were considered as relevant and understandable by the majority of participants (more than 85%). Self-care, mobility, individual needs, and care priorities were rated with lower relevancy by participants, though still by more than 60%. Participants' responses to the relevancy and understandability of the proposed chapter headings for EHRs are detailed in ►Table 4.

In addition to the listed chapter headings for EHRs, participants frequently emphasized in response to the open question some duplication or redundancy issues and suggested additional headings. For instance, energy and drive should be separated as issues related to energy are more physical in nature, and to drive more emotional. Another recommendation was to add *Pain* as a distinct chapter heading not subsumed under *Symptoms that affect daily living.* Driving and ability to use public transport were named as being important aspects to be added. With respect to participation in major life areas, participants felt that education as well as finances need to be added. Aspects related to medication and treatment, including what drug to be taken when as well as their adverse effects and interactions with other medications, were also commonly cited by patients. The chapter heading on "needs" was considered as highly relevant and further revisions of the description were suggested so that it reflects better the need for capturing personal information to provide individualized care. Based on this feedback, a revised list of 15 chapter headings for EHRs was drafted as outlined in columns 3 and 4 of ►Table 3.

Table 3 Development of standardized chapter headings for EHRs across the three stages

1st proposal of standardized chapter headings for EHRs (N = 11)		2nd proposal of standardized chapter headings for EHRs (N = 15)		Final proposal of standardized chapter headings for EHRs (N = 16)	
Heading	Descriptions	Heading	Descriptions	Heading	Descriptions
Emotions and mood	Refers to your mood and emotions that affect your daily life or your ability to deal with other health issues. E.g., depression, worry, stress	Emotions and mood	Refers to your mood and emotions that affect your daily life or your ability to deal with other health issues. E.g., depression, anxiety, worry, stress, anger, frustrations	Emotions, mood, and stress	Refers to mood and emotions that affect your daily life or ability to deal with other health issues. E.g., depression, anxiety, worry, stress, anger, frustration
Energy and drive	Refers to your levels of motivation, drive, and energy affecting your daily life or your ability to deal with other health issues. E.g., fatigue, restlessness	Motivation and drive	Refers to your levels of motivation and drive affecting your daily life or your ability to deal with health issues	Motivation and drive	Refers to levels of motivation and drive that affect daily life or ability to deal with health issues
		Energy	Refers to your energy levels affecting your daily life or your 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 you have with going to sleep, disturbed sleep patterns, early wakening, or daytime sleepiness affecting your daily life	Sleep	Refers to problems you have with going to sleep, disturbed sleep patterns, early wakening, or daytime sleepiness affecting your daily life	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 daily living	Refers to symptoms or issues that affect your daily life. Also include changes over time. E.g., pain, itchiness, cough	Symptoms that affect daily living	Refers to symptoms that you experience that affect your daily life. Include those with the biggest impact on you. Includes physical and nonphysical symptoms	Symptoms that affect daily living	Refers to important or significant symptoms that affect daily life. E.g., itchiness, cough, confusion
		Pain	Refers to long-term or severe pain that affects your life. This could include a description of the pain, how you manage it, and	Pain	Refers to long-term or severe pain affecting daily life

Table 3 (*Continued*)

1st proposal of standardized chapter headings for EHRs (*N* = 11)		2nd proposal of standardized chapter headings for EHRs (*N* = 15)		Final proposal of standardized chapter headings for EHRs (*N* = 16)	
Heading	Descriptions	Heading	Descriptions	Heading	Descriptions
			what it limits or stops you doing		
Self-care	Refers to problems you have caring for yourself which in turn affects your daily life. E.g., washing yourself, using the toilet, eating ,and drinking. Include details of any help or equipment you need or use	Self-care	Refers to problems you have caring for yourself that affect your daily life. E.g., washing yourself, using the toilet, eating, and drinking. Include details of any help or equipment you need or use	Personal care	Refers to problems with caring for yourself that affect daily life. E. g., washing yourself, using the toilet, eating, and drinking. Also covers help or equipment needed for personal care
Mobility and movement	Refers to problems you have in moving around, both inside and outside which affect your daily life. Include details of any help or equipment you need or use. E.g., moving from a bed to a chair, walking, jogging	Mobility and movement	Refers to problems you have in moving around, both inside and outside that 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	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 life	Refers to your ability to engage in your social life, with friends, relatives or colleagues that impacts on your daily life. This can include intimate relationships with a partner or spouse.	Social activities	Refers to your ability to engage in your social life, with friends, relatives or colleagues that impacts on your daily life. This can include intimate relationships with a partner or spouse.	Social activities	Refers to problems engaging socially with friends, relatives, or colleagues and romantic or sexual relationships
Work and leisure	Refers to problems you encounter in undertaking paid or voluntary work and leisure activities that affect your daily life. This includes housework, managing your finances, shopping etc.	Work, education and leisure	Refers to problems you encounter in undertaking paid or voluntary work, participating in education and leisure activities that affects your daily life. This includes housework, managing your finances, shopping etc.	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	Finance	Refers to finance or money issues that affect daily life

(*Continued*)

Table 3 (*Continued*)

1st proposal of standardized chapter headings for EHRs (N = 11)		2nd proposal of standardized chapter headings for EHRs (N = 15)		Final proposal of standardized chapter headings for EHRs (N = 16)	
Heading	**Descriptions**	**Heading**	**Descriptions**	**Heading**	**Descriptions**
		Medication or treatments	Refers to issues with medication, treatment, adverse effects, or special monitoring that affect daily life	Medication or treatments	Refers to issues with medication, treatment, adverse effects, or special monitoring that affect daily life
Understanding of your health issues and treatment	Refers to how well you understand your health problems, treatment, and care. Include any particular concerns or questions you may have	Understanding of your health issues and treatment	Refers to how well you understand your health problems, treatment, and care. Include any particular concerns or questions you may have	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
Individual needs	Refers to information you think is important that people involved in your care know. E.g., accessibility or communication requirements	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	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 your current and future care priorities and goals. Include any information relevant to your care plan	Care priorities and goals	Refers to your current and future care priorities and goals. Include any information relevant to your care plan	Care priorities and goals	Refers to a person's current and future care priorities and goals and could include details of a personalized care plan

Abbreviation: EHRs, electronic health records.

Online Consultation with Relevant Patient and Professional Bodies

Representatives of 18 of the 43 invited patient and professional bodies provided feedback via e-mail on the refined chapter headings for EHRs.[a] The overall feedback was that having standards for chapter headings for EHRs in health records is very important. The addition of headings covering cognitive and memory functions was suggested along with some minor language adjustments to clarify the meaning of some headings. Additionally feedback identified complementary efforts by other groups (in particular rehabilitation medicine and occupational therapy) and highlighted the importance of alignment with other efforts, particularly during future implementation and use of the proposed headings. The final list of chapter headings for EHRs is presented in the fifth and sixth columns of ►**Table 3**. The linking of the final chapter headings for EHRs to the ICF is displayed in ►**Table 5**. ICF categories which are not part of the ICF Rehabilitation Set—b144 Memory functions, b160 Thought functions, and d860-d879 Economic life—are contained in the final chapter headings for EHRs. Four ICF categories from the body functions—b620 Urination functions, b640 Sexual functions, b710 Mobility of joint functions, and b730 Muscle power functions—were not

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[a] Listed in alphabetical order: British Cardiovascular Society, British Kidney Patient Association, British Psychological Society, British Society of Rehabilitation Medicine, College of Occupational Therapists, Croydon Health Services NHS Trust, Lancashire Care NHS Foundation Trust, North Derbyshire Clinical Commissioning Group, Nottingham University Hospitals NHS Trust, Renal Association, Royal College of General Practitioners, Royal College of Physicians Patient and Carer Network, Royal Devon and Exeter Foundation NHS Trust, Royal Free London NHS Foundation Trust, Sussex Partnership NHS Foundation Trust, University Hospitals Birmingham NHS Foundation Trust, and Yorkshire & Humber Academic Health Science Network.

Table 4 Summary of feedback from survey on relevancy and understandability of first draft of chapter headings

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

referenced in any of the consultation stages and do not appear as specific proposed headings. However, the chapter heading "Symptoms that affect your life" is from an ICF linking perspective nonspecific and may capture these aspects. Aspects of d5 Self Care are summarized in the chapter headings for EHRs on this general level (which is equivalent to the chapter level of the ICF) while they are specified on a more detailed classification level in the ICF Rehabilitation Set (including d510 Washing oneself, d520 Caring for body parts, d530 Toileting, d540 Dressing, d550 Eating, d570 Looking after one's health). Similarly, aspects related to mobility are summarized on chapter level (d4) and listed in greater detail in the ICF Rehabilitation Set (including d410 Changing basic body positions, d415 Maintaining a body position, d420 Transferring oneself, d450 Walking, d455 Moving around, d465 Moving around using equipment, d470 Using transportation).

Linking of Existing Data Collection Tools to the Identified Chapter Headings for EHRs

The linking of the WHODAS 2.0 revealed concordance of 30 out of 36 items with the chapter headings for EHRs. The interRAI Home Care, Long-Term Care Facilities, and Community Mental Health assessment were identified as relevant for the present study. When used jointly, the identified interRAI assessments capture all of the proposed chapter headings for EHRs except *Finance, Understanding of your health issues and treatment, Your needs,* and *Care priorities and goals.* The WHODAS 2.0 contains an item linked to *Finance* and *Your needs,* respectively. No item could be identified to operationalize *Understanding of your health issues and treatment,* and *Care priorities and goals;* however, information related to these information domains might be partly derived from information documented under other chapter headings for EHRs, partly from other information sources, and partly from the patient–provider interaction.

The WHODAS 2.0 captures less domains that refer to body functions which reflects the fact that it is an outcome measure intended to assess aspects related to day-to-day functioning across a range of activity and participation domains rather than an assessment of impairment or symptoms.[34] A comprehensive overview of the linking results is provided in ►**Table 6**.

Discussion

This study provides a proposal for 16 chapter headings for EHRs, suitable for inclusion in future standards for EHRs, which will allow the perspectives of people living with chronic health conditions and their carers to be recorded. In their simplest form, these headings may act as an aide memoire during clinical care, serve as structure, and organization for free text encounter notes, and thereby also serve as a checklist and reminder of issues that should be raised with patients, documented, and incorporated into care planning. This kind of impact on clinical documentation practice has already been seen for headings and templates that reflect good practice guidelines.[37–39] Providing patients with a personal health records linked to provider EHRs significantly improves perception of patient-centeredness.[40] Harnessing new technologies and having information on what matters to patients consistently documented in a structured way within EHR systems alongside their core clinical information allows the creation of truly patient-focused records.

EHRs, including their content and management (e.g., access by whom and to what information), need to be developed in a responsive and responsible manner.[41,42] Both from the discussions in the workshop and general comments in the survey, there was feedback from patients that current clinical practice and use of patient-focused clinical information is variable, is frequently omitted, and clinical care is often very medically focused. The proposed

Table 5 Final proposal of standardized chapter headings for EHRs and their alignment with the ICF

Chapter heading	ICF category[a]
Emotions, mood, and stress	b152 Emotional functions
Motivation and drive	b130 Energy and drive functions
Energy	b130 Energy and drive functions
	b455 Exercise tolerance functions
Sleep	b134 Sleep functions
Memory and thoughts	b144 Memory functions b160 Thought functions
Symptoms that affect your life	Not definable
Pain	b280 Sensation of pain
Personal care	d230 Carrying out daily routine d5 Self-care
Mobility and movement	d4 Mobility
Social activities	d7 Interpersonal interactions and relationships
Work, learning, and leisure	d810-d839 Education d840-d859 Employment d920 Recreation and leisure
Finance	d860-d879 Economic life
Medication or treatments	d570 Looking after one's health
Understanding of your health issues and treatment	Not definable
Your needs	
Care priorities and goals	

Abbreviations: EHRs, electronic health records; ICF, International Classification of Functioning, Disability, and Health.
[a]Only the ICF codes of the linking of the main concepts are listed.

chapter headings encompass bodily (e.g., symptoms), mental (e.g., emotions and mood), and physical (e.g., mobility and movement) aspects, as well as aspects of daily (e.g., self-care) and social life (e.g., work and leisure), and personal factors (e.g., individual needs). For most of the headings, more than 80% of survey participants stated that it covers issues relevant to them. Only self-care and mobility and movement reached 64 and 67% of agreement, respectively, followed by individual needs, care priorities and goals, and work and leisure with 74, 75, and 79%, respectively. These findings may reflect the heterogeneity of the participants; for example, depending on the health condition, not all may experience a limitation in certain domains and thus consider it less relevant for them. Alternatively, these domains may reflect issues not yet asked routinely in clinical consultations and thus something that not everyone expects to be discussed with their clinician.

During the final phase of consultation with professional bodies, the need for these chapter headings for EHRs was widely supported, but concerns regarding their practical use were identified. The first issue concerned the lack of time available in clinical encounters to enquire about these issues and then record the information. We believe that future information systems, patient access to shared records, and growth in handheld devices as well as apps all enable a future where patients and carers may be supported in recording and accessing this information themselves. Additionally, it is likely that this information will be built up over time, as part of chronic health management, thus dispersing the time requirement over multiple encounters. The second issue identified was that clinicians were already providing personalized care and that consultation and communication skills taught to professional groups focused on this type of holistic care. While we accept this is the case in many areas, feedback from patients highlighted that this was by no means universal.

Implementation of innovative systems, such as EHRs, builds upon various determinants, including the innovation itself, the adopting organization, the available infrastructure, as well as influences from the external environment including regulatory bodies.[30] With regard to the external environment, the need for interoperable health records based on international terminological standards, such as the ICF, has been emphasized not only by WHO but also by the International Organization for Standardization (ISO).[43] Ensuring that these standards are aligned with international agreed-upon conceptual and terminological standards, such as the ICF, will contribute to the interoperability of EHRs in the future and their utilization to support shared clinical decision making in the clinical encounter.[44] The ICF as one of WHO's reference classifications has been proposed for this purpose and served as the starting point for this project. The comprehensive understanding of individuals' health reflected in the ICF underpins person-centered care which in turn is defined as a quality characteristic for health care services.[45] It is important to highlight that the chapter headings presented here reflect only concepts related to the Activity and Participation component in the ICF. The environment plays a significant role in describing what a person actually can do or does.

It was not the remit of this project to determine how information is gathered, recorded, or used. We have demonstrated with the WHODAS 2.0 and interRAI assessments that suitable assessment tools exist, but further work needs to be done to develop guidance not only on how to implement but also how to operationalize the identified chapter headings for EHRs. There is a wide range of tools available, including generic and health condition–specific tools, setting specific tools (e.g., for acute and post-acute, rehabilitation, and community settings), as well as tools with different administration modes (including self-report, clinician administered, and clinical tests). Many tools have been linked already to the ICF (https://www.icf-research-branch.org/). In determining how information is gathered, it needs to be also defined how information on the influence of the environmental is documented.

Table 6 Illustration of operationalization of chapter headings based on existing data collection tools

Chapter heading	WHODAS 2.0		interRAI			interRAI home care	interRAI long-term care facilities	interRAI community mental health
	Item	Response format	interRAI item	Response format				
Emotions, mood, and stress	D6.5 How much have you been emotionally affected by your health condition	None Mild Moderate Severe Very severe	Indicators for possible depressed, anxious, or sad mood	0 Not present to 3 Exhibited daily in last 3 days		✓	✓	
			Mental state indicators (mood disturbance, anxiety, psychosis, negative symptoms, other indicators)	0 Not present to 3 Exhibited daily in last 3 days				✓
			Self-reported mood	0 Not in last 3 days to 3 Daily in the last 3 days; 8 Person could not (would not) respond		✓	✓	✓
Motivation and drive			Acute change in mental status from person's usual functioning	0 No, 1 Yes		✓		
Energy			Fatigue	None to Unable to commence any normal day-to-day activity		✓	✓	✓
Sleep			Sleep problems	Coded for presence in last 3 days from 0 Not present to 4 Exhibited daily in last 3 days		✓	✓	
			Time asleep during day	0 Awake all or most of the time to 4 Largely asleep or unresponsive			✓	
Memory and thoughts	D1.2 Remembering to do important things?	None Mild Moderate Severe Very severe	Cognitive skills for daily decision making	0 Independent to 4 Severely impaired; 5 No discernable consciousness, coma		✓	✓	✓
Symptoms that affect your life	D6.4 How much time did you spend on your health condition, or its consequences?	None Mild Moderate Severe Very severe	Bladder continence	0 Continent to 5 Incontinent; 8 Did not occur		✓	✓	✓
Pain			Frequency with which person complains or shows evidence of pain	Coded for presence in last 3 days from 0 Not present to 3 Exhibited daily in last 3 days		✓	✓	✓
			Intensity of highest level of pain present	0 No pain to 4 Times when pain is horrible or excruciating		✓	✓	✓

(Continued)

Table 6 (Continued)

Chapter heading	WHODAS 2.0 Item	Response format	interRAI item	Response format	interRAI home care	interRAI long-term care facilities	interRAI community mental health
			Consistency of pain	0 No pain to 3 Constant	✓	✓	✓
			Breakthrough pain	0 No, 1 Yes	✓	✓	
			Pain control	0 No pain issue to 4 Therapeutic regimen followed, but pain control not adequate; 5 No therapeutic regimen being followed for pain; pain not adequately controlled	✓	✓	✓
Personal care	D3.1 Washing your whole body? D3.2. Getting dressed? D3.3 Eating? D3.4 Staying by yourself for a few days?	None Mild Moderate Severe Very severe	Bathing	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	
			Personal hygiene	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	✓
			Toilet use	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	✓
			Dressing upper body	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	
			Dressing lower body	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	
			Eating	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	✓
Mobility and movement	D2.1 Standing for long periods such as 30 min? D2.2 Standing up from sitting down? D2.3 Moving around inside your home? D2.4 Getting out of your home? D2.5 Walking a long distance	None Mild Moderate Severe Very severe	Transfer toilet	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	✓
			Bed mobility	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	
			Walking		✓	✓	

Table 6 (Continued)

Chapter heading	WHODAS 2.0		interRAI				
	Item	Response format	interRAI item	Response format	interRAI home care	interRAI long-term care facilities	interRAI community mental health
	such as a kilometer (or equivalent)?			0 Independent to 6 Total dependence; 8 Activity did not occur			
			Stairs	0 Independent to 6 Total dependence; 8 Activity did not occur	✓		
			Locomotion	0 Independent to 6 Total dependence; 8 Activity did not occur	✓	✓	✓
			Transportation	0 Independent to 6 Total dependence; 8 Activity did not occur	✓		✓
Social activities	D4.1 Dealing with people you do not know? D4.2 Maintaining a friendship? D4.3 Getting along with people who are close to you? D4.4 Making new friends? D4.5 Sexual activities?	None Mild Moderate Severe Very severe	Unsettled relationships	0 No, 1 Yes		✓	✓
			Strengths—Strong and supportive relationship with family	0 No, 1 Yes		✓	✓
			Social relationships	0 Never, 1 More than 30 days ago, to 4 In last 3 days; 8 Unable to determine		✓	✓
			Sexual activity—Reports persistent difficulty	0 No, 1 Yes			✓
Work, learning and leisure	D5.1 Taking care of your household responsibilities? D5.2 Doing most important household tasks well? D5.3 Getting all the household work done that you need to do? D5.4 Getting your household work done as quickly as needed? D5.5 Your day-to-day work/school? D5.6 Doing your most important work/school tasks well? D5.7 Getting all the work done that you need to do? D5.8 Getting your work done as	None Mild Moderate Severe Very severe	Ordinary housework	0 Independent to 6 Total dependence; 8 Activity did not occur	✓		✓
			Employment status	1 Employed, 2 Unemployed—seeking employment, 3 Unemployed—not seeking employment			✓
			Employment arrangements (exclude volunteering)	1 Competitive, 2 Supportive, 3 Vocational, 4 NA			✓

(Continued)

Table 6 (Continued)

Chapter heading	WHODAS 2.0		interRAI		interRAI home care	interRAI long-term care facilities	interRAI community mental health
	Item	Response format	interRAI item	Response format			
	quickly as needed? D6.1 How much of a problem did you have in joining in community activities (e.g., festivities, religious, or other activities) in the same way as anyone else can? D6.4 How much of a problem did you have living with dignity because of the attitudes and actions of others? D6.8 How much of a problem did you have in doing things by yourself for relaxation or pleasure?						
Finance	D6.6 How much has your health been a drain on the financial resources of you or your family?	None Mild Moderate Severe Very severe					
Medication or treatments			Managing medications	0 Independent to 6 Total dependence; 8 Activity did not occur	✓		✓
Understanding of your health issues and treatment							
Your needs	D6.2 How much of a problem did you have because of barriers or hindrances in the world around you?	None Mild Moderate Severe Very severe					
Care priorities and goals							

Once record systems are available which function interoperable, analytical tools can be integrated into routine health care. For instance, interventions can be allocated tailored to the specific health and related issues of a person in need of services through risk stratification and predictive-modeling algorithms.[46] Work and communication flows can be easily coordinated based on aspects most relevant to patients, which is of great value particularly where people receive care from various professionals across many settings. Additionally, compliance with organizational processes and their outcomes can be audited.[47] Changes in how we interact with patients including information gathering before traditional consultations,[48] embracing new tools for communication with patients, and allowing patients greater input to their clinical records further add to the richness of clinical information available.[49] Nevertheless, future work is required to support the implementation of the headings within electronic records. The proposed chapter headings need to be integrated into an information model necessary to enable the technical architecture that will support standardized messaging and sharing of information alongside integration with existing records. Such work is ideally done within an open-source environment to facilitate widespread adoption and use of the headings.

The methods applied in this study have strengths but also bear some limitations. Our consultation and engagement with patients and carers, while wide reaching, could not capture all possible opinions and experiences. We opted for a workshop design with a convenience sample which restricted the number of participants. The subsequent survey allowed us to reach out more widely. Since we opted for a social media communication strategy in addition to sending the survey invitation to existing networks, it is not possible to estimate the exact response rate. With responses from people related to neurological, neurodevelopmental, and musculoskeletal health condition groups as well as diseases related to the circulatory, respiratory, and endocrine system, mental disorders, and other health conditions, we were able to reach out to a heterogeneous group. While the results indicate overlap with adult and pediatric care, the suitability of the identified chapter headings for EHRs for pediatric care requires much more detailed work and was beyond the scope of our project. We also note that our methods for engagement favored a patient and carer group with access to e-mail and social media. Future work will need to consider how to engage with hard to reach groups not included here, including ethnic minorities which were underrepresented in this study. This project was conducted by a research team with an expertise in health informatics, including EHRs and interoperability, international classifications, in particular the ICF, and clinical management, including the utility of standardized tools for enhancing clinical decision making. The team consisted of a working and steering group. The working group consulted on a monthly basis with the steering group to review the progress and gain feedback on the results. This mode of operation allowed building upon the interdisciplinary and wide expertise of the group, yet remaining reflective on the scope of the project and its methodological quality.

Conclusion

The patient perspective headings that we propose provide a high level structure for the standardized recording, use, and sharing of information rated as important by patients with long-term health problems. These headings build upon the perspective of people living with chronic health conditions, carers, and professionals. We have exemplified with two existing data collection tools that they capture relevant aspects of functioning to be documented according to the identified chapter headings for EHRs. Further challenges exist on how to implement these headings into EHR and to integrate the proposed standard into a technical architecture necessary for the standardized messaging and sharing of information. It is essential that patient and professional engagement is part of this ongoing development.

Clinical Relevance Statement

The headings identified in this study represent some of the vital elements required for inclusion in person-centered clinical models. The results suggest that to meet the needs of patients, carers, and clinical professionals, the development of semantically interoperable, structured, EHRs must include these elements.

Multiple Choice Question

When implementing standardized headings for electronic health records, which of the following aspects have been neglected in records built upon the traditional medical model but must receive closer attention in records developed for people living with a chronic health condition?

a. Surgical interventions
b. Medical signs and symptoms
c. Functional, social, and financial status
d. Pharmaceutical treatments

Correct Answer: The corect answer is option c, functional, social and financial status. The traditional medical model focuses on bio-medical issues. In contrast, the bio-psycho-social model as underpinning the ICF stresses the need to give attention also to aspects related to functional, social, and financial status.

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