

## **The ICanFunction mHealth Solution (mICF): A project bringing equity to health and social care within a person-centered approach**

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### **Abstract**

*Background:* Systems for health must evolve to become learning systems, facilitating the implementation of Universal Health Coverage, the integration of social and health services, and the democratization of health data to put service users at the center.

*Objectives:* The ICanFunction mHealth Solution (mICF) is described and its application explored. mICF's primary aim is to empower service users to achieve health equity through communication of their needs and aspirations with service providers. Furthermore, mICF has potential to become a tool to enhance interprofessional teamwork and to provide meaningful data for policy development to attain health equity.

*Methods:* An international collaborative defined the project's scope, as well as the content and technology towards a viable prototype. The project development is described since conception: a comprehensive needs assessment, first prototype, and future steps.

*Results:* Responses (n=1,191) from 32 countries informed mICF's scope, content, and prototype design. A linking platform, connecting natural language to the terms of the International Classification of Functioning, Disability and Health (ICF), was developed and a first minimum viable product was tested.

*Conclusion:* mICF could facilitate a shift from disease-focused, institution-based, biomedical service provision to collaborative, person-centered, community-based services with a bio-psycho-social-spiritual approach. mICF should contribute information for more tailored interventions towards Universal Health Coverage through active participation of service users.

### **Introduction**

Globally, persons with disabilities comprise the largest minority,<sup>1</sup> and they often experience inequities in the management of their ongoing and chronic health needs due to health systems being designed for acute care and lacking integration with the other systems of care.<sup>2,3</sup> By establishing an internet-based platform, persons with disabilities will be able to describe their functioning and their specific needs. By doing so they can make an impact on the management of their health, both at an individual and population level. Against this background, health equity is primarily understood as the principle that individuals who have their own specific healthcare needs, influenced by their circumstances, should be treated with person-centered care according to their level of need.<sup>3</sup>

We present the theoretical background, conceptualization, and first stages of a global project that is developing the ICanFunction mHealth Solution (mICF). The mICF is proposed as a solution facilitating person-centered action on a complex set of factors and determinants that

are conceptualized in the bio-psycho-social-spiritual model of health that defines the functioning of people in their contexts.<sup>4</sup>

The aim for *mICF* is to serve as a technical catalyst for instructional (educational) and institutional (service) reforms in the health, social, and education sectors by empowering persons (e.g., those with disabilities and chronic health conditions) to play a pivotal role in achieving health equity. This innovative solution includes a mobile application run on a portable device and a big data analysis source housed in the cloud. It is based on the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF)<sup>4</sup> as a framework and classification for information management. The ICF conceptualizes a person's level of functioning as a dynamic interaction between their health conditions in a broad perspective by including contextual factors (personal and environmental); e.g., whether the disability is experienced as the loss of a small proportion of speed or agility in an elite athlete, or the impact of working conditions on the length of time sitting in an office worker with low back pain, or the diverse and profound restrictions and limitations in functioning associated with multiple sclerosis or blindness in different physical and social environments. At its core, ICF offers a new perspective for describing and understanding a person's lived experience of health.<sup>5</sup>

## **Background**

### *Health inequities and persons with disabilities and chronic conditions*

Seven decades after signing the Universal Declaration of Human Rights and more than a decade after the ratification of the United Nations Convention on the Rights of People with Disabilities, the global challenge to improve the health and well-being of populations, including persons with disabilities, continues. Inequities in health outcomes between persons with disabilities and the general population are widespread, persistent, unnecessary and unjust, and tackling them should be a high priority at all levels of governance.<sup>6</sup>

Inequities do not only refer to unequal access to healthcare or the distribution of funds, but also to the way the needs of individuals are understood by health and social care professionals, and how – based on this understanding – care is delivered to different populations. Health systems, designed centuries ago for the care and treatment of acute health conditions, do not address well the important aspects of functioning in a broad perspective when caring for people with disabilities and chronic conditions.<sup>7</sup>

Generally, clinical practice is still based on the biomedical model, with a focus on the underlying pathology and the use of tools and skills to establish a diagnosis and prescribe appropriate treatments.<sup>8</sup> This creates an artificial divide between clinical practice and factors that influence the health and functioning of a person with a health condition(s) in their context, some of which are referred to as social determinants of health and self-perceived health. Self-perceived health is a presumptive concept of all relevant health aspects, including social and environmental aspects. Therefore, it may contain aspects that are clinically difficult to measure. Self-perceived health is a strong predictor of somatic functions, participation, morbidity and mortality. Research has demonstrated that patients with chronic disease and comorbid conditions have a significantly poorer self-perceived health status.<sup>9–14</sup>

Julio Frenk, et al. warn against persisting on the linear, reductionist biomedical approaches in the training and practice of the health workforce as it perpetuates these inequities.<sup>15</sup> They challenge the status quo of healthcare models that sustain sub-specialization and the silos in which different health and social workforces are trained and practice. Health workers taking care of the “biomedical” and social workers of the “psychosocial” dimensions, often results

in what Frenk and colleagues coined as “professional tribalism”. In order to deliver integrated, high-quality person-centered care, collaboration between health and social care workers in interprofessional teams is needed. Reform of the current healthcare systems demands professionals who can collaborate across organizational and professional boundaries.<sup>16</sup>

ICF, with its bio-psycho-social-spiritual model, provides functioning information as a focus in health information systems and a framework to create a common language for better collaboration and interdisciplinary communication. The ICF framework (see Figure 1) demonstrates that any person at any moment of life can have health condition(s) that in a negative environment becomes more or less disabling, making disability the result of that interaction. *mICF*, a global instrument for population health, would like to promote this notion by proposing a broader and inclusive approach for all people, not only those with disabilities.

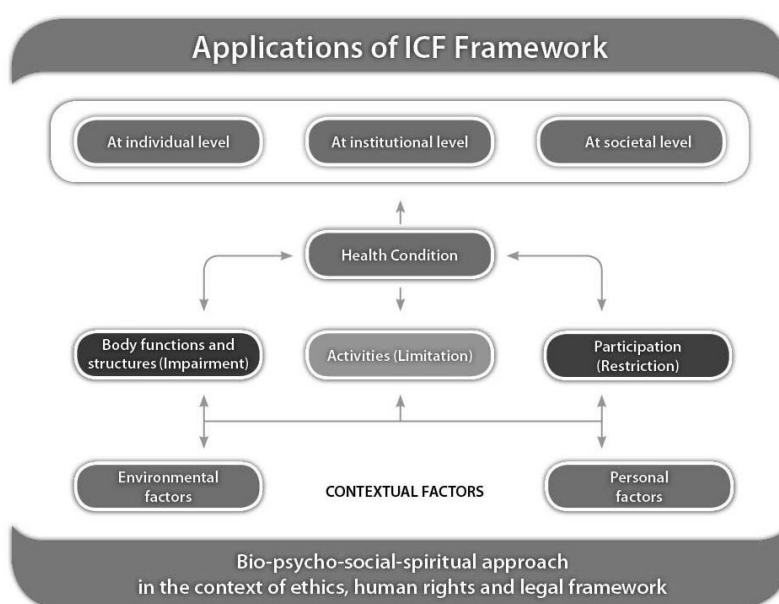


Figure 1. The ICF framework and its applications

### Concepts in Reducing Health Inequity

*Reducing health inequities by transforming education and practice of the health workforce*

A Global Independent Commission<sup>15</sup> on the education of health professionals for the 21<sup>st</sup> century recommends a major shift in health workforce education to equip them to help reach health equity. The Commission argues the health workforce needs to be equipped with the competencies to render person-, family-, and community-centered services. This challenges the current, predominantly biomedical models of workforce education and practice.

The Commission recommends:

- 1) a health workforce with the necessary competencies to collaborate in addressing health needs from a person-centered bio-psycho-social-spiritual perspective (instructional reforms), and
- 2) systems for health that empower service users to share their needs within a bio-psycho-social-spiritual framework (institutional reforms).<sup>15</sup>

The Commission further suggests a multitude of providers to communicate and collaborate effectively to provide integrated services. To reach health equity it will not be enough to just implement Universal Health Coverage (UHC). Jeanette Vega<sup>17</sup> points out that to achieve UHC it will be necessary to overcome “fragmented health systems that focus on final health outcomes related to vertical programs” and to build integrated, effective health systems. To achieve this, radical reforms are needed in the education of the health workforce and in fostering greater interdependence between professions.<sup>18</sup> The use of innovative technology, interprofessional teamwork, task shifting, and task sharing are recommended as catalysts for these reforms.<sup>15</sup>

To achieve the Commission’s recommendations, interprofessional person-centered approaches within integrated community-based services are needed.<sup>15,19</sup> Person-centeredness is a way of addressing health *with* a person, rather than *for* the person. This implies that health and social workers must ensure that services meet persons’ individual needs and aspirations. Also, that service providers and users are equal partners in planning interventions; resulting in shared decision-making, i.e., putting the person, along with their relatives or caregivers, at the center of decisions.<sup>20</sup> It is an approach to health and healthcare which acknowledges the complexity of functioning in relation to the context in which a person is striving to fulfill their life roles and goals. This systemic and holistic approach means that a person should be regarded as a relational and social being, acting within a cultural and political context.<sup>21</sup> Person-centeredness implies a bio-psycho-social approach, which has been expanded also integrating the spiritual perspective that is of utmost importance for health in many cultures.<sup>22</sup> This resonates well with the African concept of *ubuntu*, which views a human being as a person through other persons.<sup>23</sup>

#### *Reducing health inequities through reforming systems for health*

The framework for a broad reform in the conceptualization of health and health services lies in the Convention on the Rights of Persons with Disabilities (CRPD).<sup>24</sup> The World Report on Disability<sup>1</sup> and associated Global Disability Action Plan<sup>6</sup> recognize the importance of health equity, UHC, community-based services, and the need for relevant data about health and functioning. These directives suggest a new role and valuable opportunity for all persons, including those with disabilities and chronic conditions.

A person-centered approach to health and social care requires a health workforce which can collaborate in interprofessional, non-hierarchical settings across the continuum of service provision. This can only be achieved by reforming the systems for health in a way that allows the workforce to practice within a bio-psycho-social-spiritual model and collaborate across professions and disciplines. The use of a common framework and classification, such as the ICF, in interprofessional teams will contribute to the ability to communicate and collaborate within the teams. Shifting from traditional care operating in silos, towards integrated services able to guarantee UHC, requires breaking down barriers that are keeping professional tribal and hierarchical power relations alive.<sup>15</sup>

Reforming systems for health also requires a reconsideration of the role of the “patient”. “Patients” are moving from being passive recipients of “prescriptions” and “being compliant” with the instructions of the health workers, to being service and knowledge users, drivers and partners in a shared approach to services. This requires collaboration, shared decision-making and shared budgets to deliver services where the person is truly at the center.<sup>25</sup>

#### *Reducing health inequities through active participation of service users*

In more equitable systems for health, persons obtain services according to their needs and aspirations. With the technology available, they should be granted the opportunity to actively and securely share the information they identify as relevant for their health and health outcomes. Such technology requires the involvement of users in a co-creation process, empowering them to use self-directed and self-owned health data to inform their own care and by sharing anonymized data to reform systems for health.<sup>26,27</sup> Such technologies should enhance effective communication between persons with health conditions, community health workers, nurses, physicians, rehabilitation professionals, social workers, and other health workers across the continuum of service provision.

The sharing of data about what influences functioning (e.g., access to services; home and work environments; factors that determine quality of life, well-being, and healthy living), facilitates a person-centered and holistic approach to assessment. It will also serve to optimize shared decision-making, collaborative goal-setting, and continuity of care. This could result in the democratization and humanization of health-related data and service provision.<sup>26,27</sup>

#### *Reducing health inequities through capturing reliable and real-time data*

The Centers for Disease Control states in its CDC's Vision for Public Health Surveillance in the 21<sup>st</sup> Century that "with the increasing availability of clinical, insurer, social, and environmental data sets, the immediate challenge is to organize the data into a format that is accessible and useful for epidemiologists, statisticians, and others who might be able to use these data for public health surveillance. Until these data are available in a usable format, interpretation by subject matter experts is impossible and the data will not be useful."<sup>28</sup>

Public administrations need reliable, real-time data to plan and deliver health services, and to address environmental factors influencing participation of individuals and communities. These data are best gathered from the people directly, rather than only from traditional clinical records (i.e., biomedical information like diagnoses, length of hospital stay, etc.) or derived from retrospective surveys and administrative data submitted to central health agencies by frontline service providers. Being retrospective, such data are less useful in predicting holistic health needs. Current data lack timely contextual data to inform where systems for health could be strengthened, to identify barriers for social participation and to monitor accountability. Persons with health conditions – in particular those with disabilities and chronic diseases – and service providers need to understand and communicate in real time so they can become partners in eliminating health and healthcare disparities.<sup>29</sup>

Social media has changed how people communicate and will continue to enable a culture of sharing, peer-to-peer recommendations, and co-production.<sup>30</sup> The common underlying paradigm of social networking is that people are willing to share their knowledge and information for the greater benefit, which may also support health and social systems improvement. The willingness to donate and share anonymized health information is demonstrated by platforms like PatientsLikeMe.com, which have been created to allow people with rare conditions to learn from the experiences of others and generate new scientific advances faster than through the traditional researcher-driven pathways.<sup>31</sup> Furthermore, the emergence of citizen-empowered health data cooperatives (people cooperatively own the data)<sup>26</sup> could allow people who are the subjects of data to take the center stage, with benefits to society from the health-related information, including the financial benefits that aggregation of these data may bring.

These advances in health informatics enable persons to donate de-identified health data for remote analysis<sup>32</sup> using big data analytics; thus enabling a continuously-learning health information system.<sup>33</sup> The National Academies of Sciences, Engineering, and Medicine has coined the term “Learning Healthcare System,” where the experience of each person reflects the best available evidence, and, in turn, adds seamlessly to learning what works best in different circumstances.<sup>33,34</sup> This implies that the sharing of health data with the “system” contributes to a greater public good and the health of other citizens. In order for that to occur it is important that the users have trust in the system.<sup>32</sup> However, current systems focus primarily on biomedical data (e.g., diseases, nutrition or the use of medication). Such data complement new data derived from genetic and metabolic analyses capable of informing what is labelled personalized or precision healthcare.<sup>35</sup>

However, more accurate and contextually relevant information is needed to realize one of the main objectives of so-called precision public health, namely to guarantee UHC and to increase health equity globally.

*“We need to learn what interventions work for whom, data on each individual need to be compared with data from large numbers of people to identify population subgroups likely to respond differently to interventions. In addition, collecting information from large numbers of people is far more informative when diverse people are included from the underlying population. Using data from convenience samples alone (i.e., collected without regard to important factors such as race/ethnicity, age, and sex) can lead to selection bias and unreliable prediction models.”<sup>35</sup>*

Hafen, et al.<sup>26</sup> argue that implementing a citizen-initiated democratic process of storing, owning, and sharing data would efficiently unleash the huge value of personal data and result in the democratization of healthcare and of the global economy at the same time.<sup>26</sup> *mICF* pursues such a citizen-led process to obtain reliable and valid data that conceptualize functioning as a dynamic interaction between a person’s health condition and contextual factors. Such information can be used to inform improvements in systems for health and health workforce education and practice.

## **Project Development**

*ICanFunction mHealth Solution (mICF): Contribute to health equity through active participation of persons with disabilities and chronic conditions*

Building on the aforementioned background, the Functioning and Disability Reference Group (FDRG) of the WHO’s Family of International Classifications (WHO-FIC) Network discussed in 2013 how a person-driven and person-owned mHealth solution could contribute to achieve health equity and support UHC through active participation of persons with health conditions, including persons with disabilities and chronic diseases. There was consensus that an authentic interdisciplinary health agenda goes beyond the traditional “bench to bedside” and that an instrument was needed to capture a person’s individual perspectives, especially as it relates to human functioning as conceptualized by ICF.<sup>4</sup> ICF provides the common language to record, share, and interpret health information to facilitate person-centered service provision and to amalgamate data in real-time to provide a population perspective. This common language is essential in collaborating to address the needs of individuals and communities, to develop effective policies and guidelines, and for ensuring that all people have access to the available benefits.

It is foreseen that *mICF* could contribute to reform systems of health from the bottom up. It will teach the personnel working with persons with disabilities and chronic conditions to have

a broader picture of the determinants of health that impact on functioning. This will also make more evident the gaps of knowledge and the need for interprofessional teamwork. Eventually this can lead to more integrated services being provided according to needs. Driven by service users, *mICF* will utilize a system based on big data analytics to facilitate identifying individual functioning profiles for each user. For service providers the big data analysis will allow to plan for sustainable, personalized, predictive interprofessional healthcare. Figure 2 is a concept map of the theoretical and practical background that supports the development of *mICF*.

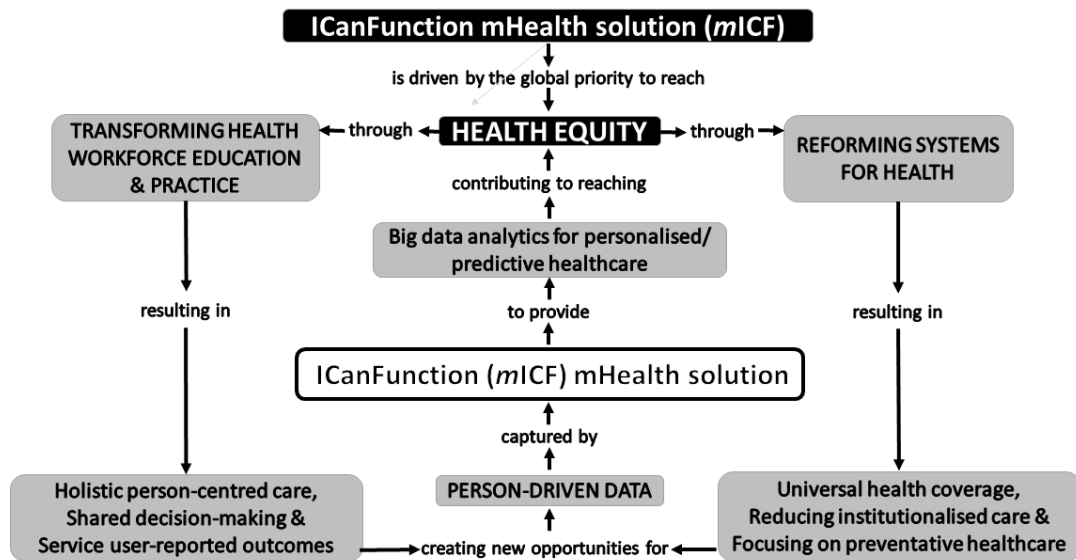


Figure 2. Concept map of the theoretical and practical background that supports the development of *mICF*.

The *mICF* will be an easy to use mHealth solution, providing an integrated care decision-support system that will facilitate more individualized, predictive care by utilizing big data models (see Figure 3). We hypothesize that it will:

- 1) empower persons to achieve health equity through communicating their goals and needs in multiple dimensions of life to service providers,
- 2) offer a common framework and classification for health and social care professionals, both in education and daily practice to enhance interprofessional collaboration,
- 3) provide meaningful real-time data for policy and administration to identify needs of populations to design systems for reaching UHC.

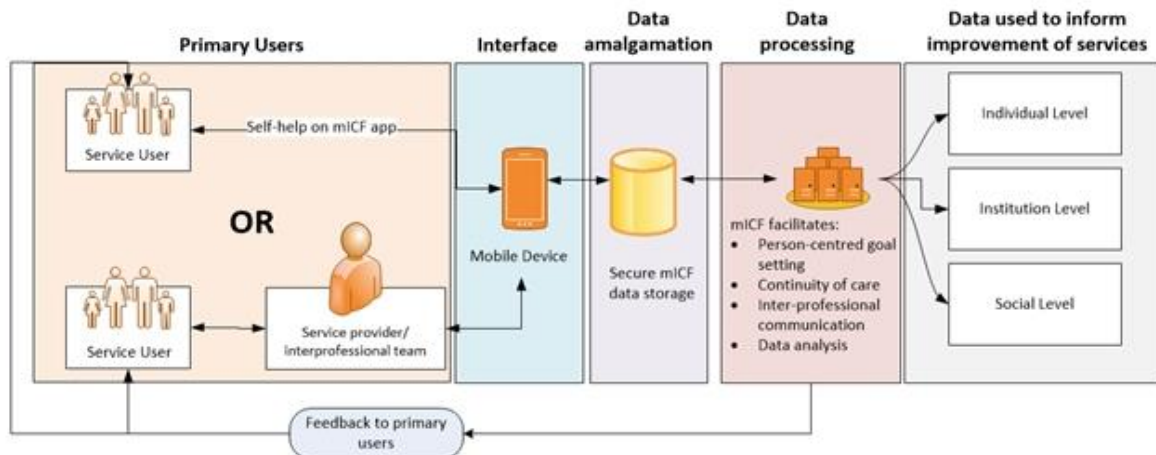


Figure 3. Visualization of the mICF information system.

### **mICF Stages of Development**

#### *Needs Assessment*

Following the FDRG discussion in 2013 the process to develop mICF commenced in 2014 by forming a partnership to collaborate in developing the solution. The International mICF partnership consists of 23 partner organizations from 12 countries. 284 collaborators from 42 countries, expressed interest to participate in the process by responding to a survey and/or signing up on the project website. A facilitation team of nine emerged to coordinate the development of mICF.

The partnership conducted an international survey to understand the needs for a mobile ICF-based application. The survey consisted of 43 questions assessing current practice of use of ICF and characteristics desired in a potential electronic application based on ICF. The survey was translated by native speakers into 14 languages aside from English and distributed worldwide through the network of WHO Collaborating Centers. Respondents were researchers, clinicians, administrators, and service user representatives.

A total of 1,191 responses were received from persons with disabilities, family members, and service providers in 32 countries.<sup>36</sup> There was global consensus to proceed in developing the mICF. The respondents agreed that mICF should enable a person to own, direct, and share functioning and contextual information to facilitate a person-centered bio-psycho-social-spiritual approach to service provision and to act as a catalyst for shared decision-making, common goal setting and the continuity of care. Respondents agreed that mICF should expand the multiple layers about what and where a person “is” by what a person “does.” By taking ICF to the people, instead of being a classification used by professionals and administrators, it should help shift the paradigm from a focus on disease towards a broader bio-psycho-social-spiritual perspective. It was also agreed that persons using mICF should have the option to share and donate their anonymized data to enable big data analytics needed for precision healthcare by incorporating ICF-related information on functioning and contextual factors.

#### *Product Development Tasks*

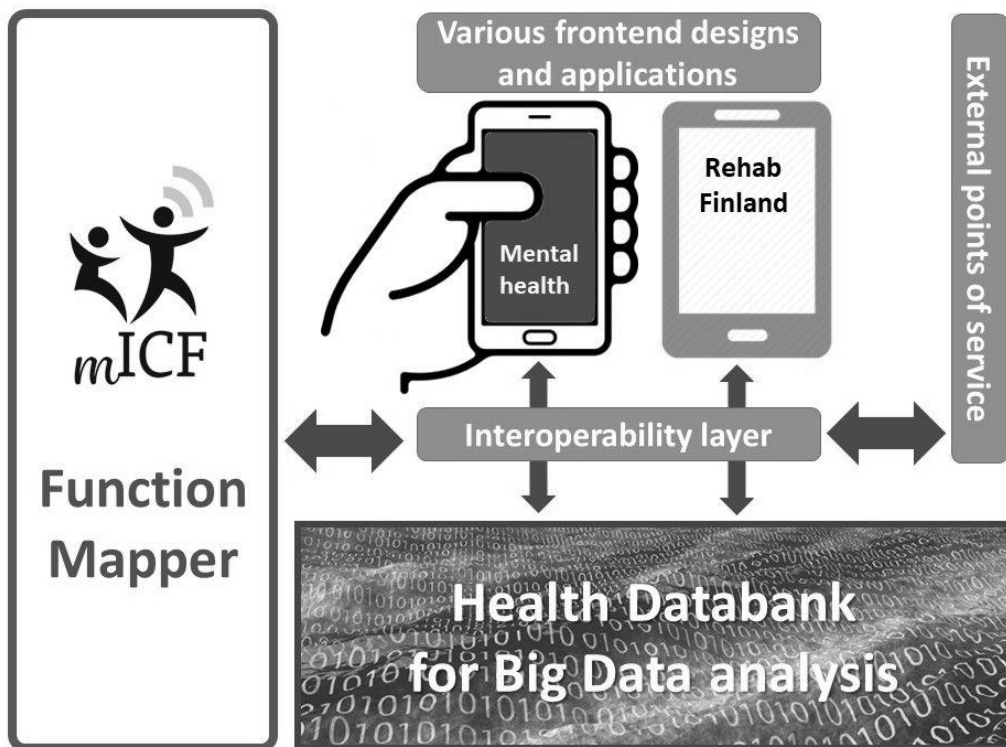
The next step, informed by the survey, was to design the first prototype, and test how it adhered to the requirements identified in the survey. The facilitation team created an overall development and innovation plan organized in several intertwined tasks. The first task consists of the continuous partnership facilitation through a project webpage and social



media. The second task is to define user-friendly ICF-based content for *mICF*, while the third task is the design of a lean minimum viable product to create prototypes in iterative, agile experimentation with end-users. The development is based on service design principles, a philosophy where a product or service is constantly being improved: learning, refining, experimenting, modifying, and then learning again. Only after a proof of concept has been achieved, we will proceed with evaluation and commercializing activities. *mICF* was accepted to the strategic work plan of WHO-FIC in 2015.

### *Product Components*

From a technical perspective, some essential, interconnected elements will need to be developed before data from persons can be transferred to external points of service. Figure 4 depicts the four main interrelated components of the *mICF* ecosystem, namely (1) at the frontend, various graphical user interfaces are needed for various user groups; at the backend, several technical components are required for data amalgamation: (2) a system to convert natural language from the users to “ICF language” enabling structured outputs (dubbed FunctionMapper), (3) the Health Databank for Big Data analysis, and (4) an interoperability layer.



*Figure 4: The components of mICF: various frontend designs and applications, FunctionMapper, Health Databank and the interoperability layer.*

The user interfaces will pull ICF-related lay terms and phrases from the FunctionMapper, saving the user data to the Health Databank. A generic information model that supports structured documentation of functioning and contextual data at the interoperability layer, will organize how the data are organized when saved, pulled back to the user interfaces, or utilized in external points of service.

### *Front-end designs and mobile application*

In February 2016 the first *mICF* proof of concept study started in Finland. The aim of this iterative, agile prototype development was to learn more about user needs and acceptance based on tests and feedback. The project included a co-created design of a mobile interface enabling users to capture ICF-related structured information and to provide a “Functioning Profile” of the user. Adults with physical disabilities, such as stroke and spinal cord injury (n=47), and children with cerebral palsy or communication disabilities (n=11), participated in several workshops to inform the front-end design for adults and children, respectively. To test the application in real-life situations, the adults (short grown people, n=19) downloaded a beta version from App Store or PlayStore to their own mobile phones or tablets and used it for a week. The children (n=11) used it in school. Users were then interviewed to determine their experience.

All users, except one adult, found the prototype easy to use, accepted it, and had a favorable response, because it enabled the description of life situations. They would especially use *mICF* if it could be connected to their health record and to all electronic health and social service systems that they use. Adults would use the application when applying for benefits or before engaging social or health services. They recommended navigation to be improved and bugs fixed. A tutorial, more visually attractive summary reports and the ability to visualize changes over time, were requested. Children were excited to use the application as a tool for their voices to be heard.<sup>37</sup>

#### *FunctionMapper*

FunctionMapper was designed by ICF experts using the Term Editor open source software of the National Institute for Health and Welfare (THL) in Finland. In the first phase of development, FunctionMapper can provide words, prompts, instrument items and goals linked to ICF’s functioning and environmental factors. The terms are mapped manually by experts using established ICF linking rules.<sup>38</sup> The accumulation of the linkages provides useful aid when adding new information.<sup>39</sup> This phase was completed in the first half of 2017. FunctionMapper will convert a person’s natural language concepts and responses to items in assessment instruments and goals related to functioning and environmental factors in every language where *mICF* is to be deployed. FunctionMapper has the ability to support all languages. It will also provide user-friendly terms to *mICF* front-end applications. FunctionMapper will be further developed to map natural language to ICF by automating ICF linking rules. The innovation of using natural language processing (NLP) and linking it to an international classification system (ICF), will eventually enable the opportunity for big data analytics through the Health Databank.<sup>40,41</sup>

#### *Health Databank*

The Health Databank comprises all data aspects related to the system. This includes not only the management of data, but also the analytics. Some of the analytical processes will be automated using machine learning techniques. Such techniques will allow not only the end user to extract data for informed decisions, but also to make provision for outcome predictions.

Distributed computing architectures are now providing platforms for big data analytics, very suitable for the types of data being produced in the *mICF* context. These architectures allow for real-time data interaction (including probing the data in an iterative manner). Being distributed and typically hosted in shared computing resources accessed by the internet, i.e., “cloud computing,” allows very short response times, much less than dealing with data in a centralized warehouse. One of the biggest advantages of modern big data architectures is the fact that they can handle complex content. This is important in the *mICF* context, since we

will be processing both structured and unstructured data. Structured data will be presented as ICF codes, but some interfaces will generate additional (unstructured) data which will inform the analytic (machine learning) models. From a cost perspective, the modern analytic architectures are also more affordable, since they are typically built on hosted services using open source software components.

### *Interoperability layer*

Interoperability (the back-and-forth exchange of data among different points-of-service/systems) is a very important aspect of the system's design. Current international healthcare enterprise standards, such as Health Level Seven International Fast Healthcare Interoperability Resources (HL7 FHIR), will be used to ensure that the various forms of user inputs and structured functioning profiles, as outputs made by the data analytics layer, are modeled and communicated to external points-of-service (for example social services). Internally, the interoperability between the FunctionMapper, mobile interfaces and the data components of the system will follow industry standard communication protocols (i.e., RESTful API) to allow extendable and flexible integration. The Open Application Programming Interface (API) is designed to allow a standard, interoperable and secure internet communication protocol between the mobile interfaces and FunctionMapper.

The generic information model for functioning data supports any data type, produced in any context, by any means or instruments, as well as coding schemes, including the ICF. Using this model, functioning data can be entered as interconnected components with essential metadata. The model also enables structured use of the information in other care-related elements such as care plans.

NLP is an artificial intelligence field where unstructured text data in the form of natural human language will be mined to enable a machine (computer) to understand the meaning of phrases.<sup>42</sup> Once the meaning of a phrase is established with a certain level of confidence, structured data (like ICF codes) can be generated.<sup>43</sup> This type of NLP application is focused on knowledge extraction and can be described as machine-assisted coding of the patient's free text. In our system, we propose a hybrid approach where we use rule-based and statistical NLP models, utilizing machine learning.<sup>43</sup> We can encode the knowledge of an ICF expert as rules (via FunctionMapper). Machine learning will inform the statistical models. Rule-based and statistical approaches are complementary and make sense in a high-data-volume environment.<sup>44</sup> As the learning models, underlying to the NLP, become more sophisticated, the technology starts to seamlessly integrate naturally into the workflows/processes and becomes less evident/visible. Fortunately, since NLP plays such an important role in modern day processes and workflows, it has undergone standardization, most noticeably in the form of Unstructured Information Management Architecture (UIMA), which is open source.<sup>45</sup> Apache Foundation's clinical Text Analysis and Knowledge Extraction System (cTAKES) was built on top of UIMA.

The necessary measures for national privacy and personal data security laws will be put in place to ensure the protection and privacy of person-owned, as well as person-shared data. Standard measures that incorporate not only compliance, but also interoperability, are to be implemented so as not to widen existing population-level inequities.

### **Current Stage of the Project**

The first *mICF* proof of concept study in Finland created the FunctionMapper and the first prototype of a user interface. The rapid prototyping of this *mICF* front-end application was initiated by co-creative service design workshops. The methodologies of lean user experience

(UX) are used in the agile, iterative mock-up prototyping for creating the proof of concept through the active participation of persons with disabilities. The user participants included adults with traumatic brain injury and spinal cord injury from Käpylä Rehabilitation Centre, and children with special communication needs from Valteri school. Four to five voluntary participants participated in each of eight workshops, where two to three researcher-service designers presented the project aim and asked the users to provide their views on how they would accept it, how they would use it, and their ideas about the various features of the mobile application content, outlook, and navigation. The workshops were facilitated using paper mock-ups and open questions. After each workshop, ideas from the users were directly put in use in the next mock-up, illustrated as a graphical interface, to be further iterated in the next workshop with different users. The graphical interface informed the technicians to code prototypes (one for children and another for adults).

The feasibility testing occurred during September and November 2016. Children and adults with disabilities were recruited to use the developed prototypes to describe their life situation before contacting health or social services. They used the application for a week to create a personal functioning profile. Thereafter, summative and formative data were collected in individual interviews. Information quality, system quality, and service quality were measured separately.

Collecting natural language will start with the feasibility testing of a *mICF* prototype front-end application. With the next prototype front-end, users will be able to actively participate by writing, speaking, adding photos, or answering simple questions to describe their life situation.

The *mICF* fulfils web accessibility criteria<sup>46</sup> and a variety of options to add personal information are available and easily adjustable to meet the need of any person, to respond to all requirements for any bodily impairment. Participants will need to consent to share this information to a research database before *mICF* content experts will link the use terms to ICF via FunctionMapper. The linkages will enable the provision of structured functioning profiles to users of a front-end *mICF* application. Linkages need to be easy to be understood and interpreted by the *mICF* user. Co-creation, active participation and feedback from persons with disabilities will assist the service designers to iteratively improve the usability of FunctionMapper and to increase the user experience of frontend application ensuring a person-centered *mICF*.

## **Discussion**

We presented the conceptualization and first stages of a global project that is developing the innovative *mICF*. This solution comprises of a mobile app run on a portable device and a big data analysis part hosted in the cloud. The rationale is based on the understanding that health workforce education and health systems reforms are necessary to achieve health equity, and that reliable real-time data provided by service users can be leveraged to support these reforms. The aim for *mICF* is to serve as a technical catalyst for the needed instructional and institutional reforms of systems of care (health, social, and education) by empowering persons with disabilities and chronic conditions to play a pivotal role in achieving health equity. With access to *mICF*, people will be able to fully describe their life situation beyond solely biomedical parameters for social and health professionals and use it in their needs assessment. The use of the *mICF* offers the possibility for health and social care professionals both in education and daily practice to enhance interprofessional communication and collaboration.

International consensus was that *mICF* should not be just another mobile application that gathers information and does not provide any response. In promoting eHealth literacy according to Kayser, et al.<sup>47</sup> it should be a solution providing knowledge about a person's own health; allowing the user to interact and engage with information having the feeling that using the application is beneficial and feel in control and secure when using the technology.<sup>47</sup>

The current development activities in *mICF* are limited to front-end applications for end-users, FunctionMapper development, and the development of specifications for the functioning information model. The next step is to further develop easy-to use front-ends integrated into professional interfaces to facilitate data integration to care.

There are many steps and pitfalls on the route from person to population and again from population to person. A cooperative model on ownership of health data will be required to avoid such inequities.<sup>48</sup> On the other hand, measurement, classification, and language issues are partially solved by *mICF* through further development of FunctionMapper.

However, we will need to be cautious about ethical implications of person-owned and person-shared data, and of widening population-level inequities. There are two ways in which data will be used. First, in the case of patient-driven data, the patient will control data that they will provide to the service-provider, in other words they only will give permission what information would be shared with service-providers of their choice (i.e., doctor, nurse, social or community health worker) for clinical purposes. The core rationale of the *mICF* is to ensure that patients themselves have effective control of their personal data. Patients therefore must consent to their data being used by different users within an ecosystem of care, with the purpose to improve their own health outcomes, and ultimately quality of life and wellbeing. The disclaimer underscores that risk reduction strategies are in place and that no data will be used in an exploitative manner that would result in personal harm of any person. Second, re-use of anonymized data acquired by the *mICF* will be made possible. Collected anonymized data will be shared and exchanged in the Health Databank. This implies the usage of data for research purposes across nations and disciplinary fields as determined by patients and the contextual focus of project participants. Datasets will be made available within the parameters of ICF guidelines and rules and strictly meet requirements for ethical and responsible conduct. Ethical risk will be managed in cases where the usage and dissemination of data might result in perceived possible harm or personal risk for any patient.

We believe that *mICF* is an encouraging contribution to achieve global health equity and UHC. We expect several benefits from the *mICF*:

- 1) The *mICF* will empower persons with disabilities and chronic conditions or their proxies to become “agents,” in their new role of “directing” the process of care. They will be enabled to describe their functioning and the interaction with environmental barriers and facilitators.
- 2) They will own their data; be free to securely share their information and consult with service providers.
- 3) They will experience improved communication with their service providers to facilitate shared decision-making; exchange information anonymously with other users of *mICF* worldwide and therefore be better informed about their treatment and rehabilitation options.

- 4) Administrators will have anonymized data available for big data analysis. Those results will contribute to improve global public health surveillance, which is the foundation for decision-making in public health. It will empower decision-makers to lead and manage more effectively by providing timely, useful evidence.
- 5) Utilizing big data analytics in real-time, *mICF* will inform all stakeholders about the most pressing health and social issues of a population. This could be described as the democratization of health data, which is necessary to inform person-centered policies and service provision.

*mICF* could catalyze a shift from disease-focused, institution-based, biomedical services to collaborative, person-centered, community-based services with a bio-psycho-social-spiritual approach. It is envisaged that *mICF* will contribute to more tailored interventions leading to more equity as part of the movement towards UHC through active participation of persons with disabilities and chronic conditions.

The *mICF* needs international validation and a broad user base to ensure the democratic and fair use of health data.

### **Conclusion**

A complex set of factors and determinants, conceptualized in the bio-psycho-social-spiritual model of health, defines activities and participation of people in society. The *mICF* is proposed as a solution capable of a person-centered approach in acting on this complexity. Persons will be able to use *mICF* to describe their level of functioning in terms of ability and disability, including their relevant facilitators or barriers. They will also be able to communicate their goals and needs with their healthcare professionals. The *mICF* facilitates interprofessional communication and collaboration for health and social care professionals. Providing a tool for persons with health conditions to express their goals and needs proactively, instead of responding to service providers' inquiry, is an advance in health equity. With appropriate protection measures for the accumulated health data, this valuable resource can be leveraged for health policy-making and better service provision.

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### **Competing Interests**

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