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## Introducing the Adults with Chronic Healthcare Needs (ACHCN) definition and screening instrument: Rationale, supporting evidence and testing

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## ABSTRACT

**Background:** Among working age adults in the United States, there is a large, heterogeneous population that requires ongoing and elevated levels of healthcare and related services. At present, there are conflicting approaches to the definition and measurement of this population in health services research.

**Objective:** An expert panel was convened by the National Institutes of Health with the objective of developing a population-level definition of Adults with Chronic Healthcare Needs (ACHCN). In addition, the panel developed a screening instrument and methods for its use in health surveys to identify and stratify the population consistently.

**Methods:** The panel employed multiple methods over the course of the project, including scoping literature reviews, quantitative analyses from national data sources and cognitive testing.

**Results:** The panel defined the ACHCN population as “Adults (age 18–65) with [1] ongoing physical, cognitive, or mental health conditions or difficulties functioning who [2] need health or related support services of a type or amount beyond that needed by adults of the same sex and similar age.” The screener collects information on chronic health conditions, functional difficulties, and elevated use of or unmet need for healthcare services.

**Conclusions:** Adapted from the Maternal and Child Health Bureau definition that identifies Children with Special Healthcare Needs, aligned with the ACS-6 disability measure, and consistent with the HHS Multiple Chronic Condition Framework, this definition and screener provide the research community with a common denominator for the identification of ACHCN.

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## Introduction

Researchers have grown increasingly concerned with the

proliferation of differing definitions and conflicting estimates of the size, composition, service utilization, quality and costs for high health service users in the United States.<sup>1–4</sup> Various methods have been used to identify these population groups in the US healthcare system, whether on the basis of specific health conditions,<sup>5–7</sup> discreet lists of chronic conditions or comorbidity indices,<sup>4,8–11</sup> the extent of functional or activity limitations and/or disability,<sup>12–14</sup> the degree of service use complexity<sup>15,16</sup> or the economic burden of disease.<sup>17</sup> Various terms referring to these groups

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are currently being popularized in the literature, such as “super-utilizers,”<sup>18</sup> “high need/high cost patients,”<sup>19</sup> or “hot spotters.”<sup>20</sup> The methods used to identify such groups have yielded divergent population estimates because they capture different, if overlapping populations. The result is a cascade of studies, each making scientific claims about the importance of the access, utilization, quality or cost-related problems of people with condition X, disability Y, with or without co-morbidity Z.

Beginning in 2012, the the Rehabilitation Medicine Department at the National Institutes of Health Clinical Center convened an expert measurement panel to better define and measure the population of working age adults with ongoing and elevated needs for healthcare. We endeavored to find a common denominator that could flexibly serve many kinds of health service research studies and to develop meaningful methods to stratify what we knew would be a large and heterogeneous population, many of whom requiring patient-centered, coordinated healthcare. We took our lead from the large body of research conducted on Children with Special Healthcare Needs (CSHCN) where such a measurement approach was already well established.<sup>21–25</sup> That research is characterized by its focus on health consequences and their associated service needs. CSHCN are therefore defined as those “who have or are at increased risk for one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”<sup>22</sup> In the early 2000s, the Child and Adolescent Health Measurement Initiative (CAHMI) initiated work on an adult adaptation of the CSHCN brief screener (the Adults with Special Healthcare Needs Screener, ASHCN), but a formal population definition was not offered. Though the ASHCN screener was documented in an extensive peer-reviewed manual to CMS,<sup>21</sup> with a loss of funding, that work was not published in scientific journals, despite its likely import.

Informed by the previous work conducted by CAHMI, and recognizing how the CSHCN definition and screener formed the basis of dedicated national surveys,<sup>24,25</sup> coordinated service delivery models,<sup>26</sup> and a platform for policy and clinical practice goals,<sup>27–30</sup> our panel pursued a parallel path. In what follows, we propose the formal definition of working age Adults with Chronic Healthcare Needs and present the newly developed screener. We provide the rationale for this instrument, supporting quantitative evidence, and initial results from cognitive testing as well. We conclude with a discussion of the research and health policy contexts, specific applications, and subgroup analyses this screener was designed to, and could potentially, support.

## Methods

### *Panel composition and operation*

The panel was purposefully composed on the basis of their combined expertise in areas of knowledge critically important to this project. Depth and breadth of publication, clinical experience, federal agency involvement and personal lived experience with chronic conditions or disability were among our selection criteria. The panel was convened for ten teleconferences and two face to face meetings over a year and a half. Panelists variously contributed to all associated work products, including scoping literature reviews, a series of secondary data analyses, presentations, publications, and a final report.

### *Scoping literature reviews*

We employed scoping literature review methods in this project. Scoping reviews are most appropriate for broad research questions

that seek to map the main domains and types of knowledge available in a given topical area.<sup>31</sup> All five reviews we conducted were limited to publications made after January 1, 2000 that were written in English and relevant to working-age (18–65) individuals. Searches included pubmed and psycINFO, as well as key journals, relevant websites and bibliographic review of seminal articles, each as recommended by the panel members. Topically, the five questions for research covered: definition and measurement of chronic conditions and disabilities in health service research; health and functional characteristics among these population groups; the impact of comorbidity or secondary conditions upon health care access, utilization, quality or cost; self vs proxy reporting in health surveys of people with disabilities; and measurement of mental health service needs.

### *Secondary data analyses*

Many of the decisions the panel made required examination of the relationships between or among chronic conditions, functional difficulties, and specific areas of service utilization. Two secondary data sources were used extensively in these analyses. The first was a pooled dataset (2006–2008) drawn from the Medical Expenditure Panel survey (including the household component, medical conditions and medical events files, N = 53,586).<sup>32</sup> The second was assembled from the 2011 National Health Interview Survey, where the adult sample file, the person level file and the ACS-6 disability test questions file were merged to yield the analytic dataset for working age adults (N = 13,043).<sup>33</sup> Work conducted with both of these datasets accommodated for the complex sampling designs involved and was weighted both to correct for non-response and to bring the results to U.S. non-military, non-institutionalized population totals for persons aged 18–64. Analyses included descriptive statistics, bivariate analyses and multivariate modeling; Taylor series linearization was used for variance estimation.

### *Cognitive testing*

At the conclusion of its deliberations, the panel proposed competing questions for each domain of the ACHCN screener, each differing in wording, scope or structure. Cognitive testing of these items was performed through an inter-agency agreement with the National Center for Health Statistics (CDC/NCHS), in their questionnaire design research laboratory. Cognitive interviews were performed with a total of 56 individuals who were sampled to include individuals with, and without, a wide range of chronic conditions and functional difficulties. Interviews were conducted over three rounds, with adjustments to the items designed to improve clarity, reduce burden, and strengthen the relationship between question intent and respondent understanding.<sup>34</sup>

## Results

### *The definition of ACHCN: concepts, terms and clarifications*

The expert panel crafted a definition that is intentionally broad, non-diagnostic and based upon real-life health consequences. This definition is purposefully brief. It describes Adults with Chronic Healthcare Needs as follows:

Adults (age 18–65) with [1] ongoing physical, cognitive, or mental health conditions or difficulties functioning who [2] need health or related support services of a type or amount beyond that needed by adults of the same sex and similar age.

This definition encompasses three main domains: health conditions, functional difficulties and service needs/use. In each domain, the panel further defined key terms and concepts upon

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