Understanding the Context of Health for Persons With Multiple Chronic Conditions: Moving From What Is the Matter to What Matters

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ABSTRACT

PURPOSE An isolated focus on 1 disease at a time is insufficient to generate the scientific evidence needed to improve the health of persons living with more than 1 chronic condition. This article explores how to bring context into research efforts to improve the health of persons living with multiple chronic conditions (MCC).

METHODS Forty-five experts, including persons with MCC, family and friend caregivers, researchers, policy makers, funders, and clinicians met to critically consider 4 aspects of incorporating context into research on MCC: key contextual factors, needed research, essential research methods for understanding important contextual factors, and necessary partnerships for catalyzing collaborative action in conducting and applying research.

RESULTS Key contextual factors involve complementary perspectives across multiple levels: public policy, community, health care systems, family, and person, as well as the cellular and molecular levels where most research currently is focused. Needed research involves moving from a disease focus toward a person-driven, goal-directed research agenda. Relevant research methods are participatory, flexible, multilevel, quantitative and qualitative, conducive to longitudinal dynamic measurement from diverse data sources, sufficiently detailed to consider what works for whom in which situation, and generative of ongoing communities of learning, living and practice. Important partnerships for collaborative action include cooperation among members of the research enterprise, health care providers, community-based support, persons with MCC and their family and friend caregivers, policy makers, and payers, including government, public health, philanthropic organizations, and the business community.

CONCLUSION Consistent attention to contextual factors is needed to enhance health research for persons with MCC. Rigorous, integrated, participatory, multimethod approaches to generate new knowledge and diverse partnerships can be used to increase the relevance of research to make health care more sustainable, safe, equitable and effective, to reduce suffering, and to improve quality of life.

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INTRODUCTION

More than 1 in 4 Americans lives with the burden of more than 1 ongoing health condition,[1-3] and the number of persons living with multiple chronic health conditions is growing dramatically.[2,4] Medical costs for persons with chronic illnesses account for 75% of US health care spending,[4] and more than 90% of the Medicare spending on older adults is devoted to persons suffering from multiple chronic conditions (MCC).[5] This heavy expenditure has not yielded the desired increase in quality of life for those affected.[4] A strategic framework of the Department of Health and Human Services (DHHS)[6] and multiple proposals and programs from the private sector highlight the growing concern about persons living with MCC.[7]

Current health care and research approaches are largely mismatched to the challenge of persons living with MCC. Both health care and research are primarily focused on single diseases.[8,9] Most prevailing scientific approaches are designed to isolate objects of inquiry, controlling for potentially confounding contextual factors that are treated as noise to be muffled. Although reductionist research can yield useful information on the causes and consequences of single diseases, it is not well suited to addressing multifaceted problems, such as understanding the complex interaction of multimorbid chronic illnesses with social, environmental, and health care systems.[10,11] Indeed, most randomized clinical trials[12] and the evidence-based guidelines derived from them not only exclude persons with MCC,[13] but attempt to hold contextual factors constant, thus contributing to evidence-based care that is fragmented and potentially harmful.[14-16]

Context involves the many factors that influence a person's life, from the biology of interacting diseases or treatments, to the values and life goals of the individual and family, the health and functioning of family and friend caregivers, and relevant health care system factors, community resources, and policies. These multilevel,[17-21] complexly interacting factors are important for understanding MCC, for ensuring optimal benefit of preventive and therapeutic interventions, and for improving the lives of persons living with MCC.

As a result of fragmented, decontextualized research and health care, persons living with chronic illnesses, as well as their family and friend caregivers, often feel isolated and unsupported. Their health care is often splintered,[10,22,23] potentially dangerous,[24-28] unguided by relevant scientific knowledge,[13,29,30] and unsustainably expensive.[31-37]

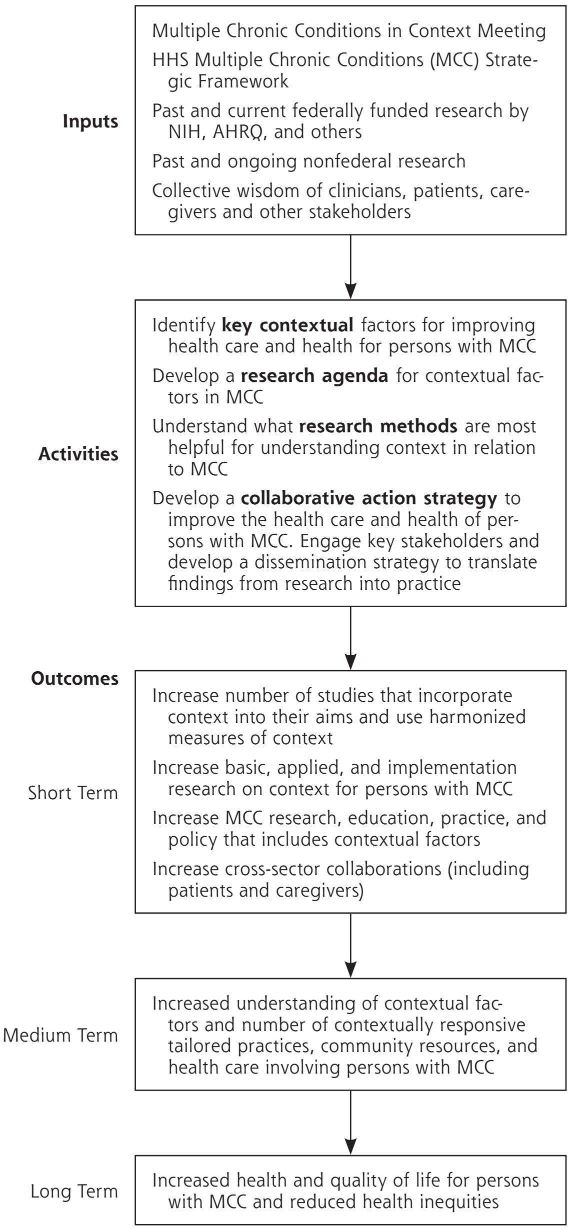
The purpose of this article is to (1) identify domains of important contextual factors for research on MCC, (2) advance the research agenda, (3) recommend relevant research methods, and (4) suggest partnerships helpful for collaborative action. Its goal is better care and a higher quality of life for persons with MCC and their families and lower costs for society.

METHODS

In 2012, planning began to bring together a diverse group of expert stakeholders to address the need to incorporate context into research to improve the health of those living with MCC. Members of the planning group included representatives of the National Institutes of Health, the DHHS Office of the Assistant Secretary of Health, the Agency for Healthcare Research and Quality, the Centers for Disease Control and Prevention, the National Council on Aging, and the Patient-Centered Outcomes Research Institute. The planning process was guided by a logic model depicted in Figure 1, which shows how input from diverse participants, focused on 4 goal-directed activities, was hypothesized to lead to short-, intermediate- and long-term outcomes for persons living with MCC.

Forty-five invited experts met in Washington, DC, February 27-28, 2013, at the Patient-Centered Outcomes Research Institute. Participants were invited by

Figure 1. Logic model guiding the multiple chronic conditions in context initiative.



Multiple Chronic Conditions in Context Meeting

HHS Multiple Chronic Conditions (MCC) Strategic Framework

Past and current federally funded research by NIH, AHRQ, and others

Past and ongoing nonfederal research

Collective wisdom of clinicians, patients, caregivers and other stakeholders

Identify **key contextual** factors for improving health care and health for persons with MCC

Develop a **research agenda** for contextual factors in MCC

Understand what **research methods** are most helpful for understanding context in relation to MCC

Develop a **collaborative action strategy** to improve the health care and health of persons with MCC. Engage key stakeholders and develop a dissemination strategy to translate findings from research into practice

Increase number of studies that incorporate context into their aims and use harmonized measures of context

Increase basic, applied, and implementation research on context for persons with MCC

Increase MCC research, education, practice, and policy that includes contextual factors

Increase cross-sector collaborations (including patients and caregivers)

Increased understanding of contextual factors and number of contextually responsive tailored practices, community resources, and health care involving persons with MCC

Increased health and quality of life for persons with MCC and reduced health inequities

AHRQ = Agency for Healthcare Research and Quality; DHHS = Department of Health and Human Services; NIH = National Institutes of Health.

the planning committee to represent the experience of individuals with MCC, family and friend caregivers, researchers, funders, nongovernmental agencies, policy makers, clinicians, and health care system and public health specialists.

Participants were assigned to small working groups with diverse representation to examine critically the 4 topic areas: (1) key contextual factors, (2) needed research, (3) relevant research methods, and (4) partnerships for collaborative action. Each group summarized their work in writing and shared their findings with all participants in an iterative process designed to challenge and refine the emerging insights.

Subsequently, one meeting facilitator (K.C.S.) blended the group reports into a common document that was refined by group leaders, and the other meeting facilitator (W.J.N.) then iteratively honed by participants after the meeting.

FINDINGS

Key Contextual Factors

The complex interaction of contextual factors relevant for persons with MCC occurs at multiple levels, from policy to health care system, community, family, person, and the underlying biology. A multilevel classification of key contextual factor categories, selected subcategories, and examples are depicted in Table 1. The World Health Organization succinctly sums it up in the statement: "The context of people's lives determines their health."[38]

These multilevel contextual factors interact in complex ways to enhance or reduce health.[39,40] Understanding and improving health and health care among persons with MCC therefore requires discerning which contextual factors are most relevant and ascertaining how these factors interact with each other to influence health or health care.[41,42]

Which contextual factors are most important varies with the person, time, and situation. This heterogeneity of contextual factors is a conceptual and research challenge that requires understanding the health and health care of persons with MCC as a complex system in which contextual factors coevolve with time.[42-49] Although it may seem simpler to ignore multilevel contextual factors, a constricted, disease-specific focus risks making misattributions about cause, effect, and intervention points of leverage in the complex and adaptive system of persons living with MCC.[48] Identifying and then considering the most relevant factors from the domains of context outlined in Table 1 at all stages of the research process, from conceptualization to actualization to implementation and dissemination, and, finally, acting on the

Table 1. Multiple Levels and Examples of Key Contextual Factors

Contextual Category	Subcategory	Examples
Biological	Organ system Cellular mechanisms Genomics	Genetic and physiological mechanisms that create interaction effects between diseases and treatments Basic understanding of multimorbidity
Person	Personal goals and preferences	Goals and preferences for process and outcomes of care Personal hopes and expectations and life goals (short and long term) Concerns about care
	Medical characteristics	Functional status Degree of symptom distress—especially pain Mental health, cognition, mood Complexity of conditions and care regimen Specific dominant conditions Capacity for self-care
	Cultural factors	Language Race, ethnicity, cultural background Personal preferences (eg, religiosity, privacy) Ability to advocate for self
	Resources	Financial resources Insurance benefits Housing, living situation Transportation and access to care Educational attainment, literacy Health literacy and numeracy Social isolation, connectedness to others, communication Presence of family, unpaid caregiver Peer support
Family	Capacity of family to provide care	Ability to provide care and personal services Emotional support Proximity and availability Financial resources Ability to advocate for patient within health care system Legal considerations
	Social and cultural context of family	Family dynamics (including potential for abuse, neglect) Cohesion and ability to make decisions as a unit Family's connection to the community and health care system Preferences for care and caregiving, including location for caregiving

continued

Table 1. Multiple Levels and Examples of Key Contextual Factors *(continued)*

Contextual Category	Subcategory	Examples
Community	Physical characteristics of the community	Climate
		Urban, rural, suburban
		Connectivity of community—eg, broadband, telephone, other resources
		Transportation system (including accessibility)
		Safety of community
		Potential for recreation
		Physical infrastructure and built environment
		Healthy food, air, and water quality
	Health care infrastructure	Link between community resources and the health care system
		Health care marketplace
		Available clinicians
		Implementation of health care policy
		Availability and skills of community health workers
	Demographics	Socioeconomic status of community
		Diversity (race, ethnicity, sex, age, culture)
		Employment
	Social culture	Civic culture (eg, organized volunteer groups)
		Employment for individuals with multiple chronic conditions
		Acceptance of diversity, openness to interventions etc
		Social networking, social norms
Health care system	Delivery	Continuity of care
		Access to mental health care
		What is measured and incentivized
		Accessibility of system: responsiveness, ease of communication, patient centeredness
		Integration, fragmentation, structure of health care system
	Resources	Financing, sources of revenue, reimbursement structure
		Physical infrastructure
		Extent of and allocation of resources
	Communications and information technology	Information systems
		Patient and caregiver access to information systems and information
		Information flow—between whom?
	Workforce	Supply—professional and nonprofessional
		Abilities and skills
		How systems use care teams and who is on them
	Education and training	Scope of practice
		Match between training and needs
		Ongoing workforce education and training
Policy	Financial	What is paid for, and what is not paid for?
		By whom? To whom? For what? Who is eligible?
		Benefit design
	Quality	What is measured? What are the outcomes that matter?
		Which measures are imposed in which settings?
	Legal, regulatory	Scope of practice, licensing laws
		Privacy protection
		Health care workforce protections, labor laws
	Political environment	Local and policy effects
	Economic environment	Effects on community, health care system
	Media environment	What is communicated? To whom?

resulting hypotheses and understanding are needed to make research both rigorous in truly understanding the complexity of MCC, and relevant in focusing on what is most important.

Advancing the Research Agenda

Goal 4 of the DHHS strategic framework for optimum health and quality of life for individuals with MCC is to "facilitate research to fill knowledge gaps about, and interventions and systems to benefit, individuals with MCC."[6] The strategic framework suggests 4 main objectives: "increase the external validity of trials; understand the epidemiology of MCC; increase clinical, community, and patient-centered health research; address disparities in MCC populations."[6] The objectives that focus on external validity, patient-centeredness, and equity are highly consistent with the research foci identified in this article. Other helpful previous research agendas for MCC[50,51] have emphasized the medical context of the person.

Table 2 displays examples of important and context-based research questions that build on these agendas. These questions cluster around 2 important themes developed at the conference.

First is developing knowledge that moves beyond a disease-driven research agenda[9] to support health- and person-driven,[52] goal-directed[53,54] therapeutic and prevention strategies[55] for persons with MCC. This effort involves shifting perspective from generating knowledge relevant for "... making sure the evidence-based commodities of care are delivered for each disease…" to systematic knowledge useful for "…assuring that persons with multiple illnesses get health care that helps them get on with what is important in

Table 2. Advancing the Research Agenda

Developing contextualized knowledge to support health and person-driven, goal-directed care for persons with MCC
How can the interacting effects of MCC on health be understood?
What are the mechanisms of interaction among relevant contextual factors and how do they affect health and health care?
What are the additive or multiplicative effects or burdens of living with or caring for multiple chronic illnesses?
What combinations of treatments, services, technologies, and resources help individuals reach their goals efficiently, effectively, and safely?
How can patients be supported in their self-management?
What are the diverse factors affecting personal goal setting and goal attainment?
What are practical and effective models for integrating mental and physical health?
How can effective models of rapid cycle knowledge generation be developed and implemented?
What can be learned from international comparisons?
What outcomes and measures are most relevant for persons with MCC and their caregivers?
What generalizable interventions are effective across different combinations of MCC?
What are the causes, duration, and severity of MCC in the population, what are the resulting disabilities, and which interacting aspects of context are most important for treatment effectiveness?
Achieving a culture, system, technology, and communities that facilitate person-driven, goal-directed care and self-management that improves health
What approaches create a culture that supports the person-driven, goal-directed management of MCC?
What supportive systems and technologies are needed to improve the health and health care of persons with MCC?
How can the needed workforce, patient, family capacity, and peer-support be enhanced?
How do multidirectional linkages that include community resources affect the health and health care of persons with MCC?
How can we provide the needed training, organizational change, and team building?
What are effect of incentives through policy and reimbursement systems?

MCC = multiple chronic conditions.

their life." Relevant research questions include assessing specific contextual factors meaningful to different persons in different situations so that health care and health promotion can be focused on specific needs and goals.

The second theme relates to achieving the needed paradigm shift. The research questions here are about developing a culture, system, technology, and communities that facilitate person-driven, goal-directed care and self-management that improves health and well-being.

Methods for Generating the Needed New Knowledge

Because contextual factors change with time in ways that may affect outcomes,[39,40] relevant contextual factors must be considered and assessed from conceptualization to completion and application of the research study. Methods need to be open to the possibility of emergence. They need to go beyond assumptions of linear effects and do more than assess central tendency. From a traditional clinical trials perspective, contextual factors would be considered as noise,[56] as effect modifiers, or as confounding variables to be controlled or their effects made irrelevant through randomization.[57-59] Decontextualized research methods, however, are a major reason why their findings are not translated into practice.[60,61] They are not relevant to either patients or their clinicians.[62-64]

Considering context can cause diverse ontological and epistemological views of research, conceptual models, and analytic approaches to surface.[65] Expanded research methods can be used to go beyond common reductionist conceptualizations to embrace new conceptual and computational models that include contextual factors.[66] Methods that take context into account can help make sense of heterogeneity[56] and of the frequent failure to replicate decontextualized studies in different settings.[67-69] These methods can help to move beyond understanding what works on average to understanding what works for whom and in what situation.[70,71]

Table 3 lists current methodological challenges relevant to research on MCC and offers suggestions for contextualized research methods. This research requires methods that are participatory, multilevel, and flexible; are conducive to ongoing measurement from diverse (and sometimes innovative or novel) data sources, including existing data; assure study integrity; integrate quantitative and qualitative methods; and generate ongoing learning. In addition, consideration of relationship-centered principles,[72,73] such as transparency and trustworthiness, responsiveness to concerns, early and consistent engagement, and openness to diverse perspectives, is necessary to ensure that research is informed by the perspectives of multiple stakeholders.[74,75]

These methods can contribute to a continuously learning health system[76-78] that includes targeted populations, surrounding communities, and all stakeholders. The needed inclusive work is facilitated by developing a common lexicon across diverse stakeholders and by consistently requiring consideration of relevant contextual factors in funding proposals and journal reporting.[79,80]

Partnerships for Collaborative Action

The multilevel nature of contextual factors in MCC, along with the associated paradigm shift in research approach, requires partnership to generate, evaluate, and apply the needed new knowledge effectively in diverse settings and situations. Such collaborative action is consistent with recent calls by the NIH and others for team science[81-83] and with the growing recognition of the need for multistakeholder partnerships to address complex multifactorial problems.[49,84,85]

Table 4 identifies suggested partners, domains in which their engagement is critical, and steps for their

Table 3. Methods for Generating the Needed New Knowledge

1. Current challenges

- There is not a common lexicon among stakeholders
- Contextual factors are dynamic, fluid, interrelated, and vary according to perspective
- Because contextual factors interact in dynamic ways, it is important to measure them from conceptualization to completion of the research study, and to have analytic techniques that do not rely on assumptions of linearity
- To be relevant, methods may need to be combined, modified, or developed
- There is tension between gathering data and burden to participants

2. Suggestions for relevant knowledge generation

- Research studies involving MCC should always consider contextual factors
- Contextualized MCC research requires methods that are:
  - Participatory (engage multiple perspectives and relevant partners)
  - Flexible (data collection, intervention delivery, outcomes ascertainment)
  - Both quantitative and qualitative (mixed methods)
  - Multilevel (from person to place to policy)
  - Sufficiently granular to address what works for whom in what situation
  - Conducive to ongoing measurement from diverse data sources
  - Generative of ongoing learning
- In all aspects of research from conceptualization to dissemination and implementation:
  - Persons with MCC and their family and friend caregivers should participate
  - Researchers should effectively engage communities
  - Researchers should ensure that shared language is developed and used among stakeholders
  - Research funders and publishers' policies should require inclusion of contextual factors in all research, unless exclusion is justified
  - Context should be measured and analyzed at multiple levels
- To reduce participant burden (eg, health care system, individuals, providers of health care), existing data (eg, EHR, marketing research, and public health data) should be mined when possible and commensurate compensation provided
- Methods that are most appropriate to the research question should be selected, rather than having the methods drive the question. Exploration of methods from multiple disciplines (eg, occupational therapy, engineering, systems science, modeling) is encouraged
- Development and adaptation of methods that are sensitive to the emergent properties of complex systems is warranted

EHR = electronic health record; MCC = multiple chronic conditions.

Table 4. Partnership for Collaborative Action

Key collaborative partners

- Research enterprise (public and private, researchers and funders)
- Health care providers, including those providing home care
- Community-based support
- Patients and their family and friend caregivers
- Policy makers and payers
- An array of other essential partners (eg, government public health, foundations)

Domains of engagement for key partners

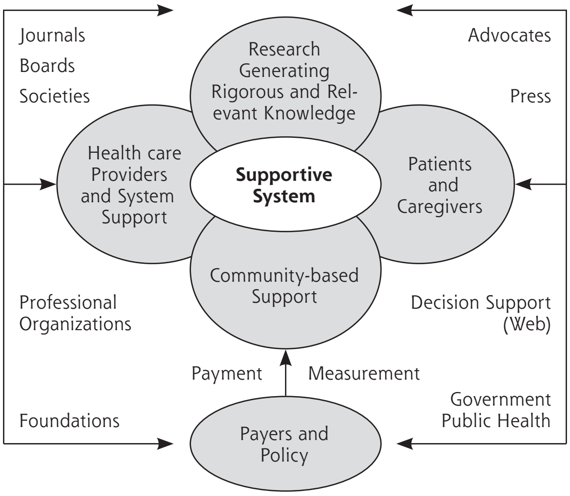
- Formulating research questions and methods that address context
- Reporting and interpreting research findings with greater attention to context
- Disseminating findings and strengthening the evidence base in prevention, management, and care for persons with MCC
- Translating findings into plain language in the patient's context
- Sustaining funding, advocacy, and other support for context in research and practice
- Ongoing measurement and monitoring of progress and impact

Steps for building and sustaining collaborative partnership

- Enumerate specific strategic partners
- Establish common and compelling lexicons and stories
- Engage partners
- Foster innovation on context-informed research (eg, encourage funding announcements, FDA, IRBs to emphasize context-informed research)
- Foster incorporation of context in practice (eg, cross-cutting clinical guidelines, performance measures, and patient-caregiver self-care management practice)
- Continue reinforcing actions by partners
- Measure and monitor effects and modulate actions

FDA = Federal Drug Administration; IRB = institutional review board; MCC = multiple chronic conditions.

Figure 2. Partnerships for Collaborative Action



engagement. The changes required for research in MCC are both instrumental and part of a larger movement and political process; therefore, the requisite partnerships will also require a combination of incremental changes and movement toward a far-reaching, boundary-spanning[86-88] new vision. Figure 2 depicts the necessary interactions across the spectrum of stakeholders generating the needed new knowledge, including payers and policy makers, community partners, patients and caregivers, the health care system, and research community.

The DHHS strategic framework for managing MCC[6] provides an important starting point for the needed collaborations, and it already has identified more than 250 programs, partners, and others working on aspects of the agenda.[7] A more general framework for collaborative impact identifies 5 conditions of collective success: a common agenda, shared measurement systems, mutually reinforcing activities, continuous communication, and backbone supports.[89] Using this framework, 5 short- to midterm recommendations emerge to support inclusion of key contextual factors in the initiatives:

1. Establish a measurement framework that includes a shared lexicon around priority contextual factors and indicators at the person, population, and system levels to monitor progress. The National Committee on Vital Health Statistics[90] and the National Quality Forum[91] would be logical homes for such efforts.

2. Build a national network of organizations interested in collecting and disseminating best practices in assessing and acting on context for persons with MCC. The national network would begin by identifying and building on current initiatives and identifying dissemination channels through which best practices can be shared.

3. Create a national public awareness campaign for consumers around key contextual factors. The campaign would build on emerging research and empower persons with MCC and their families to engage clinicians in contextual-based discussions that influence their care. (See the patient handout in the Supplemental Appendix.)

4. Activate and deploy a workforce that is skilled in incorporating context into research and practice. To do so will require the inclusion of contextualized understanding of MCC in the curriculum for health professionals and in training for early career scientists, as well as current researchers who need additional training in new methods and cross-cutting content.[7]

5. Develop a supportive policy environment. A broad-based coalition of private sector and government organizations is needed to think through policy options and help effect desirable policy changes as part of a long-term process of social change.

A longer term recommendation is to create an inventory and synthesis of interventions and best practices across all partner groups and convene a national-level entity (eg, an Institute of Medicine panel) to consider how contextual factors can be brought into research, implementation, and dissemination.

The fundamental premise among an emerging MCC-in-context collaborative is that government agencies, business, nonprofit organizations, and others can work together in a strategic, coordinated way to achieve ambitious societal goals focused on improving health and health care for those with multiple chronic illnesses while controlling health care costs.

DISCUSSION

Understanding contextual factors is vital to generating the new knowledge needed to improve the health of persons with MCC and to create a high-value health care system that is person-centered, goal-based, individualized, and sustainable. Such an effort will require a paradigm shift in how knowledge generation is understood and how research is conducted and implemented. The shift involves moving from a linear, reductionist view of the world to an understanding of the complexity of health and health care that is particularly apparent in persons with MCC.

The challenges to this work are substantial. Moving the research enterprise from a well-established and well-regarded reductionist approach that asks, "What is the matter?" to a research community that values context and asks, "What matters?" will require bold action by leaders within a research community supported and informed by persons with MCC, their family and friend caregivers, and clinicians. No group alone will be able to drive this movement forward. New coalitions and groups will need to form. Research and improvement efforts will need to be more congruent, so that contextualized knowledge generation and its application become part of the same learning community process.

New partnerships will involve researchers, clinicians, patients, caregivers, policy makers, and other stakeholders paying attention to contextual factors in generating questions, making observations, and doing interventions while continuing to learn during implementation, dissemination, and reinvention in new settings.[92,93] New policy initiatives will involve the development of infrastructure and relationships for real-time shared learning in research and practice. Funders and journal editors[40,79,94] can play a prominent role in calling for context to be included in the research that is needed to take the science to next step by more closely linking research, practice, and the lived experience of persons with MCCs.

A focus on incorporating the perspectives of key stakeholders in research, especially persons with MCC, resonates with the mission of the new Patient-Centered Outcomes Research Institute.[95] It also aligns with the NIH focus on precision medicine[96] that identifies key individual lever points to tailor interventions, as well as with growing initiatives around integrated care and care plans.[32,54,97-99]

The strengths of this report include findings generated by diverse stakeholder groups working together in an iterative process. Developing the working manuscript as a team provided an opportunity to bring together perspectives that are not usually apparent in the development of a research agenda, such as those of patients and family/friend caregivers, as well as community organizations and advocacy groups. The limitations of this article are that, despite its diversity, many stakeholders were not represented, and the results of our deliberations are only a first step in a large and diverse ongoing effort toward a more detailed blueprint for future action. Nevertheless, the meeting produced a set of principles for an ongoing inclusive process.

For those who have or who are at risk for MCC (which is almost everyone), developing an evidence base that includes context will ultimately lead to more integrated, effective, high value health care that is responsive to individual needs, preferences, and desires.

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