

# The science and art of value in healthcare: Measures, voices and methods

**Edited by**

Jon Arsen Chilingirian, Laura Lorenz, Gala True, Stephen E. Chick and Christopher Tompkins

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# The science and art of value in healthcare: Measures, voices and methods

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# Editorial: The science and art of value in healthcare: Measures, voices and methods

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## KEYWORDS

healthcare value, healthcare quality, healthcare performance, patient experience, caregiver wellness

## Editorial on the Research Topic

**The science and art of value in healthcare: Measures, voices and methods**

Every country entrusts its population's health to autonomous medical practitioners and institutions. The health and wellness of the population depends on how well these clinical professionals and institutions perform (1–3). Understanding, evaluating, managing, and improving performance requires the measurement of value (4). So, how do we understand and define value?

Value is not about quality<sup>1</sup> or technical outcomes alone, any more than value is about prices and costs alone—although both are constraining factors. Today “value” means the simultaneous pursuit of (1) improving patient outcomes, (2) improving patient experiences, (3) lowering long-term costs by reducing or eliminating waste, and (4) taking responsibility for the wellness of the caregiver workforce (5, 6). Given that definition, it becomes clear that when value improves, patients, caregivers, medical organizations, and payors benefit. Contrarily, when value deteriorates, so too do outcomes, patient experience, safety, efficiency, convenience, and patients' and health workers' wellness.

This Research Topic aims to better understand the science and art of high-value medical care for patients and populations, clinicians and staff, medical care delivery, and ecosystems. This includes measuring and assessing value in healthcare and how innovation, efficiency, and care redesign can improve value. An aligned understanding of value across healthcare stakeholders is fundamental to improving innovation, access, efficiency, payment and finance systems, and research vis-à-vis patient care.

1 Quality of care has both objective dimensions, e.g., technical outcomes, as well as affective dimensions, such as patient satisfaction. Quality is best understood as a multidimensional construct, operationalized by the following variables: technical outcomes; overall patient experience and satisfaction; decision-making efficiency; relationships with caregivers and staff; and convenience and amenities (5).

We have organized the 12 publications in this Research Topic into five categories<sup>2</sup>:

1. Value creation for patients and populations ( $n = 5$ ).
2. Value creation for the people working in medical care ( $n = 2$ ).
3. Value creation for medical care organizations ( $n = 3$ ).
4. Value creation for health systems ( $n = 1$ ); and
5. Value creation for payors ( $n = 1$ ).

The studies take place on three continents and in seven countries: viz., Australia, Canada, India, Oman, Spain, Switzerland, and the United States. These papers suggest that high-value healthcare may be emerging as an international trend. The five categories of value creation will be discussed in more detail in the following section.

## Value creation for patients and populations

Value for patients involves a patient's perception that the medical services offered benefited that patient in terms of outcomes and experience in relation to the sacrifices made to obtain those services. [Durosini et al.](#) report on a qualitative study protocol that uses focus groups and nominal group discussions to elicit lung cancer patients' views on the most important treatment options. Illustrating what scholars have stated, "value can only be defined by the 'ultimate' customer" (7).

[Hajjar and Kragen](#) examine the use of telehealth during COVID-19 for a child with a chronic illness. Their work demonstrates the added value of telehealth in providing more timely communication and improved care coordination, ensuring person-centered care for families coping with chronic disease. [Bhyat et al.](#) report that after COVID-19, the lethargic utilization of telehealth in Canada changed from 4% utilization in 2019 to 14% in 2020, with almost 56% strongly satisfied. This points out the downside of looking for value too soon and the importance of comparative results to realizing patient value.

[Goff et al.](#) describe a protocol for a multi-method study intended to explore barriers and facilitators to value creation in a state-wide implementation of a population health program in Massachusetts for people with limited income and resources. Given the \$1.8 billion USD investment, it makes sense that policymakers will benefit from protocols that support value creation.

[Nanda et al.](#) challenge health resource allocation based only on the global burden of disease weights and expert

opinion. Studying two communities in India, they create community-derived disability weights for 14 illness conditions. Researchers found some significant differences between the two Indian states, but more importantly, a low correlation with the global burden of disease weights. Again, this case demonstrates the importance of patient input to understanding patient experience, especially when making resource allocation decisions.

## Value creation for medical practitioners, caregivers, and staff

Patient-centricity, as defined here, is a pivotal value designed to enhance patient outcomes and experience while motivating healthcare workers. This gives rise to two questions. As value-based healthcare is adopted and assimilated into medical care organizations, how has the drive for patient-centered care affected the wellness of healthcare professionals? And how do we mobilize and energize direct care staff to want to offer higher-value care?

[Engen et al.](#) report a systematic meta-review of value-based healthcare. They found two contrasting aspects of value-based care by differentiating job resources from job demands. Embedding people-centered values in the workplace and culture may be equally important as the drive for patient-centered values.

Another untapped source of value creation for caregivers is the power of social connections and relationships. [Warfield et al.](#) describe an action research project with employees and direct care staff at a residential home and the surrounding. Increasing organizational awareness of the relational strengths and weaknesses resulted in deeper engagement and resident-community involvement, thus effectuating both caregiver and care recipient wellbeing.

## Values creation for medical care organizations

How much value can healthcare managers add by adopting a high-value care strategy and challenging the status quo of core medical care processes? [Bertke and Nufer](#) suggest a three-step methodology for value creation with no trade-offs between quality and efficiency. Their approach reports significant improvements in patient satisfaction, readmission rates, shorter lengths of stay, and significantly lower costs.

[Rodriguez et al.](#) build execution into a high-value care strategy with ten lessons. The strategy measured quality and cost per patient for conditions ranging from breast and lung cancer to coronavirus. They estimated that the average time of a value-based management project could take between 18 and

<sup>2</sup> There are other value creating stakeholders that are beyond the scope of this Research Topic. For example, there can be value creation for biotech and medical technology innovators, developing treatments and tools to benefit patients and clinicians. These suppliers should coordinate with care delivery to ensure compelling value is being created by reducing long-term costs and prices.

24 months to implement at an average cost of @90.000 euros for a more complex medical condition care process improvement.

Majewski presents a case study of a non-traditional partnership between an Australian university and a primary healthcare service organization. Adopting a structured innovation tournament and a collaborative process resulted in sustainable value creation for relatively small investments.

## Values creation for a health system

Offering a behind-the-scenes analysis and review of Oman's health response to COVID-19, Khalili et al. highlight the challenges that all governments face when a “wicked problem”<sup>3</sup> becomes part of everyone's lives. The courage to move forward by taking action with curfews, night store closures, and putting schools online, underscores the need to inspire and mobilize the community to create, not undermine, value.

## Values creation for third-party payors

In general, third-party payors also want to reduce or eliminate unnecessary services that do not improve health but increase per-unit costs/prices. The paper by Lorenz and Doonan explores outcomes and cost-savings resulting from patients with traumatic brain injury having access to multi-disciplinary rehabilitation after injury. Employing a societal model of value, the authors identified significant lifetime savings per patient, creating a compelling case for payors.

Success in commercial and non-commercial enterprises and their eco-systems requires providing higher value to end users

<sup>3</sup> COVID-19 is an example of a wicked problem—a class of social system problems that are not well-formulated, the stakes are extremely high, there is ambiguity, there are no technical experts, and stakeholders have conflicting values (8).

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for a fair price and at a reasonable cost to the organization (7, 9–11). In this editorial, we have assumed that high-value healthcare is an appropriate aim of medical organizations and health systems—time will tell if that assumption is valid. This Research Topic surfaces several important and challenging questions about value, needing more research and analytic case studies. Improvement should always be our goal, and we have only scratched the surface.

## Author contributions

JC and GT contributed to the design and analysis of results. SC made additional analysis. All authors contributed to the article and approved the submitted version.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Patient Preferences for Lung Cancer Treatment: A Qualitative Study Protocol Among Advanced Lung Cancer Patients

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**Introduction:** Lung cancer is the deadliest and most prevalent cancer worldwide. Lung cancer treatments have different characteristics and are associated with a range of benefits and side effects for patients. Such differences may raise uncertainty among drug developers, regulators, payers, and clinicians regarding the value of these treatment effects to patients. The value of conducting patient preference studies (using qualitative and/or quantitative methods) for benefits and side effects of different treatment options has been recognized by healthcare stakeholders, such as drug developers, regulators, health technology assessment bodies, and clinicians. However, evidence-based guidelines on how and when to conduct and use these studies in drug decision-making are lacking. As part of the Innovative Medicines Initiative PREFER project, we developed a protocol for a qualitative study that aims to understand which treatment characteristics are most important to lung cancer patients and to develop attributes and levels for inclusion in a subsequent quantitative preference survey.

**Methods:** The study protocol specifies a four-phased approach: (i) a scoping literature review of published literature, (ii) four focus group discussions with stage III and IV Non-Small Cell Lung Cancer patients, (iii) two nominal group discussions with stage III and IV Non-Small Cell Lung Cancer patients, and (iv) multi-stakeholder discussions involving clinicians and preference experts.

**Discussion:** This protocol outlines methodological and practical steps as to how qualitative research can be applied to identify and develop attributes and levels for inclusion in patient preference studies aiming to inform decisions across the drug life cycle. The results of this study are intended to inform a subsequent quantitative



preference survey that assesses patient trade-offs regarding lung cancer treatment options. This protocol may assist researchers, drug developers, and decision-makers in designing qualitative studies to understand which treatment aspects are most valued by patients in drug development, regulation, and reimbursement.

**Keywords:** patient preferences, drug decision-making, lung cancer, drug development, patient-centered research, patient involvement, focus group discussion, nominal group technique

## 1. INTRODUCTION

Lung cancer is the deadliest and most prevalent cancer worldwide (1–3). The *World Health Organization* (WHO) estimates that lung cancer death rates will continue to rise, mainly as a result of some lifestyle and environmental factors such as cigarette smoking (4, 5). Lung cancer incidence and mortality rates are highest in developed countries and peak between 65 and 84 years (6). There are two main forms of lung cancer: *Non-Small Cell Lung Cancer* (NSCLC) and *Small Cell Lung Cancer* (SCLC). NSCLC is the most common type of lung cancer, accounting for 85% of patients. Frequent symptoms include cough, dyspnea, hemoptysis, and chest pain (7). Clinical outcomes for NSCLC depend on the stage at the time of diagnosis. Often, patients are diagnosed with NSCLC in an advanced-stage, resulting in a poor prognosis and a 5-year survival rate below 20% (7–10). Treatment options for lung cancer vary widely according to disease stage and characteristics. (Locally) advanced NSCLC patients may have received several treatments, in combination or sequence, including chemotherapy, targeted therapy, immunotherapy, surgery, and radiation therapy (6, 11–18).

Lung cancer treatments are associated with different treatment attributes (or features), such as benefits (e.g., in terms of progression-free survival, overall survival, response rate), risks (side effects such as fatigue and hair loss), route of administration and treatment schedule. Such differences may raise uncertainty among drug developers, regulators, payers, and clinicians regarding the value of these treatment attributes to patients. Patient preference studies provide evidence from patients on what treatment attributes are important, how important these attributes are, and which trade-offs patients are willing to make between attributes (19).

Recent research highlights that results from studies that investigate patients' preferences, called *patient preference studies*, could inform decisions across the drug life cycle. Using patient preference studies to inform these decisions may improve the decision-making process and patients' experience with the treatment, leading to better outcomes and better use of resources (20–22). The drug life cycle is the process of developing a drug and bringing it to patients. It consists of the following subsequent stages and decisions, all of which may be informed by patient preference studies: discovery, preclinical development, clinical development, marketing authorization, *Health Technology Assessment* (HTA), pricing, reimbursement and post marketing. Stakeholders involved in the drug life cycle—HTA bodies, payers, academics, patients and

patient organizations, physicians, industry, and regulators—are exploring how to design, conduct and use patient preference studies to inform drug decision-making (19, 23–25).

An important step in the design of patient preference studies is the selection of the attributes and attribute levels further investigated in the quantitative phase of the preference study. Attributes may include different types of benefits and risks associated with treatments and other clinical and non-clinical aspects that can influence desirability or acceptability of treatments to patients (26). Authors have also described attributes as characteristics or features. Examples of attributes are mode of treatment administration, treatment benefits (e.g., survival or tumor reduction in the case of cancer) or treatment risks (side effects such as nausea, diarrhea). Attribute levels are the values or categories used to characterize the performance of a treatment under each attribute in a preference survey. As qualitative methods, such as focus groups, allow to examine patients' experiences and enable sensitive topics to be discussed, their use for identifying the treatment attributes and levels is being increasingly recognized. Attributes and levels developed through qualitative methods have been described to be richer, and qualitative methods with patients reduce the potential for misspecification of attributes through overreliance on the views of experts and researchers (27, 28).

However, detailed information on methodological and practical questions as to how to use qualitative research to identify and develop the attributes and levels for inclusion in patient preference studies aiming to inform decisions across the drug life cycle is currently lacking. This absence of methodological consensus and practical guidance underscores the importance of testing qualitative methods and reporting on them in the published literature.

This paper describes the protocol of a qualitative study that aims to understand which treatment characteristics are most important to advanced lung cancer patients and to identify attributes and levels for inclusion in a subsequent quantitative preference survey. This study will illustrate the value of using a qualitative approach with patients to identify preferred treatment characteristics and develop attributes from these characteristics.

The results from applying this study protocol will be used to develop a subsequent preference survey that quantifies: (i) the relative importance of the attributes and attribute levels identified in this qualitative phase among a larger group of patients and (ii) the trade-offs patients are willing to make between lung cancer treatments that vary with respect to these attributes and levels.

This qualitative study is conducted as part of the *Innovative Medicines Initiative* (IMI) *Patient Preferences in Benefit-Risk*



*Assessments during the Drug Life Cycle* (PREFER) project. PREFER will develop evidence-based recommendations to guide industry, regulatory authorities, and HTA bodies (including reimbursement agencies and payers) on how patient preference studies should be performed and used to inform decision-making throughout the drug life cycle (29, 30). Taking attention to patients' preferences in the drug life cycle becomes increasingly important not only for companies that develop new medical products, but also for the authorities that regulate, assess, and decide which products are safe, effective, well-tolerated, and cost-effective (31–33). Exploring patient preferences may provide information on medical products from the patients' perspective (such as information on the importance to patients of clinical outcomes and safety issues) and can lead to patient-centric decision making processes (34). More specifically, patient preference studies could be included in the following decisions in the drug life cycle: (i) industry decisions on which medical product to develop, based on the unmet needs of patients, as revealed through preference studies, (ii) decisions on which clinical trial endpoints to include in clinical trials, and (iii) value assessments concerning the clinical relevance of a products' outcomes and the trade-offs patients are willing to make between the benefits and risks at the time of regulatory benefit-risk assessment and HTA (35). The initial phase of the PREFER project included discussions with a broad representation of stakeholders, for example, patients, patient organizations, regulatory authorities, HTA bodies and reimbursement agencies. These discussions highlighted interest from these stakeholders in preference studies but also the need to further explore and test methods and their usefulness for decision making (36). The recommendations from PREFER are expected to lead to changed practices, in that stakeholders, including industry, will routinely assess whether a preference study would add value at key decision points in the medicinal product life cycle and, if so, implement patient preference studies according to the PREFER project recommendations (37).

## 2. MATERIALS AND EQUIPMENT

This qualitative protocol was developed and described by adhering to the following guidelines for the use and reporting of qualitative research, attribute and level development: (i) the recommendations by Coast and colleagues on the use of qualitative data collection and analysis methods for attribute development (28), (ii) the steps concerning attribute and level development in health care preference research described by Bridges and colleagues (38), (iii) the criteria for good attributes described by Hensher (39), and (iv) the framework method for thematic analysis described by Lacey and Luff (40) (see "analysis and reporting" section). As recommended by Hollin, Coast, and Bridges (27), this protocol covers: (i) the rationale for the method used to develop attributes, (ii) the nature of the included sample in the focus group discussions, (iii) details on the nature of the sampling, (iv) the focus group guides, (v) who conducted the focus groups and in what setting, (vi)

whether the focus groups were transcribed, and (vii) details of the analysis.

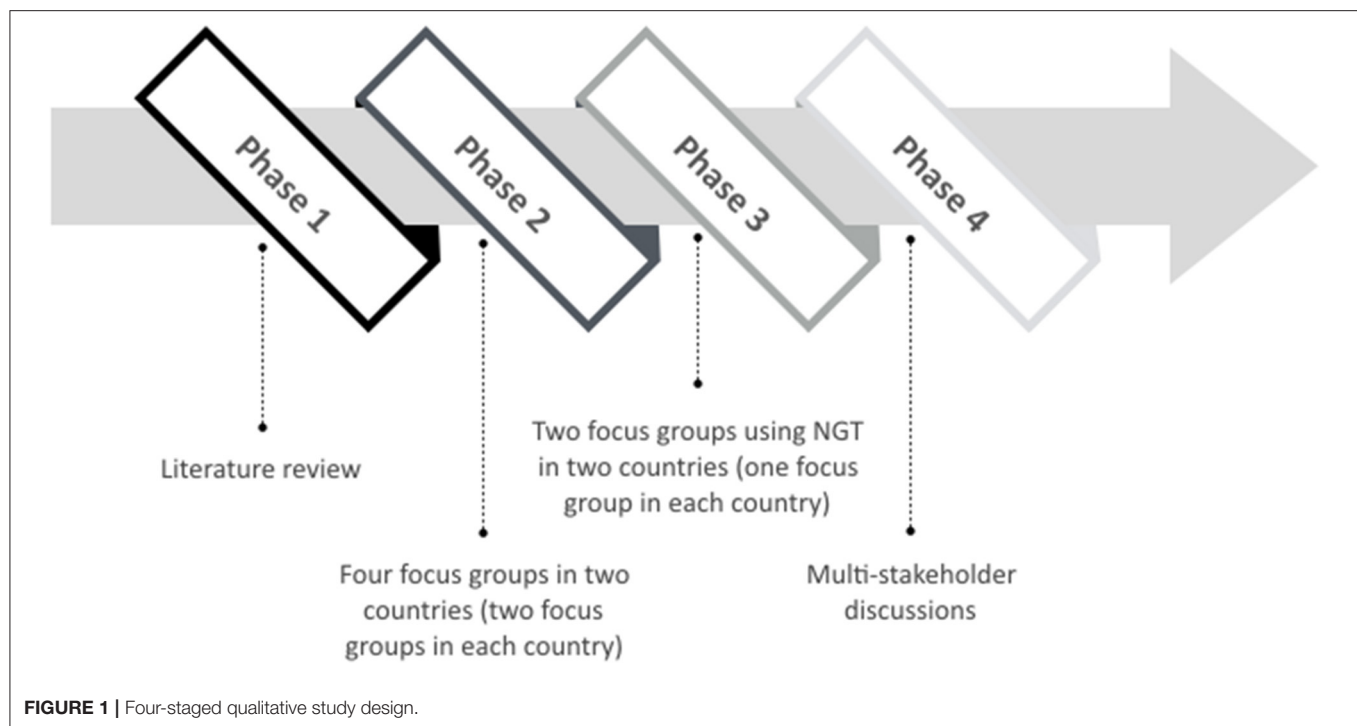
## 3. METHODS

### 3.1. Step-by-Step Procedures

Since there is limited recently published research regarding patient preferences for lung cancer treatment (including newer types of therapies such as immunotherapies), an extensive exploratory qualitative phase will be conducted involving different phases. Several authors recommend using qualitative methods with patients and performing a literature review to inform the attribute and level development (27, 28, 38, 41). Bridges et al. (38) describe that this process should be supported by evidence on the potential range and values that people may hold and that consultation with clinical experts, qualitative research or other preliminary studies can provide the basis for attributes and levels evaluated in preference surveys. Hilligsmann and colleagues conducted a *Nominal Group Technique* (NGT) in the context of drug choices and confirmed its usefulness to identify attributes for subsequent preference surveys. The authors describe that because of its advantages of being rigorous, systematic, and transparent, the use of NGT may improve the validity of subsequent preference surveys (41). Therefore, this study will involve the following four phases, with results from each phase informing the next phase (see **Figure 1**).

#### 3.1.1. Phase 1: Scoping Literature Review

In the initial phase of this study, a scoping literature review of patient preference studies in the lung cancer treatment setting will be performed to identify an initial list of treatment characteristics searching will be conducted in: (i) previously performed preference studies among lung cancer patients, (ii) benefits and risks of treatments already being prescribed to lung cancer patients, and (iii) treatment characteristics of medicines that are currently being studied in clinical trials for the treatment of lung cancer patients. Searches will be conducted in two electronic databases (Web of Science and PubMed), by using free text terms and *Medical Subject Headings* (MeSH). Since different electronic databases have different MeSH terms, the key search terms will be adapted to each specific database. Therefore, variations of the following key search terms will be adopted: "Lung Cancer" AND "Patient preferences." Only research papers published in English will be considered. In case of reviews or meta-analyses, included original articles will be evaluated for inclusion in this scoping review. The results will be screened using a two-fold process. First, the title and abstract will be screened based on the inclusion criteria that the studies have to assess the treatment of lung cancer and assess patient preferences for these treatments. Afterwards, the full text of the selected article will be reviewed to ensure that the article will be relevant to the scoping review based on the above inclusion criteria. If the article meets the inclusion and exclusion criteria, it will be included in the review and information from the study will be extracted for analysis. The list of treatment characteristics emerged from this literature search will be used to trigger further discussion in the initial focus group discussions (see Phase 2).



### 3.1.2. Phase 2: Initial Focus Group Discussions

The list of treatment characteristics emerged in the literature review (Phase 1) will be used in the second phase of this qualitative protocol: focus groups discussions to identify which treatment characteristics lung cancer patients find most relevant and why. Focus groups discussions were selected as the method for data collection instead of interviews because they allow for interactivity between participants, active discussions guided by the researchers, and thereby may generate topics that patients and researchers may not have recognized through other means. The choice for focus group discussions considered the recommendation by Coast and colleagues (28) that the choice between qualitative methods for attribute development may ultimately be determined by practical considerations such as the sensitivity of the topic.

Regarding representativeness, we envision that several patient characteristics, such as socio-demographics, type of cancer, staging and treatment experience may influence their opinions and we want to ensure that the particular attributes and levels identified in this study are not geared to only patients with a specific disease, treatment history or country of origin. Therefore, we aim to introduce heterogeneity in terms of country and include patients in different stages of their disease (III and IV), see “inclusion criteria” section. The scoping review of Phase 1 will help to increase the chance that the eventually found attributes are important to different types of patients, as it will identify the characteristics that will be evaluated by patients in the focus groups and will include characteristics from previously conducted preference studies in different countries in lung cancer patients, as well as side effects of products currently being administered to lung cancer patients across countries.

Participants will first be asked to complete an answer sheet to gather information on the socio-demographic background and health literacy, using Chew’s Brief Literacy scale (42). We will aim to transparently describe and characterize the participants by means of the patient characteristics collected through this answer sheet. We will also include a transparent description of the methods used (including recruitment, setting of the focus group) when we describe the results. Further, in the survey following this study, we aim to include a larger population and we will describe the representativeness when we report the results through the characterization of patients using the same patient characteristics. Finally, in the quantitative survey based on this qualitative research, we will investigate the influence of several patient characteristics (socio-demographic data, treatment and disease experience) on their preferences.

Since our goal is to identify “core” attributes in lung cancer treatments, we estimate to conduct four focus groups in two different countries (two focus groups for each country). There are no clear guidelines on when “enough is enough” (43), although literature highlighted that some projects reach saturation after conducting 4–6 focus groups (43–45). Saturation is defined as the point when “no new information or themes are observed in the data” (46) (p. 59). In qualitative studies, data saturation occurs when redundancy is reached in data analysis and signals to researchers that data collection may cease (47). Hennink and colleagues (48) have underlined that few focus groups are enough to reach data saturation when the goal is to identify “core” issues. Thus, we expect that four focus groups will be enough to reach data saturation. If data saturation is not achieved with these focus groups, additional focus groups will be considered.

As part of the recruitment process, an invitation letter will be sent to those expressing interest in the study and fulfilling inclusion criteria (see “Participants” section). Those interested in participating will then be contacted by a member of the study team to verify their willingness to participate and if so, arrange the practicalities of the focus group discussion. A participant information sheet will be posted, emailed or given to participants prior to the discussion. At the start of the discussion, an informed consent procedure will take place and a consent form will be signed by the participants before proceeding with the focus group discussion. Each focus group is anticipated to last around 90 min to avoid excessive fatigue and will include a mid-session break of approximately 10 min.

Potential differences in moderating styles will be minimized by using a focus group guide (see **Appendix A**). Each focus group will be led by a team consisting of one moderator, one assistant, and/or one note-taker who have experience with qualitative research approaches and conducting focus group discussions. To increase the quality of the attribute development, the team members will also be involved in the subsequent quantitative preference survey.

Both bottom-up and top-down approaches will be used to develop attributes in these initial focus group discussions; patients will be first asked openly about which treatment characteristics matter most to them (= “bottom-up”) and only afterwards reflect on examples of treatment characteristics retrieved *via* the literature search described in Phase 1 (= “top-down”) in order to trigger further discussion.

All focus group discussions will be audio-recorded (with the participants’ permission) and will later be professionally transcribed verbatim to a digital document with any identifiable data removed to preserve participant confidentiality.

### 3.1.3. Phase 3: Additional Patient Focus Groups Using Nominal Group Technique

The aim of this phase is to refine and rank in a standardized manner the list of treatment attributes emerged in Phase 2 through the NGT (41, 49). The NGT method is specifically suitable for attribute development because it involves a ranking exercise and allows the identification of lung cancer treatment characteristics rated most highly by patients (28, 50). Compared to other qualitative consensus methods, NGT is more efficient in enabling groups to reach consensus quickly (28, 50). Additionally, the highly structured process minimizes the information loss that can sometimes occur with focus groups and responses are assumed to provide interpretable and valid ordinal data that reflect implicit prioritized views held by participants because equal weights are given to all group members (51, 52). The NGT method will be applied in two focus groups in two countries (one focus group in each country) and will consist of three steps:

(i) First, following the informed consent process, participants will be provided with a pre-developed list of characteristics generated by the previous focus groups (Phase 2). This will allow the participants to silently internalize the concepts to be discussed during the focus groups discussion. All treatment characteristics will also be orally explained by the moderator. Subsequently,

each participant will be asked to individually rank the list of characteristics according to how important they found them (from most important to least important) and if they feel a particular characteristic is missing, they will have the opportunity to include this in their ranking sheet. The assistant will collect the individual ranking sheets once finished and determine a group score and rank order for each of the characteristics from the individual rankings.

(ii) In the second step, the group scores and rank order will be presented to participants, and a discussion will be held on the group scores and rank order. During the discussion, participants will be asked to reflect on how their individual rank order compares to the group rank order.

(iii) Finally, participants will have the opportunity to reconsider their initial ranking in light of the group discussion. They will be under no pressure to achieve consensus, and all rankings will again be made individually. As for Phase 2, all the focus group discussions will be audio-recorded (with participants’ permission) and later transcribed to a digital document with any identifiable data removed for confidentiality. As for phase 2, potential differences in moderating styles will be minimized by using a guide (see **Appendix B**) and the moderator, the assistant, and/or the note-taker will have experience with qualitative research approaches and conducting focus group discussions.

### 3.1.4. Phase 4: Multi-Stakeholder Discussions

In the final phase, discussions with oncologists, patient organization members, and stakeholders from different areas of medicine and scientific disciplines including preference research, psycho-oncology, oncology, health economics, drug development, pharmaceutical sciences, and biomedical sciences will be held. These discussions will aim to define each attribute based on the rank order and qualitative analysis of the focus groups, to identify and define the levels of each attribute and to reduce the number of the attributes, if necessary.

## 3.2. Participants

Guidance on focus groups’ size is common and seldom goes beyond a minimum of 4 and a maximum of 12 participants per group (53–57). McMillan and colleagues (50, 58, 59) highlighted that groups of between 2 and 14 participants have generally been used in NGT research, and an average of seven participants for each group is recommended to collect a diversity of information and facilitate sufficient group interaction. On these bases, each focus group will consist of around seven NSCLC patients at stage III and IV. A much larger number would slow the staged process of the discussion that aims to reach consensus in a relatively short period of time (around 90 min).

All focus groups will be conducted in Italy and Belgium. These countries are chosen because they are characterized by differences such as unequal financing, service provision, and access to healthcare (60). This will allow researchers to understand which treatment characteristics are most important to lung cancer patients who live in countries who offer different kinds of healthcare systems (60–63). Specifically, Belgian insurances that cover healthcare expenses are compulsory and are chosen

directly by citizens. Further, Belgium has a high level of health expenditure, a moderate level of inpatient healthcare, a high level of outpatient healthcare and patients have a high freedom of choice. Italian's healthcare system is mixed, public and private and is characterized by a medium level of total health expenditure. The system is financed by taxes directly paid by citizens to the state and by population and economic entities' contributions. Compared to Belgium, the level of inpatient healthcare providers is similar but the outpatient provider level is low. The access to doctors is highly regulated.

Italian participants will be recruited at the European Institute of Oncology in Milan and Belgian participants will be sampled at the University Hospital in Leuven. Patients will be recruited by the treating oncologists who will be able to evaluate their clinical and psychological status as well as their motivation to provide information on their preferences. Different patients from the one recruited in the second phase will be contacted and offered to participate in the third phase of the qualitative research.

The following eligibility criteria will be used:

### Inclusion Criteria

- Adult patients ( $\geq 18$  years old);
- In treatment patients with a histological or cytological diagnosis of NSCLC stage III or IV as classified by the *Union for International Cancer Control TNM Classification of Malignant Tumors* (UICC TNM VIII Edition). The reason for including NSCLC patients at stage III and IV is that late-stage patients often have received multiple types of treatments and are thus able to reflect on a broad range of different treatment characteristics, thereby increasing the chance that all relevant treatment characteristics will be identified.

### Exclusion Criteria

- Cognitive impairment or inadequate verbal skills that may render them incapable of agreeing to participate in an informed and voluntary fashion (as evaluated by the clinician);
- Inability to understand study materials (as evaluated by the clinician);
- Physical or psychological impairment that prohibits their participation in the focus group (as evaluated by the clinician).

## 3.3. Analysis and Reporting

The audio-recordings will be transcribed verbatim in the language used in the focus group and then will be translated into English by a professional transcribing company. In the first set of focus groups (Phase 2), transcripts and notes from the focus groups will be thematically analyzed using an iterative approach as described in the framework method by Lacey and Luff (40) and summarized in **Table 1**. The thematic analysis is a "method for identifying, analyzing, and reporting patterns (themes) within data" (64) (p. 6) and will be used to generate a list of potential attributes. The analysis will follow the following recommendations for attribute and level development:

- An iterative, constant comparative analysis approach should be used to constantly modify and extend categories to ensure that all key aspects can be incorporated through this modification (28);

- Attributes should be relevant to patients and/or policymakers, relevant to the decision context, plausible and capable of being traded (28, 38);
- Attributes should include all those that might be important for an individual in coming to a decision, as ignoring important attributes may bias findings (28);
- Qualitative work to determine overarching attributes encompassing key themes combined with piloting should be used to avoid the above problem (28);
- Attributes should not be too close to the latent construct, for example, overall happiness with a product (28);
- Single attributes should not have such a large impact on decisions that large numbers of respondents essentially make no errors in decision-making (28);
- Attributes should not be intrinsic to person's personality; instead, such aspects that may determine preferences should be included as variables for investigating preference heterogeneity (28);
- Attribute development should be thought of as a process that consists of conceptual development where the attributes are identified, followed by refinement of language to convey the intended meaning to the participants of the preference survey (28);
- All attributes that potentially characterize the alternative treatments presented to participants in the preference survey (in this case different lung cancer treatments) should be considered, while considering that some may be excluded to ensure the alternative treatments are plausible to subjects (38);
- A good attribute meets the following criteria: realistic, plausible, relevant, tradable, clear and unambiguous, distinctly different from the other included attributes, comprehensive, and of salience to respondent's decisions (38, 39).

Transcripts will be independently coded by researchers. These lists of attributes will then be compared and combined across sites to generate a comprehensive list of possible attributes for preference instrument development. In the second set of focus groups (Phase 3), the list of attributes will be prioritized using the NGT. During the NGT process, the individual rankings will be summed across participants to derive the rank order at the group level. To obtain a final rank order of characteristics, the mean for each of the treatment characteristics will be calculated by combining the two rank orders reached in the two countries.

## 4. COMPLIANCE WITH ETHICAL STANDARDS

The study will be conducted according to the EU *General Data Protection Regulation* (GDPR). Additionally, this study was approved by the *Ethische Commissie Onderzoek UZ/KU Leuven* (Belgium; reference S63007) and the *Ethical Committee of the European Institute of Oncology IRCCS* (IEO, Milan, Italy; reference 1027/19-IEO 1093). An information sheet and informed consent form will be provided prior to conducting focus groups. The information sheet will inform participants that participation will not affect their healthcare, that participation is voluntary and that they can withdraw their consent at any time.



**TABLE 1 |** Iterative steps of the framework method used in the thematic analysis of the initial four focus groups (Phase 2).

1. Familiarization	Researchers of each country involved in the study will thoroughly read and re-read the transcripts. They will use the margins of the transcripts to write down analytical notes, thoughts, or impressions (e.g., when focus group participants expressed exceptionally strong or contrasting views).
2. Identifying a thematic framework	To identify an initial thematic framework, four researchers will independently code the transcripts for each focus group, meaning that they will attach specific themes or concepts to particular paragraphs, based on the research aims of the study. These codes will be different factors, such as treatment outcomes, side effects, and symptoms patients mentioned during the focus groups.
3. Coding	Researchers will discuss these preliminary codes to assess whether they interpreted the focus group in the same manner and to reach a consensus about the final coding list. The final coding list (i.e., framework) will consist of the final list of attributes to be used for ranking in the final focus group. NVivo Software, version 11.0 will be used to code the transcripts using the final coding list.
4. Mapping and interpretation	Meetings will be organized between researchers involved in the study in order to discuss their interpretations. This process will take into consideration potential differences between the Italian and Belgian focus groups but also between the first two focus group discussions within each country.
5. Charting	The charting step will involve summarizing and reporting the data based on the themes identified through the analysis, as described by Lacey and Luff (40) and will be performed after the final two focus groups and multi-stakeholder discussions involving clinicians and preference experts.

Participants will have the opportunity to ask questions and to discuss concerns with researchers involved in the study. Written informed consent will be obtained without any coercion of study participants. Participants will be made aware that any identifiable information will be deleted and that their names will be replaced with codes (pseudonymized).

5. DISSEMINATION

The findings of this study will be disseminated *via* international peer-reviewed journals and scientific conferences. A summary of the study results will also be written for the lay audience and made available to participants and relevant patient organizations for distribution on their own channels. Patient organizations will be approached to help to disseminate the publication to their members.

6. ANTICIPATED RESULTS

This study protocol will define a list of attributes and attribute levels that will inform the design of a quantitative preference survey. Additionally, this study will provide information relevant from the patient perspective:

- 1. A summary of insights obtained from focus group discussions with NSCLC patients at stage III and IV;
- 2. An identification of themes relevant to patients that will be evaluated in the quantitative phase of the study.

Understanding which treatment attributes patients find important may be especially relevant in lung cancer, where the existence of different (novel) lung cancer treatments with different benefits (e.g., regarding progression-free survival, overall survival, response rate), risks (e.g., fatigue, negative body perception) and other characteristics (e.g., route of administration and treatment schedule) creates uncertainty on the value of these treatment attributes according to lung cancer patients (65). Such uncertainty underlines the value of decision-making by drug developers, regulators, payers and clinicians that takes into consideration evidence from patient preference studies.

This research protocol will be useful to collect information on advanced lung cancer patient preferences. Results from such studies can also inform clinicians and healthcare providers of relevant factors on patient preferences and these characteristics can be incorporated in decision aids that aim to improve shared decision-making between patients and clinicians (12). Understanding what patients believe to be important attributes of their treatment and which risk(s) they are willing to tolerate, could facilitate medical decision-making and could also promote personalized decisions regarding the therapeutic approach and ensure a more precise and collaborative approach with patients (66–69).

This protocol can be used as a resource for drug developers as well as HTA and regulatory bodies who themselves can be interested in designing and conducting patient focus group discussions to enrich their decisions with patient values. The *European Medicines Agency* (EMA) has stated its intent to conduct disease-specific focus groups to include patient preferences in regulatory benefit-risk assessment (25). Another example concerns an exploratory preference study that received advice from the HTA body in the United Kingdom, the *National Institute for Health and Care Excellence* (NICE) (24, 70). This study aimed to determine how patient preference data could be used in HTA; the project consisted of a focus group with multiple myeloma patients to inform a subsequent preference survey. Learnings from this qualitative study can also inform the development of PREFER’s evidence-based recommendations for future preference study developers and assessors on how to assess and use patient preference studies.

Additionally, in view of limited evidence from lung cancer patients regarding newer lung cancer therapies, we believe that the attributes identified through applying this study protocol may be informative for different healthcare stakeholders involved in the development, evaluation, and prescription of lung cancer treatments to understand the value of treatment outcomes as evaluated by advanced lung cancer patients. Specifically, these attributes may inform drug developers, researchers, and patient organizations on patient-centered drug development such as *via* the identification of patient-centered clinical trial endpoints and the development of so-called *Patient Reported Outcome*

*Measures* (PROMs) in clinical trials. Finally, the use of qualitative and quantitative evidence on how important patients find different cancer treatment attributes in marketing authorization and reimbursement decision-making could add to the available clinical evidence on benefits and risks, already considered in these decisions, as well as complement existing decision criteria for marketing authorization and reimbursement.

## 7. DISCUSSION

This protocol describes the four-steps approach of a qualitative study aiming to identify patient-relevant lung cancer treatment attributes and to understand which treatment characteristics are most important for advanced lung cancer patients through a qualitative methodology. The use of qualitative methods will allow transparently document and report the lung cancer patient preferences on treatments.

In this study, the attributes will be developed by adopting both bottom-up and top-down approaches: we will allow to transparently document and report lung cancer patient preferences for treatment characteristics matter most to them, before they are asked to reflect on examples of treatment characteristics retrieved *via* the literature review. Focus groups and the NGT will allow us to select those treatment characteristics found most important for patients and use these for developing the attributes in the subsequent quantitative preference survey.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

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## ETHICS STATEMENT

This study was reviewed and approved by the Ethische Commissie Onderzoek UZ/KU Leuven (reference S63007) and the Ethical Committee of the European Institute of Oncology IRCCS (IEO, Milan, reference 1027/19-IEO 1093). The participants will provide their written informed consent to participate.

## AUTHOR CONTRIBUTIONS

ID and RJ drafted the manuscript. All authors provided substantial input during the study design, critically revised the manuscript, and read and approved the final manuscript.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2021.622154/full#supplementary-material>

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The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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# Barriers and Facilitators to Implementation of Value-Based Care Models in New Medicaid Accountable Care Organizations in Massachusetts: A Study Protocol

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**Introduction:** Massachusetts established 17 new Medicaid accountable care organizations (ACOs) and 24 affiliated Community Partners (CPs) in 2018 as part of a large-scale healthcare reform effort to improve care value. The new ACOs will receive \$1.8 billion dollars in state and federal funding over 5 years through the Delivery System Reform Incentive Program (DSRIP). The multi-faceted study described in this protocol aims to address gaps in knowledge about Medicaid ACOs' impact on healthcare value by identifying barriers and facilitators to implementation and sustainment of the DSRIP-funded programs.

**Methods and analysis:** The study's four components are: (1) Document Review to characterize the ACOs and CPs; (2) Semi-structured Key Informant Interviews (KII) with ACO and CP leadership, state-level Medicaid administrators, and patients; (3) Site visits with selected ACOs and CPs; and (4) Surveys of ACO clinical teams and CP staff. The Consolidated Framework for Implementation Research's (CFIR) serves as the study's conceptual framework; its versatile menu of constructs, arranged across five domains (Intervention Characteristics, Inner Setting, Outer Setting, Characteristics of Individuals, and Processes) guides identification of barriers and facilitators across multiple organizational contexts. For example, KII interview guides focus on understanding how Inner and Outer Setting factors may impact implementation. Document Review analysis includes extraction and synthesis of ACO-specific DSRIP-funded programs (i.e., Intervention Characteristics); KIIs and site visit data will be qualitatively analyzed using thematic analytic techniques; surveys will be analyzed using descriptive statistics (e.g., counts, frequencies, means, and standard deviations).

**Discussion:** Understanding barriers and facilitators to implementing and sustaining Medicaid ACOs with varied organizational structures will provide critical context for understanding the overall impact of the Medicaid ACO experiment in Massachusetts.

It will also provide important insights for other states considering the ACO model for their Medicaid programs.

**Ethics and dissemination:** IRB determinations were that the overall study did not constitute human subjects research and that each phase of primary data collection should be submitted for IRB review and approval. Study results will be disseminated through traditional channels such as peer reviewed journals, through publicly available reports on the mass.gov website; and directly to key stakeholders in ACO and CP leadership.

**Keywords:** value-based care, accountable care organization, implementation, Medicaid, disparities

## CONTRIBUTIONS TO THE LITERATURE

- This study will be one of the first to systematically identify barriers and facilitators to implementing and sustaining a large-scale systems transformation initiative across the duration of the 5-year program.
- Understanding implementation barriers and facilitators will provide important context for interpreting the overall impact of the systems transformation initiative on quality and costs of care.
- Findings of the study are expected to have utility for policy-makers and health system leaders considering implementation of innovative health care delivery models in the U.S. and abroad.

## INTRODUCTION

Global efforts to address the rising costs of healthcare while maintaining or improving quality of care have increasingly included implementation of accountable care organizations (ACOs) (1–3). The value-based payment models used by ACOs incentivize quality of care and cost reduction through payer-provider partnerships in which financial risks are shared. The ACO model aligns financial incentives with improvements in care integration and coordination across health and social service sectors (4), differing from fee-for-service payment models' prioritization of volume and intensity of care. This important shift in financial incentives prioritizes prevention and population health, which has the potential to improve healthcare delivery and clinical outcomes for patients at higher risk for experiencing healthcare inequities and health disparities.

The majority of research on ACOs to date in the U.S. has focused on changes in quality of care, costs, and patient outcomes associated with Medicare and commercial ACO programs (5–17) in the Medicare system, which insures patients age 65 year of age or older. Identifying and understanding the barriers and facilitators to implementing and sustaining the changes in

healthcare delivery encountered by ACOs from the early stages of their inception is critical for interpreting the downstream effects on health care value and patient outcomes. However, prior studies of ACO implementation have focused on Medicare ACOs or been limited to a narrow timeframe or scope (18–20) and none to our knowledge have examined barriers and facilitators to long-term sustainment over time.

The state of Massachusetts's (MA) Medicaid program (MassHealth) contracted with 17 new ACOs and 27 associated Community Partner (CP) organizations in 2018 as part of a 5-year experimental demonstration project, subsequently referred to as the Demonstration. The CPs, an innovative feature of the MA model, work with the ACOs to coordinate and manage care for ACO patients with behavioral health diagnoses or for those who need long-term services and supports (LTSS). This study aims to identify barriers and facilitators to implementation and sustainment of interventions funded by the Delivery System Reform Incentive Payment (DSRIP) program across these new Medicaid ACOs and CPs. The protocol for studying the MA Medicaid ACO experiment's effectiveness at improving quality while maintaining or reducing costs will be reported elsewhere.

## METHODS AND ANALYSIS

### Overview

This study aims to determine the extent to which the organizations that comprise the ACOs and CPs are able to implement the system transformation initiative as intended and to identify facilitators and barriers to implementation and sustainment. The study has two primary aims: to use a mixed-methods, developmental approach to identify issues with implementation early in the ACO experiment so that adaptations may be made if indicated (21) and to produce generalizable knowledge for federal policy-makers and healthcare systems seeking to transform how healthcare is delivered and supported to vulnerable populations.

The study's theoretical framework draws on the Consolidated Framework for Implementation Research (CFIR) (22). CFIR was chosen as the theoretical framework for the study because its domains (Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of Individuals, and Process of Implementation) and the constructs within the domains are pertinent to studying the implementation and

**Abbreviations:** ACO, accountable care organization; MA, Massachusetts; CP, Community Partner; LTSS, long term services and supports; DSRIP, Delivery System Reform Program; SWI, StateWide Investments; CFIR, Consolidated Framework for Implementation Research; MD, Medical Doctor; DO, Doctor of Osteopathy; NP, Nurse Practitioner; PA, Physician's Assistant; LPN, Licensed Practical Nurse; LICSW, Licensed Social Worker.

sustainment of complex interventions, such as healthcare delivery transformation. CFIR is also an appropriate framework for this study because its flexible structure is designed to be used across multiple phases of a study, from design through dissemination. Each of the five domains is explored in at least one of the study's four phases.

## ACOs and the Delivery System Reform Incentive Program (DSRIP)

Accountable care organizations (ACOs) are networks of doctors and hospitals that share financial and medical responsibility for providing coordinated care to patients in hopes of limiting unnecessary spending, meaning they aim to increase the value of the care provided (23). The Patient Protection and Affordable Care Act of 2010 made provisions for Medicare, which insures nearly all people age 65 or older in the U.S., to implement ACOs in its program (24, 25). DSRIP funds “support the restructuring of MassHealth’s delivery system to promote integrated, coordinated care and hold providers accountable for quality and total cost of care (26).” DSRIP funding in MA is a one-time federal investment of \$1.8 billion dollars that phases down over the course of 5 years, after which the programs are expected to be self-sustainable. DSRIP funds pay for programs that support health care delivery transformation in the ACOs and CPs; DSRIP funds also support the MA Statewide Investment program (SWI), which funds activities related to workforce development and retention, technical assistance, enhanced diversionary behavioral health activities, and increasing access for patients with disabilities or for whom English is not the first language (26). Each ACO and CP developed a unique plan to use the DSRIP funds that was tailored to their implementation and sustainment needs and to meet the needs of the patient population they serve (27). The activities funded by the DSRIP program support the ACOs and CPs in achieving the goal of increased value of the care delivered.

## Methods

To achieve the study’s aim, implementation and sustainment data will be collected in four-phases: (1) Document Review to characterize ACOs and CPs; (2) Key Informant Interviews (KIIs) with ACOs’ and CPs’ leadership as well as MassHealth patients in two waves; (3) Site visits conducted with select ACOs and CPs; and (4) Surveys of ACO clinical team members and CP staff. The methods and the analytic plan for each phase are described in detail below; the timeline and goals of each phase of the study are outlined in **Table 1**. The Institutional Review Board (IRB) at the research team’s institution requested to review the procedures for each phase of data collection sequentially. To date, the IRB has determined that Phases 1 and 2 do not constitute human subjects research. Phases 3 and 4 will be submitted prior to beginning these phases and IRB determinations followed.

## Systematic Characterization of the MA ACOs and CPs

The design of the Demonstration gave ACOs and the CPs flexibility in determining their organizational structures and how they plan to utilize DSRIP funding. Given this heterogeneity, we will systematically characterize the organizational structures

**TABLE 1 |** Data sources and timeline.

	Year 1–2	Year 3	Year 4	Year 5
Document review	✓	✓	✓	✓
State interviews		✓		✓
ACO, CP, and MCO interviews	✓		✓	
Consumer interviews	✓		✓	
Provider and staff survey		✓		✓
ACO and CP site visits		✓		✓

of each ACO and CP, patient population, budget for DSRIP funds, and plans for implementing DSRIP-funded programs in Phase 1. This will be achieved through extraction of pertinent data from the Participation Plans submitted by each ACO and CP prior to being approved to participate in the Demonstration. The Participation Plans include ACOs’ and CPs plans for their governing structures, a description of their patient population, and plans for DSRIP implementation. The Participation Plan data describes how each organization intends to change healthcare delivery within their organization, such as by using health information technology to address health-related social needs and hiring community health workers to support care coordination and management. Data elements to be extracted were determined using the CFIR framework: Intervention Characteristics (specific plans for use of DSRIP funds); Outer Setting (population characteristics), and Inner Setting (governance structures, partnerships/networks, and prior experience with value-based care models). The extracted data will be summarized in streamlined reports that provide systematic categorization of the ACOs and CPs. The reports will be made available to the research team members conducting the KIIs (See section methods and analysis) to enable them to tailor interview questions to pertinent aspects of each ACO’s or CP’s unique organizational structure and plans for DSRIP spending and implementation of DSRIP-funded activities and programs.

## Key Informant Interviews (KII)

### Overview

Two waves of semi-structured in-depth interviews will be conducted with representatives of four stakeholder groups: (1) ACOs; (2) CPs; (3) MassHealth staff responsible for administering the DSRIP program, and (4) MassHealth patients. Sample sizes for each group are intended to strike a balance between breadth and depth and to achieve theoretical saturation (no new concepts emerging over three sequential interviews) while minimizing respondent burden (**Table 2**). Interviews will be conducted with each stakeholder group at interim and end-points of the Demonstration; efforts will be made to interview the same participants in each wave to reduce the chance that any changes reported may be more reflective of change in participant rather than change in implementation processes.

### Sampling and Recruitment

ACOs and CPs will be notified by MassHealth that the research team will be reaching out to invite them to participate in the interviews. The research team will then send a standardized

**TABLE 2 |** Sample sizes for study procedures.

	Years 1–2	Year 3	Year 4	Year 5
KII MassHealth Leaders		<i>N</i> = 10		<i>N</i> = 10
KII ACOs (2–3 reps per ACO at 17 ACOs)	<i>N</i> = 34–51		<i>N</i> = 34–51	
KII CPs (1–2 reps per CP at 27 CPs)	<i>N</i> = 27–54		<i>N</i> = 27–54	
KII Patients	<i>N</i> = 30		<i>N</i> = 30	
Provider staff survey		TBD		TBD
ACO site visits for case studies		4 sites		4 sites
CP site visits for case studies		4 sites		4 sites
KII - Key Informant Interview				

introductory e-mail to the contact listed on the ACO's or CP's Participation Plan document. The e-mail will briefly explain the goals of the KIIs and will ask the contact to identify appropriate key informants in their organization; the e-mail will include an attachment with a synopsis of the study. The research team will then contact the key informants identified by the ACO or CP contact *via* e-mail to address any questions and to schedule the interview.

A Senior Manager at MassHealth will provide the research team with contact information for MassHealth leaders responsible for administering the DSRIP program. These representatives will be invited to participate in an interview *via* e-mail. Sampling will aim to achieve a breadth of experience among those administering the DSRIP program.

For interviews with MassHealth patients, MassHealth leadership will inform contacts at the ACOs and CPs that the research team will be reaching out to them to identify patients who may be willing to share their experiences with changes in healthcare related to the DSRIP program. To understand the needs of as many patients as possible, the research team will review the nominations and purposively recruit patients who are most likely to have experienced changes in healthcare delivery related to the DSRIP program due to the following conditions: (1) medical complexity (multiple medical conditions, which may involve multiple medications and/or high utilization of medical care); (2) living with a disability; (3) receipt of LTSS and/or behavioral health services through a CP; there will be an emphasis on recruiting patients with substance use disorders (SUD); and (4) parents of children utilizing MassHealth (Table 3). Patients who have conditions or life situations that place them in multiple categories (i.e., medical complexity and raising a MassHealth pediatric patient) will be recruited based on one of the target conditions.

### Interviews

Interviews will be conducted by trained research staff using semi-structured interview guides tailored to the interview population (Appendix B). Interview questions were developed using the CFIR framework as a guide and include questions pertaining to Outer Setting, Inner Setting. The interviewer will review a study fact sheet with the participant and answer questions prior to beginning the interview. The interview guides for ACO and CP

**TABLE 3 |** Sampling strategy for patient key informant interviews.

Patient category	Number of interviewees	Percent
Medically complex	10	33.3%
Patients with disabilities	5	16.7%
Pediatric patients	5	16.7%
CP-BH	6	20%
CP-LTSS	4	13.3%

leadership were developed by the research team and pilot-tested with one ACO and one CP. For the patient interviews, an external stakeholder with extensive experience in this arena reviewed the guides for accessibility. Interviews are expected to last ~60–90 min and will be audio recorded and professionally transcribed.

Interview questions for ACO and CP leaders will elicit perspectives on state actions to support delivery system transformation and the effectiveness of these actions. The interviews will aim to understand the factors that facilitate and impede organizational transformation in relation to three CFIR domains: Inner Setting, Outer Setting, and Process. For example, ACO and CP leaders will be asked how prior experience with other value-based payment models informed early stages of implementation in their organization (Inner Setting) and what, if any, factors external to the organization and the DSRIP program they feel may have facilitated or hindered implementation of DSRIP activities or may facilitate or hinder sustainment (Outer Setting).

Interviews with MassHealth leaders will similarly focus on implementation of the DSRIP program, but given their high-level administrative roles, interview questions will also explore implementation of the DSRIP program in the broader context of program and policy implications for the future. Interview methods will otherwise follow those described for ACO and CP interviews.

Interviews with MassHealth patients and caregivers of pediatric MassHealth patients will be conducted *via* telephone and will include questions relative to Outer and Inner Settings in the CFIR framework. To ensure patient interest, accessibility requirements, and understanding, an initial outreach call will be made to inform patients about the project, determine if there are any barriers, such as language or disability, and schedule a time to conduct the interview. Efforts will be made to involve translation services or to accommodate other needs as they arise. Patients will be given a \$50 gift certificate as a thank you for their time and candor.

### Analysis

Interview data will be analyzed using framework analysis (28, 29) and will focus on barriers and facilitators to implementation and sustainment within the three CFIR domains that were the focus of interview questions. We will first establish Interrater reliability among coders (through a process of concurrent open coding of an initial set of interviews, comparison of coding approaches, and refinement of code definitions as needed); the remaining interviews will be coded independently by patients of the analytic



team. Once all interview data are coded, secondary coding (combining codes and creating sub-codes) will be performed and analytic matrices with the final coded data created to facilitate across- and within-stakeholder group analysis with respect to perceptions of state actions supporting delivery system transformation, barriers and facilitators to care, and the overall patient experience. Dedoose software (30) will be used to manage, code and analyze interview data, and calculate Cohen's Kappa coefficients (31) to monitor agreement among coders over time.

## Case Studies

### Overview

Two waves of site visits will be conducted with a subsample of ACOs and CPs at interim and end-points of the Demonstration to inform case studies (Table 1). The first and second wave of site visits will aim to achieve a deeper understanding of the specific healthcare delivery system innovations that ACOs and CPs are implementing and the contextual factors that may be facilitating or impeding implementation of DSRIP-funded activities and programs (32). The second wave of site visits will also seek to achieve a thorough understanding of facilitators and impediments to sustainability of the ACO and CP models after the end of the DSRIP program.

### ACO and CP Sampling

In the first wave of site visits, the research team will examine up to four ACOs and four CPs that have achieved different levels of success in transforming care delivery for their MassHealth patients. ACOs and CPs will be selected based on a combination of: (1) their progress in implementing DSRIP-funded projects and (2) differences in organizational structure and populations served. The timing of the site visits will be determined by what is learned from the other data sources with respect to the two dimensions sampling is based upon. For instance, if the research team is able to identify ACOs and/or CPs that excel on implementation of the DSRIP program or are struggling by the 2nd year of the Demonstration, each could be the subject of a site visit. At the same time, it may take until Year 3 of the Demonstration for such patterns to emerge. In sum, we will conduct up to eight site visits between Year 2 and 3 of the study (Table 1). The second wave of site visits will take place in Year 5; up to four ACOs and four CPs that represent higher and lower levels of performance as defined by level of change and/or achievement related to accountability scores being used by MassHealth to determine shared risk payments. For both waves, the site visits will focus on the healthcare delivery transformation activities related to DSRIP that the ACOs and CPs have initiated and the barriers and facilitators to effective implementation, performance, and sustainability.

### Site Visit Procedures and Case Study Development

Semi-structured interviews and focus groups will be conducted with front-line clinical team members, including providers and staff, who are closely involved with DSRIP implementation and who represent a range of functional roles. Participants in site visit interviews and focus groups will differ from participants in the KIIs, focusing on those responsible for coordinating and delivering clinical care at the ACO and

CP practice sites. Participants will include: (1) clinical leads (e.g., medical directors and nurse managers); (2) operational leads (e.g., office managers); (3) heads of health information technology (HIT)/health information exchange (HIE); (4) heads of quality improvement; and (5) heads of support services such as case management. In addition, we will interview representatives of ACO governing boards, Patient and Family Advisory Committees, and selected CPs. At CPs, interviews will be conducted with the following functional roles: (1) clinical leads; (2) administrative directors of CP programs; (3) heads of Health Information Technology/Health Information Exchange. Interview guides will cover similar topics/CFIR domains to those used in key informant interviews with leaders, but will explore more pragmatic aspects of implementation experienced by front-line providers and staff, including constructs in the Characteristics of Individuals domain.

### Analysis

Analysis of semi-structured interview and focus group data will follow the process described for KIIs to construct a case study for each site (32). In addition, the site visit data will be triangulated with data collected Phases 1, 2, and 4 to compare and contrast perspectives of those in different roles within the ACO and to explore how the site visit data confirm or conflict with related data from other sources.

## Survey of Front-Line Providers and Staff at ACOs and CPs

To understand how a large sample of front-line providers and staff (e.g., community health workers, social workers, MDs, DOs, NPs, PAs, nurses) experience changes in care delivery related to the DSRIP program, two waves of front-line provider and staff surveys will be conducted at interim and endpoints of the Demonstration. Surveys will aim to assess the degree to which implemented projects and ACO/CP formation are translating into changes in care delivery from the perspective of front-line ACO providers and CP staff. The survey will provide an opportunity to quantitatively measure and compare these experiences between groups of providers, practice types, and ACOs that differ in important characteristics.

### Questionnaire Development

The questionnaire used for the survey will incorporate the previously validated measures of perceptions of care integration from the Provider and Staff Perceptions of Integrated Care (PSPICs) (33) and new questions developed and pilot tested by the research team to address specific aspects of implementation of the DSRIP program. CFIR domains explored will include Inner Setting (care coordination within the practice site and with external providers and community resources); Outer Setting (patient engagement, MassHealth policies and processes, payment and financial incentives) and Processes (practice site structures and processes). The questionnaire will be pilot tested with a convenience sample of ~10–15 ACO providers and 5–10 CP staff with similar roles to those to be included in the survey sample. Pilot testing will include cognitive testing and assessments for clarity, completeness, and respondent burden.

### Sampling and Administration

The sampling frame for the ACO provider survey will include providers practicing at group practices, community health centers, and hospital licensed health centers participating in the ACO program at the time the program launched (i.e., 2018). Providers at solo physician practices, outpatient hospitals, practice sites located outside of Massachusetts, sites with fewer than 50 MassHealth patients, and sites with an unknown number of MassHealth patients will be excluded. From within the sampling frame, up to 30 practice sites per ACO (including all sites for those with <30 sites and a random sample of practice for ACOs more than 30 practice sites), thereby oversampling the ACOs with fewer practice sites. The providers practicing at the 353 unique practice sites in this sample will constitute the sample frame for the survey of ACO frontline providers.

The research team will collect provider contact information from practice and ACO administrators. The questionnaire will then be emailed to a random sample of eligible providers (MDs, DOs, NPs, PAs, RNs, LPNs, and LCSWs) for each ACO. Stratified random sampling is expected and the sampling fraction will vary by ACO and provider type such that less prevalent characteristics are oversampled. The contact information for CP staff will be collected from administrators at all 27 CPs and the questionnaire will be emailed to a random sample of staff. As with the ACOs, stratified random sampling is expected and the sampling fraction may vary by CP staff roles such that less prevalent roles are oversampled. The required sample size will be determined based on anticipated response rates and power calculations performed prior to random selection of providers and staff.

### Analysis

The results of each survey wave will be analyzed overall, by ACO characteristics, practice site characteristics, and by provider/staff characteristics to explore heterogeneity in provider/staff perspectives of the ACO and CP programs. Changes over time between wave one and wave two of the survey will also be examined overall, by ACO characteristics, practice site characteristics, and by provider/staff characteristics. Findings from the survey will be used to measure provider/staff understanding of the ACO and CP programs, their perceived effectiveness, and the concordance of perceptions between front-line providers/staff and their organizational leaders. Findings will also be used to assess the relationship between providers' perceived experience of transformation and ACO/CP care quality and cost performance. In addition to crude analyses, sampling and non-response weights will be applied to obtain estimates that are adjusted for the multi-stage sampling approach and observed sources of non-response bias.

## DISCUSSION

This will be one of the first in-depth longitudinal studies of barriers and facilitators to implementation and sustainment of a large scale, policy-driven, state and federal government funded intervention that aims to improve healthcare value for a vulnerable population of publicly-insured patients. The patient population served by the new Medicaid ACOs in

MA is a experiences socioeconomic and racial/ethnic health disparities and healthcare inequities that are not addressed well in traditional models of healthcare delivery in the U.S. The shared risk ACO model, which incentivizes increased value, has the potential to transform healthcare delivery to better address the complexity of social determinants of health within the healthcare system.

The Demonstration is a natural experiment; as such, the DSRIP-supported interventions to facilitate implementation and sustainment of the new ACOs are taking place in uncontrolled settings. Although this limits the capacity to directly compare specific strategies for implementing and sustaining the transformations each ACO and CP undertakes, it also allows for in-depth study of the implementation in a real-world setting. This study is expected to offer important insights into the mechanisms of transforming healthcare delivery and finance to meet the complex medical and social needs of patients in health disparity populations.

## ETHICS AND DISSEMINATION

### Ethics

The Institutional Review Board (IRB) at the investigative team's institution determined that the overall study did not constitute human subjects research. Each phase of primary data collection will be submitted for IRB review and approved protocols adhered to. Because the investigation is part of a federally mandated evaluation of a state-led intervention, reports of the investigation will ultimately be made available to the public. This level of transparency reinforces the need to ensure that all data be reported in aggregate and ensure that any individuals will not be identifiable.

### Dissemination

Study results will be available to the public on the mass.gov website. Results of the study will be disseminated through multiple channels: (1) peer reviewed journal publications; (2) presentations at national research meetings; (3) publicly available reports to the Center for Medicare and Medicaid Services; (4) publicly available summaries posted on the MassHealth website; and (5) directly to key stakeholders in ACO and CP leadership.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by University of Massachusetts Medical School. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.



## AUTHOR CONTRIBUTIONS

SG contributed to development of the protocol to study implementation of the DSRIP program and led writing of the manuscript. DG led development of the protocol, reviewed the manuscript, and approved the final version. MA, AK, and JN contributed to development of the protocol, revisions of the manuscript, and approved the final version of the manuscript. JH oversaw development of protocol, reviewed the manuscript, and approved the final version of the manuscript. All authors contributed to the article and approved the submitted version.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2021.645665/full#supplementary-material>

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The reviewer DR declared a shared affiliation, with no collaboration, with one of the authors, DG to the handling editor at the time of the Review.

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# Universities as Partners in Primary Health Care Innovation

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Universities have a unique role in the health ecosystem as providers of trained staff and discoverers of health innovations. However, often they sit in silos waiting for their rare blockbuster discoveries to change clinical care or seeing health services simply as future employers of their graduates or clinical trial sites. It is a transactional and targetted relationship. This present case study is of a primary health service Access Health and Community (AccessHC) in Australia and its university partner Swinburne University of Technology. Together they established a Kickstart Program which was to provide seed funding for small joint innovation projects generated by both organisations. One project exemplifies the approach. Swinburne who has a Design School was encouraged through the Kickstart Program to design a clinical waiting room of the future. This project started with a needs analysis. The written report was to inform the design. University staff linked with their internal University animations expertise to better communicate the needs analysis. The “Access me Not” animation was created, unknown to the staff at AccessHC. At initial presentation, the way the animation communicated was not imaginable by AccessHC. “Access me not” was submitted for the 2018 International Design Awards and received an honourable mention. However, the AccessHC staff saw other uses for the approach and contacted Swinburne to design a client journey animation for the newly introduced National Disability Scheme (NDIS). The co design produced an animation of immense help to parents in navigating the scheme for complex and chronic disability care and for AccessHC the scripting served as a framework to develop its new internal NDIS care systems and processes. The Swinburne team is now producing health navigation animations for the State Department of Health and Human Services. The Kickstart Program was an engagement strategy that has produced a set of health communication tools that the health service could not have envisaged and which the University could not have imagined an application. Small low risk seed funding can indeed introduce innovations and create beneficial relationships between health services and universities.

**Keywords:** university, primary care, partnership, innovation, community

## INTRODUCTION

Universities occupy a privileged place in society as centres of the creation of knowledge and core facilitators of advanced teaching. Universities are significant economic entities within the communities in which they are located. There has been historical research into the relationship between Universities and the communities in which they are embedded (1). However, University

linkages to communities in which they are located are often weak and there has been limited research into how to improve the connexions between Universities and communities, including commercial entities (2, 3). The focus has been on linkages with large corporations rather than community organisations which are often excluded in the analyses. There may be multiple reasons for the perceived lack of interaction between Universities and primary care organisations.

Firstly, in health care, the tertiary sector is well-organised in large hospital networks in most countries and is well-understood. Primary health care, on the other hand, involves the local diagnosis and treatment of acute and chronic illnesses in health care settings outside of hospitals. This also includes health promotion and disease prevention programs. Primary health care is often in the hands of small and even solo scale practises. In 2018, only 15 of the 38 countries in the OECD had primary health care services based on integrated teams or networks (4). This fragmentation makes interactions and translation of research between Universities and primary health difficult because of different scale, different resource capabilities and limited opportunities for cross communication. Small community organisations do not have the ability to expend resources in developing the relationship (5). In a review of primary health care research in Canada it was found that there was limited capacity within the primary health care sector for research (6). Partly this was due to the service delivery imperatives but also the isolation of potential researchers within small organisations. This is similar to many countries.

The University drivers for engaging in primary health research and innovation are not strong, especially outside the discipline of general medical practise.

In general, most governments fund primary health research at a lower level than other areas of health research as for example happens in the UK (7), despite the UK being an example of a well-organised primary health system. Major primary health journals are lowly rated in the health journal rankings (see<sup>1</sup>). There is also a bias towards traditional research areas which are better funded and where the risks and rewards are well-understood. An impact at a local community level may be perceived to be of less value than broader research areas, especially those that are product and not systems oriented. Finally, community based innovation is unlikely to produce a commercial pay off so commercially funded research in the sector is also limited.

The initiation of this case study was the dilemma of a resource constrained, primary health service Access Health and Community (AccessHC), with little tradition of innovation. AccessHC sought to embed an innovation culture to support service development and improvement. The task was set as a whole of organisation initiative applicable to all health and clinical disciplines within its services. AccessHC reached out to Swinburne University of Technology (Swinburne) in Melbourne, Australia, with a view to develop a sustainable innovation partnership which was of mutual benefit. From the outset the case recognised that the drivers for the University to participate

in the collaboration were not strong and the emphasis was on relationship development rather than a targeted research area.

The case describes the processes which led to the establishment of an ongoing relationship and some of the tangible outcomes for both parties in primary health care.

## CONTEXT

Melbourne, Australia is a large well-developed city of about 5 million residents with sophisticated Universities, health research institutes and teaching hospitals. Its population has access to free health care in a public/private model but disparities in health access for people of different economic status are significant. Access Health and Community is a small not for profit, independent primary health service in Melbourne Australia. It provides access to health services regardless of ability to pay. It is a charity. Relative to hospital networks in Melbourne, AccessHC is small and relies on a mix of government and fee for service income. It is different from solo-practise primary health care in that it sees its role as integrative and delivers almost all primary care disciplines and activities with over 300 staff. The clinical delivery areas are broad leading to an aspirational multidisciplinary approach over primary care medicine, mental health, dentistry, aged care health services, disability care, nursing, and physical therapy. Its purpose is “Building Healthier Lives Together” [See (8)]. In terms of primary health services, it fits the description by the OECD of being part of a typically small and fragmented system (4). Innovation and change are at the edge of possibilities for AccessHC in a budget stretched to meet community demand.

Swinburne University of Technology has about 42,000 students and 3,000 staff in Melbourne. It is one of seven Universities in Melbourne, Australia. Its footprint in health is small relative to some of the other universities in Melbourne. It does not have either a medical or dental school for example and at the start of the case study no nursing and limited allied health programs. Part of its strategic plan is to connect with business, industry, and community (9). It only recently became a University in 1992.

Prior to 2014, the two organisations had little contact beyond some linkages of individual staff members. The main Swinburne Campus was less than 15 metres from the largest AccessHC clinic. The question was could the two organisations connect for mutual benefit. The case began in 2014 and was still ongoing in 2021.

An important part of the context was the limited direct disciplinary connexion between Swinburne University and AccessHC. This prompted a focus on relationship and cross-disciplinary relationships rather than a targeted research topic.

## DETAIL

### Starting the Relationship

The initial steps were from AccessHC in a reach out for a collaboration with Swinburne. Initially this included information about AccessHC for distribution through the Swinburne University Office of Collaborations and Partnerships (10). This office proved fundamental in creating opportunities with the

<sup>1</sup>[https://scholar.google.com/citations?vie18w\\_op=top\\_venues&hl=en&vq=med\\_primaryhealthcare](https://scholar.google.com/citations?vie18w_op=top_venues&hl=en&vq=med_primaryhealthcare) (accessed 5 July, 2021).



wider university beyond expected health faculty contacts in all phases of the program. Indeed, all areas of the University engaged in discussions including more distant disciplines such as accounting and engineering. Looking back, the most prolific engagements and outcomes came from the Design faculty, not health.

As can be seen in **Figure 1** the initial step was setting the framework for collaboration and leadership buy in. A memorandum of understanding (MOU) was created. This was a non-legally binding document that described both organisations desire to collaborate. This was signed off at the highest levels of both organisations: the Vice Chancellor in the case of Swinburne University and the Chair of the Board in the case of AccessHC [See (11)]. The high-level support was fundamental in establishing the collaboration as important for both organisations through public acknowledgment to both staff groups. The MOU was signed after about 18 months of low-level interaction. For AccessHC, it was a visible step in making innovation important for the strategic leadership group which largely was focused on operational development. The MOU gave a prestige touch point for the Board of Directors of AccessHC to value the relationship and commit to its success despite important competing demands of a small health service.

Behind the memorandum of understanding were two other initiatives. The first was the Kickstart Program. The Kickstart Program is a fund created by AccessHC to facilitate collaborations with Swinburne. Its intention was small scale seed funding to facilitate interactions between AccessHC and Swinburne University and to create links between Swinburne and AccessHC. The Kickstart Committee had equal numbers of representatives from each organisation. Its annual budget was modest between \$30,000 and \$50,000 (AUD). The preamble was: "AccessHC has the ambition to be an excellent primary health service founded on encouraging innovation. In these Kickstart Fund Projects, AccessHC is looking for ideas about something that ultimately would make a practical difference. Some ideas will come from AccessHC but equally ideas may come from Swinburne." It should be noted that from the outset there was not an overarching project idea, discipline area or single focus. Rather the Kickstart Program was designed to facilitate the relationship. To some extent the Kickstart Program was an incentive for Swinburne University to value to relationship, at least in the beginning. It also was a process which both organisations could contribute to meaningfully.

The projects funded by the Kickstart Program were governed by a Master Research Agreement between Swinburne and AccessHC and this was the second background structure. This agreement detailed generic legal project requirements including intellectual property arrangements. Its chief benefit was that any new project could be approved quickly without reference to legal representatives of either organisation or any new negotiation. The agreement protected existing intellectual property but gave AccessHC certain rights on any intellectual property created by the project. This was the second important step in **Figure 1** in having the systems and processes to make collaboration easy.

## Generating the Ideas: Innovation Tournaments

From the outset, AccessHC had only a small understanding of the interests and capabilities of Swinburne University to contribute to its health service. AccessHC also did not have a firm idea of its own problems seeking solutions. There was an ever present operational focus which was all consuming. This background meant that time had to be created to generate ideas for interaction and innovation. Innovation tournaments of various descriptors have been proposed and utilised as an idea generator forum (12). Based on this, the Darwinian team (Davis, Lee, Ulrich, Girotra, and Terwiesch) have developed an innovation tournament tool Darwinator (13) which assists in the core tournament processes of idea generation, idea shortlisting, idea pitching and idea selection. This was brought to AccessHC after the Author's participation in an INSEAD Program Innovating Health for Tomorrow (14). The key issues for implementation at AccessHC were selecting the participants, background learning and creating the time for staff to participate. The time pressures were acute as AccessHC was in a constrained funding situation and not all staff were located at the same location. It was decided to limit the tournament to managers and above. A short YouTube video was prepared on the basics of the innovation tournament and an email campaign instituted to solicit initial ideas over a period of several weeks culminating in an innovation workshop. At the day long innovation workshop, the group of about 20 managers generated 125 ideas with a final shortlist of about five decided at the day workshop.

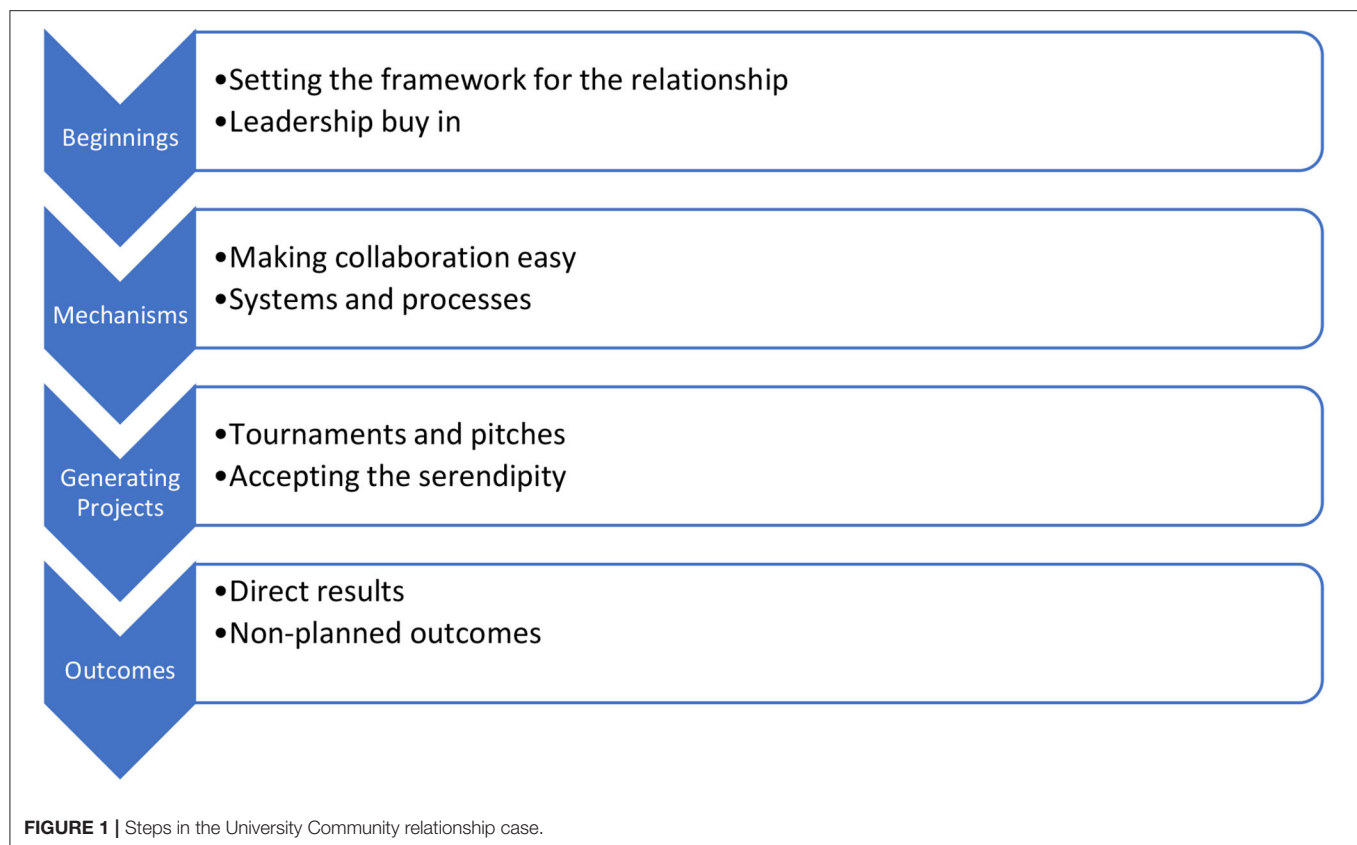
The second iteration of an innovation tournament was an organisation wide innovation tournament with no face-to-face component but with YouTube videos to support the process supported by staff emails. This yielded only 25 ideas and very limited engagement despite email follow ups.

The final iteration was to ask the University to utilise the Darwinator tool. This had limited engagement by the University who indicated that it had its own tools but did not generate any take up by the University.

The key learnings from these exercises is that innovation tournaments require much work to promote engagement particularly in an organisation such as AccessHC with little background in innovation, facing day to day operational challenges. Face to face and dedicated time seems quite fundamental for success and this fits with other studies that participation intensity is required for tournaments to be successful (15).

## Generating the Ideas: The Innovation Pitch

Swinburne University arranged an innovation pitch session. Within the University there was an invitation for academics to consider if their work areas could align with AccessHC. There were preliminary meetings between senior Swinburne and AccessHC staff where the background of AccessHC was explained. These meetings were a combination of understanding AccessHC values and history and needs. This was followed up with a broad outline of intent of the collaborations and hints at potential opportunities. They were facilitated by the Swinburne



Office for Partnership and Collaboration and involved Senior Executives of AccessHC. Following up on this was a Swinburne wide invitation for staff to participate in a “pitch session.” The pitches were in a formal context with Swinburne staff pitching to AccessHC executive and management in the audience. No decisions were made at the pitch session which in general were descriptions of current Swinburne Research directions seeking alignment with potential projects at AccessHC. At the end of the sessions, introductions were made between the two groups for further discussion and development which in many cases led to a submission to the Kickstart Program. Those staff unable to pitch were able to make a written submission to the Kickstart Program. From the pitches about 12 opportunities were presented to the Kickstart Program.

### The Kickstart Program: Making Things Happen

The Kickstart Program was funded by AccessHC to stimulate interactions with Swinburne University and was managed by a Kickstart Committee. In the initial iteration the projects emanated from AccessHC and had a design focus: Design of the Consulting room of the future and the Waiting room of the future both were initial projects. In both projects the biggest findings were the feedback from patients and clients consulted by the University staff and students involved rather than the design work itself. These findings continue to influence program design even if laterally. After the 2 years of operation the Kickstart Program was presented with a larger list of potential projects

from both AccessHC and Swinburne University where only a few were actually funded. However, in many cases, even the unfunded projects were used to bring academic staff and clinical staff together and the projects outcomes were facilitated without funding allocations. In recent times the projects have been more likely to have a clinical or advocacy dimension. For example, recent projects were on the value of routine exercise on treating depression and the social media influences on alcohol drinking behaviours both of which are in the process of being published. Importantly both may produce changes in AccessHC strategy in its mental health and alcohol and other drug programs. Ultimately, the seed investment by AccessHC opened the doors to wider interaction and positive return on investment. This is the third step of the process in **Figure 1**.

### One Idea Leads to Another

Whist directed research and innovation was funded in Kickstart, Kickstart was always meant to seed ideas so that they could develop in multiple directions. An example was the waiting room project. Swinburne who has a Design School was encouraged through the Kickstart Program project to design a clinical waiting room of the future. The project was suggested by AccessHC as a response to one of its outdated clinic waiting rooms within a repurposed heritage Post Office which was over 100 years old. This project started with a needs-analysis of needs by Swinburne University over a 6 month period with interviews of patients and staff in the current waiting room. The written report was created to inform the design. However, University

staff linked with their internal University animations expertise to better communicate the needs-analysis to AccessHC. The “Access me Not” animation was created, unknown to the staff at AccessHC as a clarity aid to the written report [see (16)]. At initial presentation, the way the animation communicated the patient experience was not envisioned by AccessHC. “Access me not” was submitted for the 2018 International Design Awards and received an honourable mention.

“Access Me Not” is not publicly available as it is an internal document. However, the use of animations to explain a patient experience was new for AccessHC staff. Many of the issues in primary health revolve around patient engagement (17) and the Swinburne animation was a new avenue for AccessHC staff to explore. For example, AccessHC staff saw other uses for the approach and contacted Swinburne to design an animation of a client journey for the newly introduced National Disability Insurance Scheme (NDIS) a new scheme to support members of the community with a disability. The co design produced an animation of immense help to parents of children with developmental difficulties in navigating the scheme for complex and chronic disability care. For AccessHC the scripting was timely and served as a framework to develop its new internal NDIS care systems and processes [see (18)]. The Swinburne team is now producing child health navigation animations for a range of health organisations. Latest iterations include producing the animation in other languages and a Chinese language version has been completed. It is unlikely that in a traditional project funding process that the serendipity effects could be as easily exploited as happened through Kickstarter. In the case of Access Me Not, the total ultimate funding for all of the downstream initiatives was probably equivalent to a regular funded project but it came in small quickly developing steps worked on by both AccessHC and Swinburne.

## Traditional Interactions Value-Add

From the very outset, the relationship did not rely on a prescribed activity or research area but on facilitating the relationship. However, there were also traditional interactions which acted as trust building activities. Trust is recognised as a major enabler of Community-University collaborations (19). AccessHC opened its clinical areas to provide placement training for postgraduate Swinburne students in occupational therapy. Indeed, the clinical training is a well-recognised way of Universities seeing benefit in interacting with health services through meeting accreditation requirements in professional degrees, preparing students for the workplace and staying contemporary with current clinical practise (20). This linkage proved valuable for both organisations. Often clinical training places are limited and Universities struggle to deliver the workplace training required for accreditation purposes. The AccessHC environment of community as well as clinical services opened enhanced learning opportunities particularly in interacting with diverse client groups. The benefits were mutual. Swinburne University hosted TOM Makeathon (21), which was a hackathon weekend to develop aids for those with a disability in a multi-disciplinary innovation workshop (22). The initial event, which now happens annually, was hosted by Swinburne University. AccessHC occupational therapy staff

were invited to participate. This opened a new innovation opportunity beyond their day-to-day clinical requirements. Staff feedback and engagement were facilitated by the opportunity and an example outcome was a prototype for a portable wheelchair ramp where AccessHC staff participated as part of a multidisciplinary team (23). Without the Swinburne association it would have been unlikely that the event would have engaged AccessHC staff.

## Outcomes

Some of the outcomes from the collaboration are listed on the Swinburne website (24). They include significant health service design tools and work such as a homelessness tool, a social prescribing framework and design work some of which is also published and informs AccessHC practise and service delivery (25–27). The animation work on the AccessHC YouTube channel (25) and numerous other publications and conference presentations. The animation work led to a wider use of the format in health information campaigns beyond AccessHC. AccessHC also used private animations custom produced by Swinburne in advocacy campaigns with politicians. These in part may have resulted in wider health policy development.

The more intangible outcomes were participation in strategy development in both organisations. AccessHC had staff represented on Swinburne Advisory Committees such as supporting the foundation of the Swinburne Living Lab Initiative (28) and conversely, Swinburne academic representation on the youth mental health Headspace: Hawthorn service (29) that AccessHC led the formation of. The outcomes are ongoing.

## DISCUSSION

The essence of the case is a planned interaction (**Figure 1**) between a University (Swinburne) and a small primary health service (AccessHC). The planned interaction replaced previous piecemeal approaches based on individual relationships. Swinburne was used to dealing with large and even multi-national strategic partners. However, there was an alignment of values with AccessHC where impact in the local community was important to the University and embedded in the Swinburne Strategic plan (30). This local community view was explicit in the Swinburne Strategic Plan and gave alignment to the initial relationship with AccessHC. AccessHC had “innovation” as a value (29) but its day to day operational requirements made this somewhat aspirational. Its embeddedness into community was a fundamental part of the AccessHC strategic plan (31). Discussions with AccessHC at the beginning was an exploration of values and the history of AccessHC which is a health charity with a 150 year history (32). Without values alignment it is unclear whether the relationship would have started. The groundwork was laid from that shared perspective through multiple background meetings.

Four elements were important in setting the framework for the relationship and making collaboration easy. The first was the Swinburne Office of Collaboration and Partnership who guided the discussions within the University, organised meetings and promoted the potential relationships across all discipline areas



within Swinburne. This was a significant resource commitment by the University maintained over 4 years of organisational and personnel change. It maintained momentum throughout.

The second was a formal memorandum of understanding between AccessHC and Swinburne (11) which was a public affirmation of the relationship particularly for staff of both organisations in deciding whether to engage or not. Within AccessHC this also played a role within its Board of Governance highlighting the strategic importance of the activity and elevated the relationship to a major imperative.

The third element, making collaboration easy, was a master research agreement which once negotiated simplified approvals of subsequent projects and removed bureaucracy. It was not unusual for a 24 h approval process.

The final element was the AccessHC Kickstart Program. This was funded entirely but modestly by AccessHC. There have been 5 years of operation and it continues. It served as both a conduit for projects and a beacon for the relationship which everyone could point to. In a transactional sense it was a joint forum for the approval of projects. Without the Kickstart Program there would not have been such a visible sign of potential collaboration. The visibility of Kickstart was important for both organisations in justifying the effort in the relationship.

There were several ways tried to generate projects. The results of innovation tournaments were mixed. An intense innovation tournament campaign which was resource intensive produced better results than an online campaign without face-to-face interactions. This is broadly in line with research into characteristics of successful innovation tournaments (12, 15). The Darwinator program (13) which is an innovation tournament platform was a useful aid. However, without intense engagement activities with staff, the tool was not a significant generator of ideas. To some extent this may reflect the need to create workspace and time in a service delivery organisation, such as AccessHC, for innovation to occur. The importance of dedicated resources to manage innovation tournaments has been previously reported (15). This suggests that for innovation tournaments to be successful in a busy work environment that the resource issue in people, time and place are very important. The case suggests that if this cannot be met that the program may not be of benefit.

The pitch session organised by Swinburne for academics to describe their work and ideas was a safe environment for academics. It offered them an opportunity to describe their research interests to AccessHC staff without necessarily adopting a problem-solving mission for AccessHC problems. The lack of relevance in some cases meant a low level of take up. On the other hand, it proved useful in developing connexions and subsequent discussions between the two staff groups which in some cases resulted in joint projects at a later time. This highlighted that successful projects satisfied both the AccessHC goal and the Swinburne goal.

The missing part of the case study was a robust mechanism for the generation of ideas, problems and solutions which involved both organisations and which would lead to active projects. From the learnings, a well-resourced and facilitated innovation tournament involving both organisations with face to

face components seems to offer most prospects. It would fulfil the getting together for a purpose with the added benefit of shared ideas generation.

The role of serendipity or unforeseen consequences cannot be under-estimated in generating both projects and outcomes. The relationship spawned unforeseen projects, events and ideas. The easiest example was the consequences of the design project to create a waiting room of the future. The waiting room design project initiated by AccessHC and fulfilled by Swinburne led to the wide use of animations to help navigate health programs within AccessHC but also beyond to other organisations (33). It was borne by Swinburne colleagues using animations to describe their analysis of waiting room issues to AccessHC and was completely unexpected by AccessHC. The reason for the success of serendipity probably rested with the Kickstart funding being small, flexible and easy to approve. This meant that there was little risk in halting or changing directions. Some of those direction changes were funded independently of Kickstart fulfilling the seed funding ambition of Kickstart.

## Influence of COVID

In 2020 Australia had stringent international and interstate travel bans due to COVID-19. Melbourne had a prolonged hard lockdown of 112 days (34). This affected both organisations in different ways. For Swinburne University, the most of 2020 was without on-campus learning and most staff were working from home. For AccessHC COVID was a major health event to which it had to respond with staff having to deliver more health and community services safely in very constrained circumstance. Even in the midst of the COVID waves, the two organisations discussed how they could work together in setting up boutique manufacturing of face masks through the Swinburne Manufacturing faculty and repurposing of laboratory supplies to functional hand sanitizers. Neither eventuated, but the supportive relationship continued.

The Swinburne project was put on hold during COVID. However, it seems resilient and coming out of COVID in 2021 both organisations have re-committed to the relationship. The formal Memorandum of Understanding was updated for a new signing with a new University Vice Chancellor and new CEO of AccessHC. The Kickstart projects previously not allowed to operate during lockdown in 2020 are again in operation. The Kickstart Committee reviewed its operations to again solicit projects and ideas later in 2021.

## The Future

Not all discussion led to viable projects. In some cases, it was because of lack of relevance to AccessHC, lack of interest to University Academics or practical or resource issues. Nevertheless, the relationship endured and continues to generate new projects. The Kickstart Program continues to be a focus to harness projects and ideas. As outlined by Swinburne (19), prior to COVID the majority of “live” projects did not require funding and simply the bringing together of staff of both organisations. The question is whether the case study could be used as a framework to other organisations. The elements appear sound but a missing part of the approach is the unwritten a dedication

from both organisations to make it work. Without this upfront commitment the results may not be so evident. Some of the case study elements are instructive in generating commitment and engagement.

## DATA AVAILABILITY STATEMENT

The original contributions generated for the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## AUTHOR'S NOTE

Towards the end of the case study, the author was appointed as an Adjunct Professor of Swinburne University of Technology,

which is an unpaid honorary position, and served in an unpaid honorary capacity on external advisory committees for the Bachelor Health Sciences at the University and the Swinburne Centre for Mental Health.

## AUTHOR CONTRIBUTIONS

The author confirms being the sole contributor of this work and has approved it for publication.

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**Conflict of Interest:** The author was CEO of AccessHC during the case period reported, a paid position with chief executive responsibility.

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# Digital Health Value Realization Through Active Change Efforts

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Digital health has massive potential in health care but has been slow to evolve in comparison to other information-intensive industries, which have more readily taken advantage of new technology. One of the key barriers has been the complex relationship between the perceived return on investment for the investor and the resulting value to patients and caregivers. Those actors who pay for technologies do not always see an appreciable return for themselves, while those actors who must apply the technology to generate value are not always incentivized to do so. This misalignment across health system payers and administrators, clinicians and patients must be better understood and addressed to help accelerate digital health. This paper will examine this challenge through the clinician experience, using empirical case examples from Canada to illustrate opportunities for change. While many factors may influence digital health adoption, this paper specifically aims to explore the shifts in the balance of the perceived value of implementing digital health tools, vs. the efforts required to adopt them. It will explore two contrasting case examples: clinical adoption of EMRs in Canada from 2009 to 2015, and clinical adoption of virtual care technologies during the COVID-19 pandemic from 2020 to 2021. In 2006, Canada lagged peer countries significantly in the adoption of electronic medical records (EMR) in community-based care. Financial support and cooperation of multiple levels of government and clinical stakeholders were required to address the misaligned incentives, which led to significant uptake by care providers. The rapid adoption of virtual care in Canada in response to the pandemic provides another relevant example of the importance of alignment among the factors of clinical workflows, clinical appropriateness, technology integration and payment models. Experts have highlighted the need for standardization, regulation, and clear policy to ensure sustainable, high quality virtual care that complements in-person care. In both cases, the costs and effort of adopting new technologies outweighed direct clinician value, requiring change initiatives to catalyze progress. This imbalance could be unique to these examples in Canada, and may not be globally generalizable to the adoption of all digital health tools. However, how change efforts can be tailored to adjust to a rapidly evolving health care workforce, spanning diverse jurisdictions and stakeholder groups will be critical to the sustainability of virtual care adoption. Furthermore, what key elements must be considered to guide change initiatives for successful implementation, designed to influence change while

adding value for patients, clinicians and Canada's health care systems? Using insights from successful change initiatives past and present, this paper aims to answer these questions to enable a smoother transition to digital health innovations of the future.

**Keywords:** digital health, value realization, change efforts, electronic health record, virtual care, digital tool adoption, benefits - case study

## INTRODUCTION

*“One essential characteristic of modern life is that we all depend on systems—on assemblages of people or technologies or both—and among our most profound difficulties is making them work.”*

- Dr. Atul Gawande, The Checklist Manifesto: How to Get Things Right

Digital health, particularly virtual care, holds significant promise for modernizing health care delivery in Canada. However, the value proposition derived from implementing digital health tools is complex in the Canadian health care setting.

Within the Canadian context, those players that are responsible for funding the adoption and use of digital health technologies (such as government bodies) do not always see immediate, appreciable value for themselves, while the actors (e.g., clinicians) who must adopt the technology in order to generate that value are not always incentivized to do so. The barriers to digital health adoption can therefore appear greater than the benefits resulting from more widespread use.

Digital health tools and initiatives can potentially add value to the health system by helping to achieve the goals of health care's Quadruple Aim (1): improving the health of the population, improving the patient experience, reducing costs and improving the health care provider experience.

Despite this potential for a positive impact, Canada has historically lagged peer nations with regard to integrating digital tools and services into its health system, as noted in Commonwealth Fund surveys (2). The costs of adopting new technologies (monetary costs, as well as time and effort) must not outweigh direct value to clinicians and must have clear benefits to patients. In cases where costs may be perceived as outweighing benefits, change initiatives are required to catalyze progress and “balance the scales.” To reach success and maturation, these change initiatives must present a compelling value proposition to the technology's adopters.

Traditionally, articulating this value proposition to clinicians has proven challenging, as demonstrated through analyzing Canada's experience implementing electronic medical records (EMRs). As a result of these challenges in driving adoption, digitization in Canadian health care has been slower than in other industries, such as banking.

However, the onset of the COVID-19 pandemic in March 2020 presented an emergent, highly compelling value proposition to clinicians. The implementation of physical distancing measures to slow the transmission of the virus created an urgent need to reduce in-person contact and to keep patients out of crowded waiting rooms. Fewer in-person interactions could lower patient

and provider risk of exposure to the virus. Health systems and clinicians thus faced a sudden urgency and necessity to integrate virtual care technologies into care delivery.

Newly available temporary provincial and territorial billing codes no longer disadvantaged clinicians for providing care virtually (3). Where appropriate, patients could access care from their physician remotely, keeping all parties safe from the inherent risks of physical contact. While multiple clinical organizations initiated change efforts in the form of virtual care best practice guides and implementation toolkits, these strategies were short-term in nature. Indeed, they were responses to an emergency situation.

While many factors may influence digital health adoption (4), this paper specifically aims to explore the shifts in the balance of the perceived value of implementing digital health tools, vs. the effort required to adopt them. It explores two contrasting empirical case examples: clinical adoption of EMRs in Canada from 2009 to 2015, and clinical adoption of virtual care technologies during the COVID-19 pandemic from 2020 to 2021.

International analysis of clinical engagement in digital health conducted by the Global Digital Health Partnership has found that while contexts and technology adoption differ around the globe, clinician change challenges and requirements for creating value are common (5). Nonetheless, it is important to note that while in these two cases, the costs and effort of adopting new technologies initially outweighed direct clinician value, this imbalance could be unique to the context of the Canadian health care system and may not be globally generalizable to the adoption of all digital health tools.

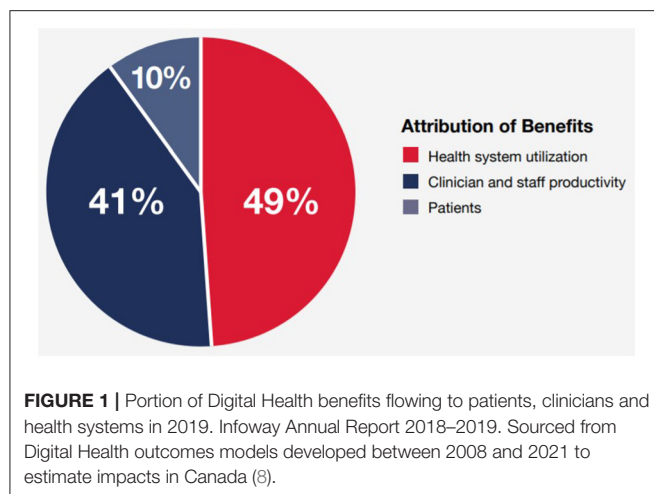
## WHO BENEFITS FROM DIGITAL HEALTH?

There is a longstanding business case for investments in digital health. Cited benefits range from the basic efficiencies of productivity (task automation, for example), to enhancements in patient safety (6), to opportunities to improve the quality of patient care and the health of populations.

In Canada, the uptake of digital health has been gradual and unevenly distributed across health care settings and among health professionals, including nurses, physicians and pharmacists.

Canada Health Infoway (Infoway) developed a methodology for estimating benefits from a defined set of digital health solutions (7). This analysis illustrates the distribution of those benefits between patients and caregivers, clinicians and their staff, and health systems. As **Figure 1** shows, results collected prior to the COVID-19 pandemic demonstrate that health systems recoup half the value, followed by clinicians with another





substantial share (8). Patients received only 10% of the estimated value. However, changes in health care delivery throughout the pandemic, notably the shift to virtual care and heightened use of digital health tools, are seeing patients receive an increasing share of that value.

As the Canadian experience demonstrates, technological infrastructure alone is insufficient to generate the momentum for widespread clinical adoption of digital health technologies—so long as the value to clinicians is not evident. Digitization in itself does not necessarily lead to functioning, clinician-friendly digital systems.

As a result, sluggish adoption of digital health by clinicians has a cascading effect on potential benefits to patients. The benefits of technological efficiencies cannot be realized if those technologies are not in use, or if their use is not optimized for enhancing patient care and the patient experience.

In the early 2000s, Canadian provinces and territories implemented the foundational elements of digital health, including the gradual introduction of provincial/territorial electronic health record (EHR) systems, hospital information systems (HIS) and community-based electronic medical records (EMRs) in physicians' offices.

As **Figure 2** demonstrates, a combination of federal, provincial and clinician-based funding helped to increase EMR adoption in primary care nationally, with some variation between jurisdictions. These early digitization efforts resulted in many siloed clinical information systems across the country: at the jurisdictional, health authority, hospital and individual clinician practice levels. Systems could not and did not easily share information with each other, limiting their early utility and value proposition. Additionally, clinician challenges with multiple logins for disconnected systems led to frustration, possibly contributed to burnout (9) and further limited the value proposition of these digital tools for clinicians of all disciplines.

As noted in **Figure 3**, Canadian nurses reported challenges in multiple domains relating to digital health. While efforts to increase interoperability have led to improvements in recent years, many of these challenges persist. As a result, nurses

and many other clinicians have had to adapt their practices to digital systems which were not designed for their unique clinical workflows. For these clinicians, the added physical and mental effort required to adapt to these digital systems might outweigh any perceived value for themselves and for their patients.

The lack of a compelling value proposition is compounded by the remuneration models for large groups of clinicians, specifically physicians. Despite efforts to reform payment models in Canada's health system, most physicians (73%) in both primary and specialty care in Canada operate under some form of a fee-for-service (FFS) model (11). Essentially, they operate as individual small-to-medium-size businesses and are responsible for any investments into their own technological infrastructure.

Prior to the pandemic, Canadians often wondered why it was challenging to email their physicians (12). As seen in **Figure 4**, only 23% of physicians reported communicating with patients by email in 2019. The 2018 Canadian Physician Survey (CPS) provided insight into the reasons behind this modest implementation of a seemingly basic form of communication. Physician remuneration structures had not kept pace with technological changes, nor with society's expectations of modern communication.

In Canada's single payer health system, physicians are remunerated by provincial or territorial ministries of health and cannot unilaterally adjust the cost of their services to offset technological infrastructure investments. For example, a family physician cannot charge the government more for seeing a patient in her office to offset the upfront cost of implementing a new EMR, nor can she charge for communications via a patient-facing secure messaging tool if a government-endorsed fee code does not exist for this type of communication. Without compelling evidence that these digital tools could enhance patient care, the impetus to change was limited.

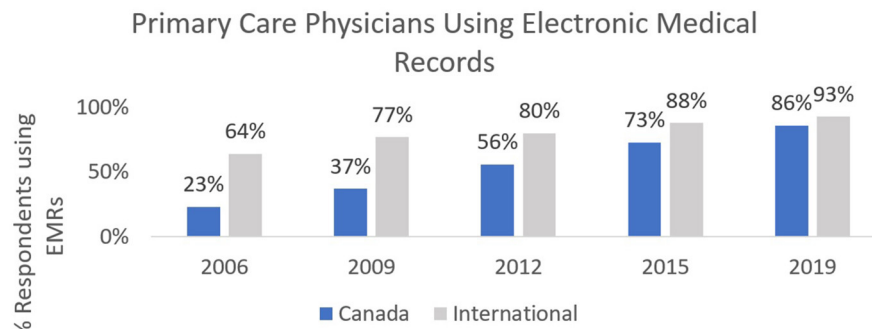
As noted in **Figure 5**, the Canadian Physician Survey explored the supports required by physicians to advance virtualization of care. The results show that the actual technology is important, but remuneration (the fee or billing schedule) was the most reported issue. Physicians also need support to make these digital tools safe, secure and effective parts of their practice.

## EMPIRICAL CASE EXAMPLES

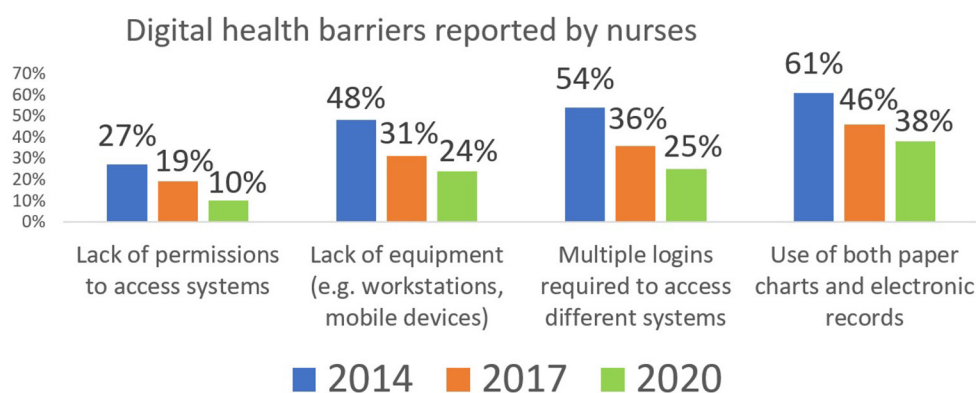
### Empirical Case Example—EMR Adoption in Canada

In 2006, Canada lagged peer countries in national reported adoption of EMRs in primary care. The Commonwealth Fund International Survey of Primary Care Physicians found that leaders like the UK, New Zealand and the Netherlands had almost completed the digitization of primary care records. At 23% adoption in 2006, Canada ranked among the lowest of the 11 participating countries (14).

For some, an early business case for EMR adoption was emerging: efficiencies for submitting billings to provincial and territorial ministries of health; enhanced quality of record keeping, particularly with respect to legibility;



**FIGURE 2 |** Canadian and International Primary Care Physician adoption of Electronic Records from 2006–2019. Sourced from the Commonwealth Fund International Survey of Primary Care Physicians, which surveyed 500 or more primary care physicians in each of 11 countries every 3–4 years from 2006–2019 (2).



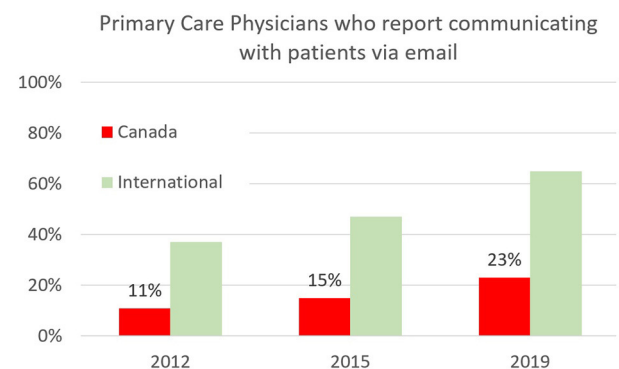
**FIGURE 3 |** Portion of Canadian Nurses Reporting Digital Health barriers. Sourced from the national surveys of Canadian Nurses, with responses from over 1,500 nurses in each of 2014, 2017 and 2020 (10).

and improved patient safety relating to prescribing and medication management (including legibility of prescriptions, comprehensive medication profiles and basic clinical decision support tools).

However, to most clinicians, the value proposition of EMRs was neither clear nor apparent. At that time, the body of clinical evidence relating to the benefits of EMRs for clinicians and patients was limited. Local Canadian evidence was even sparser. Between 2010 and 2020, more papers were published in the Canadian context outlining some of the value proposition of EMRs to clinicians, including EMRs' return on investment for clinical practices (15) and the ability to leverage EMRs for population-level health management and insights (16).

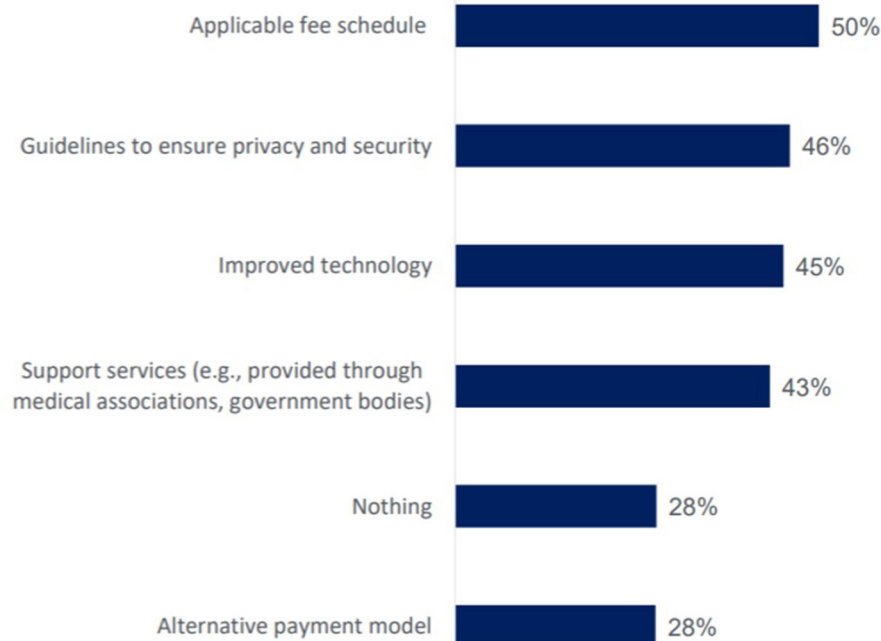
The technological infrastructure available to clinical practices in the initial phase of EMR adoption (mid-2000s to 2015) was also a barrier. Not all clinics were using computers, and most did not have reliable high-speed internet access. In addition, most clinicians and health care workers did not have adequate education and training relating to the use of technology in clinical practice.

Furthermore, incentives to adopt digital health tools such as EMRs were non-existent. As noted above, adoption occurs slowly



**FIGURE 4 |** Primary Care Physicians in Canada and internationally who report offering patients the option to communicate via email from 2012–2019. Sourced from the Commonwealth Fund International Survey of Primary Care Physicians, which surveyed 500 or more primary care physicians in each of 11 countries every 3–4 years from 2006–2019 (2).

in fee-for-service systems without modernized remuneration to support the implementation and appropriate use of digital health tools.



**FIGURE 5 |** Factors Canadian physicians report would support electronic communication with patients in practice. Sourced from a survey of 1,400 Canadian Physicians in 2018 (13).

In the context of this misalignment between the perceived efforts and benefits of implementing new technologies, and the inertia that resulted, a catalyst was required to spur adoption.

Specifically, it had become clear that clinicians, policymakers, vendors and other stakeholders would need to collaborate to address this gap. Leading Canadian provinces and territories, including Quebec, British Columbia, Alberta, Ontario, Nova Scotia and the Northwest Territories, established change management initiatives in the form of EMR Support programs.

These programs typically leveraged a federal and provincial/territorial funding partnership, and critically, involved a jurisdictional medical association as well. Each program was uniquely tailored to the province or territory in question, but most shared a similar template influenced by Infoway's National Change Management Framework (17). In addition, the programs were underpinned by two fundamental elements: financial incentives for clinicians to adopt EMRs, and a Clinician Peer to Peer Network to support clinicians throughout their EMR adoption journey with regards to change readiness, education, training, implementation and optimization of EMRs for improving patient care.

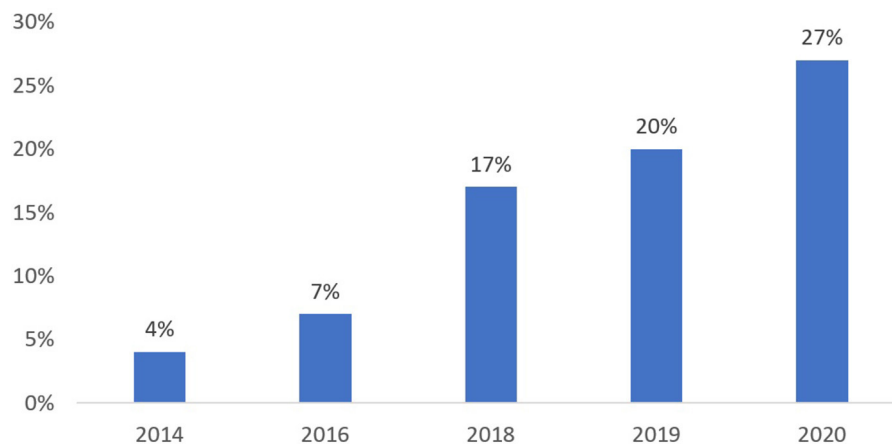
These EMR support programs acted as a critical change management catalyst to advance digital health in primary care. Data noted in **Figure 2** demonstrate the success of this catalyst: increasing adoption of EMRs in primary care from 23% in 2006 to 86% in 2019. Crucially, this change initiative played a role in establishing EMR-enabled clinical practice as a modern standard of care (18) and helped to lay the foundation for the rapid pivot to virtual care in 2020.

## Empirical Case Example—Virtual Care During COVID-19

As the EMR case example demonstrated, supporting clinicians through digital health change initiatives is difficult to scale in Canada. Projects have faced challenges when they aim for implementation across organizational or provincial/territorial health system boundaries.

As a result, change initiatives have typically been short term and project-based. The complexity of larger scale, national change is compounded in part by the statutory divisions of health care responsibility within the Canadian federation, and Canada's relatively small, diverse population spread over its vast land mass. Nevertheless, with collaboration between interested policymaking stakeholders (federal, provincial/territorial and clinical), successful change initiatives are possible.

Due to past investments, some of the technological infrastructure required to support virtual care was in place for many clinical environments. By 2015, EHRs were in place in all provinces and territories, with variations in some key types of patient information. While they were an important improvement, this infrastructure was neither interoperable, nor optimized for enhancing the patient or provider experience. Most clinics and clinicians had computers with internet access. EMR adoption in primary care, as previously noted, had improved significantly. However, the ability to access and exchange information between systems—EMRs, Hospital Information Systems (HIS), provincial/territorial EHRs—was still limited, as the Commonwealth Fund's 2019 survey of primary care physicians revealed (19).



**FIGURE 6 |** Canadians reporting they have accessed their health record. Sourced from routine representative surveys of the Canadian population conducted between 2014 and 2020, with sample sizes ranging from 1,500 to 6,000 individuals (21).

In the five years between the conclusion of most EMR support programs and the onset of the COVID-19 pandemic (2015 to 2020), numerous initiatives across Canada sought to enhance patients' digital health experiences. Eight in 10 Canadian adults reported they would like access to their own health information, generating momentum through provincial/territorial electronic patient portals, hospital-system associated patient portals, lab service provider results portals, pilot projects relating to virtual care (20) and more. As shown in **Figure 6**, Canadians were gradually taking advantage of these new services. Eighty six percent of those who access their health information online said they felt more informed about their health, 80% said they can better manage their health and 43% said they avoided an in-person visit (21).

More generally, Infoway survey data indicated a strong interest from patients in engaging electronically with the health system leading up to the pandemic. Electronic prescription renewal, electronic booking and virtual visits were all of interest to a majority of Canadians (21). By 2020, more Canadians were connected on a broader scale, with general access to potent video-capable technology on home computers, tablets or mobile phones.

While the value proposition and benefits of more advanced, patient-focused digital health tools were becoming more evident to patients, they remained unclear to clinicians prior to the pandemic. This scenario was reminiscent of the EMR case example, in which a slowly emerging body of clinical evidence on the value of patient-focused virtual care tools had yet to make an impression on clinicians, who would be the ones required to make investments of time and money to effect their implementation.

A prescient 2018 paper by Shaw et al. (22) about virtual care in the province of Ontario concluded that, "Policy planning for virtual care needs to shift toward a stronger focus on patient engagement to understand patients' needs."

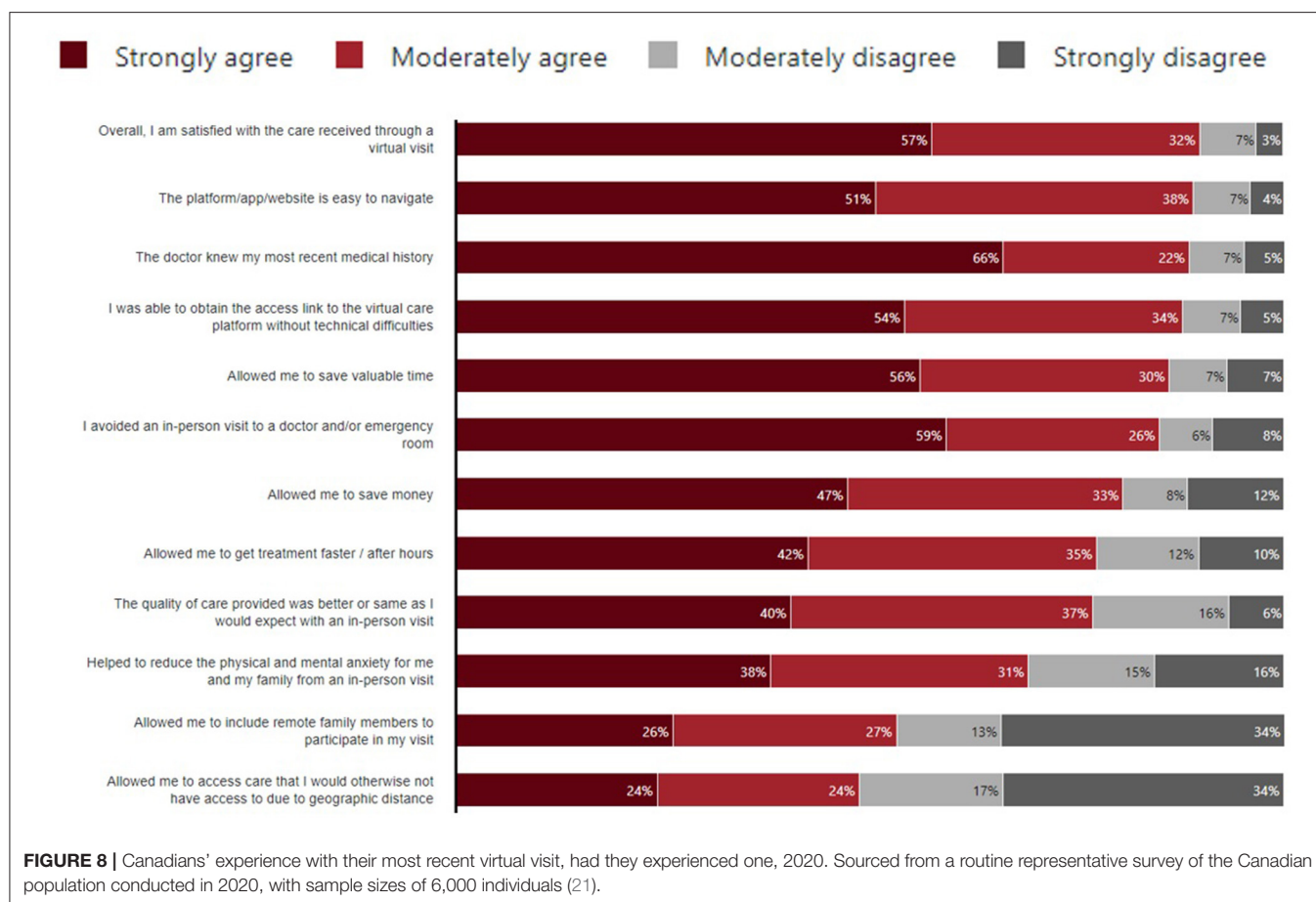
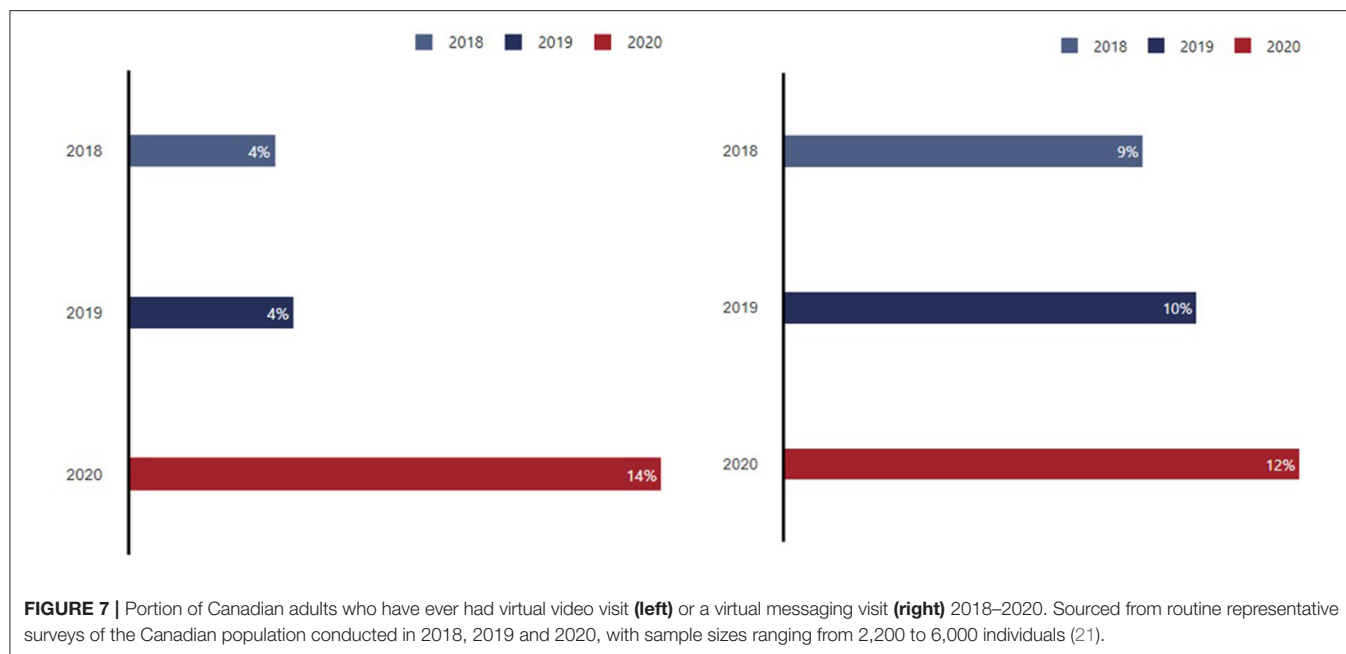
While Canada had been an early pioneer in telehealth, these services were not available at scale, making up a relatively small proportion of billable visits (23). Some of the conditions

were present for virtual care to take place, in the form of video visits, telephone visits and secure messaging, but a key ingredient was missing: an incentive to move away from the status quo of health care delivered almost exclusively in-person. Once again, true digital transformation had not accompanied advancing digitization within the health system. Digital health transformation requires a mixture of the right digital health tools, innovative models of care and appropriate policies, as well as relevant change management mechanisms to support well-designed processes, a virtual-first mindset and strong clinician and patient engagement.

Prior to the pandemic, remuneration for physicians providing virtual care services was noticeably absent in most Canadian provinces and territories. Without modern remuneration models reflecting changing technologies and patient expectations, clinicians had limited incentive to invest in added technological features or workflow modifications, even if these changes would enable efficient, patient-focused virtual care. This reticence was particularly resonant for clinicians in fee-for-service models. Several publications and reports have commented on this proverbial elephant in the room (24–26).

In the absence of credible incentives to innovate, inertia sets in. However, incentives and disruption arrived in the form of the COVID-19 pandemic in March 2020. COVID-19 created an urgency within global health care systems and clinical communities to rapidly pivot toward adopting digital technologies to enable virtual care.

Within the context of the pandemic, the value proposition of virtual care was suddenly very clear to clinicians, patients and health care system policy makers, "...because it provides access to medical care that is timely, convenient, efficient, and safe with reduced risk of transmission (27)." Bhatia et al. neatly summarize the new thinking required by decision-makers to both quantify the value of virtual care in the context of COVID-19, and to redesign care. They suggest thinking about the Costs of Physical Contact (CoPC), "...a new dimension against which to measure health," (28) avoiding physical interactions in health care unless required.





At this critical juncture, several additional catalysts were added to the mix. The first was a coordinated effort by provincial/territorial governments and medical associations to surmount a key policy obstacle for virtual care: the implementation of temporary billing (fee) codes that allowed physicians to be remunerated for providing a visit virtually (by telephone or video) rather than in-person. Numerous clinical organizations also created change management educational materials (videos, how-to guides, webinars) to support clinicians in the rapid pivot toward virtual care. These materials were essential to complement the billing codes. Many of the tools, processes and policies had been built over decades of work providing telehealth to rural and remote communities and building capacity in remote monitoring programs.

The second additional catalyst was a collaboration between federal and provincial/territorial governments to make rapid investments in high yield virtual care tools to facilitate further virtualization of care for patients during COVID-19. These investments accelerated remote patient monitoring (also called home health monitoring), patient portals providing access to COVID-19 and other test results, and virtual care platform licensing agreements. The rapid deployment of these tools, made possible by the EHR, EMR and other infrastructure investments discussed earlier, was essential for tasks like remotely accessing patient information and sharing test results.

The results of these and other drivers was an increased use of virtual care. As shown in **Figure 7**, in August 2020 the Canadian Digital Health Survey captured increases in reported use of virtual visits. While virtual care use has fluctuated throughout the pandemic, it remains significantly more prevalent than before.

Early data from patient experiences with virtual visits, noted in **Figure 8**, has shown promising value for Canadians and the health system, thus creating momentum to sustain and optimize virtual modes of care delivery.

This case example demonstrates that a public health crisis of enormous proportions was the initial catalyst required to move Canada's health system from a state of inertia regarding virtual care into a more dynamic state that benefits patients, clinicians and the health system.

Part of the challenge has been business cases that focused on the outcomes for health system funders and clinicians. While evidence is mounting that virtual care can offer significant benefits from both those perspectives, the complex trade-offs, uncertainties and upfront investment are sufficient to dampen progress. With the benefit of new evidence around patient impacts and the significant value in areas like time and financial savings, the overall value proposition becomes much stronger when all perspectives are considered.

In effect, the crisis produced a normalization of virtual care in just a few months, significantly condensing a process of transformation that transpired over years in sectors like travel and banking.

## DISCUSSION

Implementing and optimizing new technologies in Canada's health system has been a challenge for over two decades. This

paper has shown that one key element of this challenge has been the mismatch between the efforts and investments required, and the perceived or realized value for stakeholders. As these two case examples have outlined, this misalignment can be overcome with coordinated change management efforts involving the collaboration of multiple stakeholder groups, such as clinician groups, governments and citizens/patients.

Admittedly, the rapid adoption of virtual care has been imperfect. Some clinicians have described it as "making it up as we go along." (29).

While this may be hyperbole, the transition to a virtual-first mindset in the Canadian health care landscape will require longer-term consideration in order to create sustainable, meaningful change that leads to high quality, safe virtual care in the future.

Clinicians and patients need to know when the use of virtual care is most appropriate and will have the greatest benefit for them. Clinicians and patients will benefit from the refinement of clinical workflows and access to better, more standardized, truly interoperable virtual care tools. Clinicians and the broader health care workforce need additional support and training to supplement what educational institutions have not yet included in their curricula. Patient and caregiver advocacy groups must continue to play a key role in enhancing broad digital health literacy, and in encouraging governments to maintain the momentum around high-quality, patient-centered virtual care that meets the goals of the Quadruple Aim.

Finally, governments and clinician groups will need to collaborate on continuous efforts to modernize remuneration structures to incentivize the provision of modern health care.

Digitization alone is not transformation (30). When the conditions for digital health adoption are present, further catalysts and change management efforts are needed to alleviate the misalignment between perceived costs and benefits to health stakeholders, and to free the modern health system from the inertia of a past status quo. To achieve a goal of full digital transformation, we must invest in change.

## AUTHOR CONTRIBUTIONS

This article has been primarily authored by RB, with contributions by SH, KB, and JK. All authors agree to be accountable for the content of the work.

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# Timely Communication Through Telehealth: Added Value for a Caregiver During COVID-19

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**Objective:** This caregiver case study applies the lens of relational coordination theory (RC) to examine the value of telehealth as a medium of care coordination for a pediatric patient with hypermobile Ehlers-Danlos Syndrome (hEDS) during the COVID-19 pandemic.

**Background:** The COVID-19 pandemic has placed an unprecedented burden on the delivery of healthcare around the globe and has increased the reliance on telehealth services. Delivering telehealth requires a high level of communication and coordination within and across providers as well as between providers, patients and their families. However, it is less clear how telehealth impacts the coordination of care. In this paper, we provide insight into the quality of care coordination between providers and an informal caregiver following policy changes to the provider payment structure in Massachusetts.

**Methods:** This paper employs a single-case, autoethnographic study design where one of the authors uses their experiential insights, as mother of the patient, to inform a wider cultural and political understanding of the shift to remote caregiving for a pediatric patient with hEDS. Data was collected using reflective journaling, interactive interviews, and participant observation and analyzed using content analysis.

**Results:** Findings revealed four interrelating roles of the caregiver including, logistics support, boundary spanner, home health aide, and cultural translator. The adoption of telehealth was associated with improved timeliness and frequency of communication between the caregiver and providers. Findings about the impact of telehealth adoption on accuracy of communication were mixed. Mutual respect between the caregiver and providers remained unchanged during the study period.

**Conclusions:** This paper highlights areas where payer policy may be modified to incentivize timely communication and improve coordination of care through telehealth services. Additional insight from the perspective of an informal caregiver of a patient with a rare chronic disease provides an understudied vantage to the care coordination process. We contribute to relational coordination theory by observing the ways that caregivers function as boundary spanners, and how this process was facilitated by the adoption of

telehealth. Insights from this research will inform the development of telehealth workflows to engage caregivers in a way that adds value and strengthens relational coordination in the management of chronic disease.

**Keywords:** telehealth (TH), care coordination, caregiver, chronic disease, Ehlers-Danlos Syndrome, relational coordination, health policy

## INTRODUCTION

The COVID-19 pandemic has placed an unprecedented burden on the delivery of healthcare around the globe and has increased the reliance on telehealth services for remote care. Responding to such a complex and changing environment has required coordinated efforts between providers, payers, and consumers of healthcare to maintain patient safety and quality of care. One such effort took place in Massachusetts in March 2020 with the enactment of an emergency order which required insurers to reimburse telehealth delivered over video and phone at the same rate as in-person visits to ensure provider and patient safety (1). This payment policy shift allowed patients and their caregivers to access health and mental health services from the comforts of their home. However, delivering telehealth requires a high level of coordination within and across providers as well as between providers, patients and their families and more research is needed to understand how telehealth impacts the coordination of care among caregivers. In this paper, we provide insight into the quality-of-care coordination between providers and an informal caregiver of a pediatric patient following policy changes to the provider payment structure and service delivery method in Massachusetts. This case study looks at the use of telehealth and care coordination during the COVID-19 pandemic, a time when a large amount of care was shifted from in-person to remote delivery.

## BACKGROUND AND LITERATURE REVIEW

Care coordination has been identified by the Institute of Medicine (IOM) and the Agency for Health Research and Quality (AHRQ) as a key strategy in this effort to create value in health care (2). Care coordination can be understood as the organization of patient care activities between two or more roles involved in the delivery of healthcare services (3). It is an increasingly influential concept in health services research for its demonstrated ability in improving the effectiveness and efficiency of health care delivery (4). Care coordination is associated with a variety of performance outcomes including clinical outcomes, patient reported experience outcomes, and treatment adherence outcomes (4–7). Together these performance outcomes generate additional value for the health care system. Looking at ways to increase care coordination for children with complex chronic conditions, Golden and Nageswaran (8) noted a need for more information sharing and quality communication between caregivers and the rest of the clinical team.

Caregivers, typically family or friends, provide unpaid health care labor. They are increasingly being recognized for their contributions to patient care. Informal caregivers account for a

large portion of the healthcare workforce in the United States. Approximately 65.7 million adults in the United States provided unpaid care to an adult or child in 2009 (9). On average these caregivers spent 20 hours each week providing care, totaling over a billion hours of informal care work each year in the United States (9).

Incorporating unpaid caregivers in care has been shown to contribute substantial value to the quality of care delivery. Informal caregivers help patients to make decisions about their treatment, making them an important stakeholder in the process of care delivery. Seminal medical anthropologists including Claude Levi-Strauss and Madeleine Leininger have long stressed the importance of incorporating patient's family and friends into the process of care delivery and their ability to illuminate aspects of the patient's personal and social life, such as dietary preferences or cultural practices, that must be taken into account when designing a treatment plan that works *in vivo* (10, 11). Nesting the treatment in the social lives of patients has been shown to improve critical measures like treatment adherence (12–14). The fact that caregivers are often unpaid and provide large amounts of labor means that they have the potential to generate quality without having to sacrifice efficiency, something that generates new value for the health care system. Telehealth is one mechanism that has been found to support the informal caregivers' role in health care delivery (15).

## Telehealth and Informal Caregivers

The COVID-19 pandemic has placed an unprecedented burden on the delivery of healthcare around the globe and has increased the reliance on telehealth services. Telehealth refers to the use of one or more electronic platforms to exchange health information, and is delivered by using synchronous video and audio-only technologies, as well as asynchronous messaging and remote patient monitoring. Generally, these platforms are accessed in one central location referred to as a patient portal. In response to the call for social distancing, Massachusetts policy leadership passed legislation that mandated reimbursement parity for the delivery of telehealth services for the duration of the pandemic (1, 16). The comprehensive legislation entitled, "An Act Promoting a Resilient Healthcare System that Puts Patients First", broadly defines telehealth to include "the use of synchronous or asynchronous audio, video, electronic media or other telecommunication technology, including but not limited to, interactive audio-video technology, remote patient monitoring services, audio-only telephone and online adaptive interviews" (17). The new law addresses several important factors in making healthcare accessible including rate parity for primary care and chronic disease management telehealth services and



increasing the scope of services for many specialists, including mental health providers.

Policy at the national level through the Office of Civil Rights has also increased the bounds of acceptable technology from Health Insurance Portability and Accountability Act (HIPPA) compliant technology to familiar applications like Apple FaceTime and Zoom (18). Another change to reimbursement policy was the development of virtual check-in codes by the Centers for Medicare and Medicaid Services, which allowed providers to be reimbursed for shorter appointments that occurred over the phone or through text-based secure messaging (19). Together these policy shifts enabled health care organizations to expand telehealth use by over 3,000 percent during the first month of the COVID-19 pandemic (20). Researchers are moving to study the effects of telehealth technologies on patient outcomes. This study observes the impact of this transition to remote care on care coordination with a caregiver of a patient with Hypermobile Ehlers-Danlos Syndrome (hEDS), a rare chronic disease.

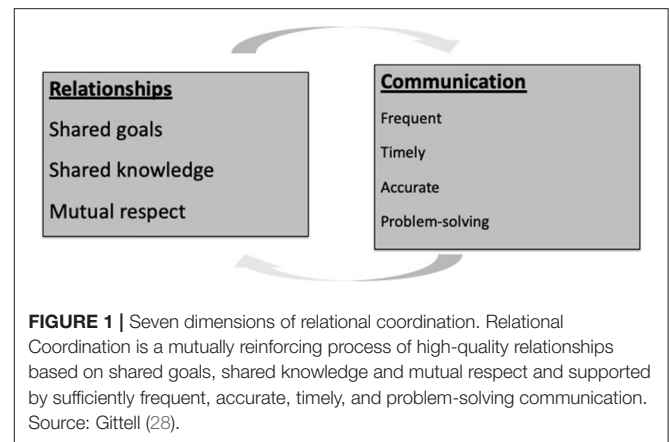
Telehealth has been widely used by informal caregivers to aid in the delivery and coordination of care. Zulman et al. (21) found that 79% of respondents wanted informal caregivers to access some or all features of their patient portal. Of these respondents, 65%, 54% and 73% respectively indicated that they wanted to delegate communication with health care providers to a partner, family member, and unrelated caregiver respectively.

Tieu et al. (22) observed that informal caregivers generally report optimism about the ability of patient portals to support them as effective partners in care delivery. Telehealth can reduce critical barriers to care that are associated with in-person visits, such as transportation and child care (23). Researchers at the Veterans Health Administration found that a telehealth intervention designed to coordinate care has been shown to reduce hospital admissions by 19 percent, and bed days of care by 25% (24).

## Hypermobile Ehlers-Danlos Syndrome

Hypermobile Ehlers-Danlos Syndrome (hEDS) is an inherited chronic connective tissue disorder that primarily impacts the patient's skin and joints though can impact multiple systems in the body. It is common for patients to experience one or more of the following: joint hypermobility, early onset osteoarthritis, soft, velvety skin, variable skin hyper-extensibility, fragile skin with easy bruising, severe scarring and poor wound healing, musculoskeletal pain, arterial/intestinal/uterine fragility or rupture; scoliosis, poor muscle tone, mitral valve prolapse, and gum disease (25). The hEDS patient in this case experiences joint and skin related symptoms mentioned above in addition to co-occurring fatigue, gastrointestinal distress, dysautonomia, and anxiety.

Because hEDS can impact multiple systems in the body, patients are often referred to specialists for preventative screenings and/or to receive treatment depending on their symptoms. The genetics provider is considered a core member of the care team due to the inherited nature of hEDS. Other providers include: primary care, cardiology, orthopedics,



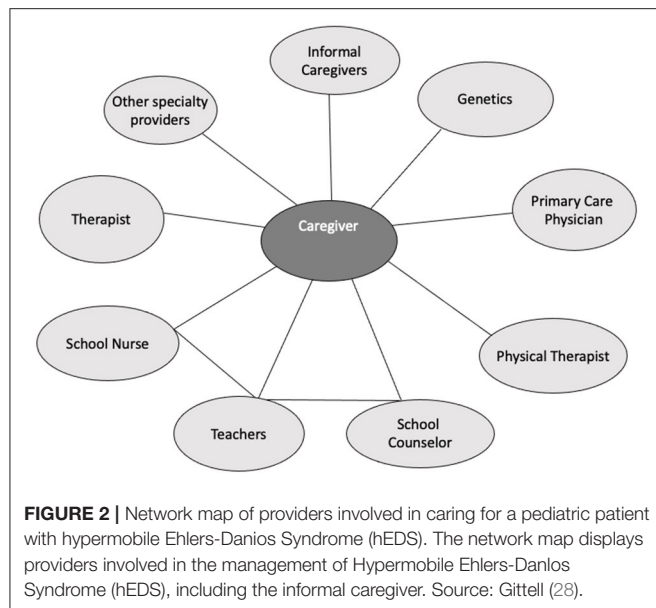
rheumatology, physical therapy, gastroenterology, psychiatry, school nursing staff, counselor, teachers, etc. In the case discussed in this paper, each of these provider groups are associated with a different practice or hospital in various locations, with individual clinicians having varying degrees of knowledge of and experience working with hEDS patients. Connecting this disparate network is a feat, particularly during the COVID-19 pandemic, considering that many key stakeholders, like caregivers, do not operate within the healthcare system. Additional research is needed to understand how telehealth use impacts coordination of caregiving for patients with complex chronic diseases like hEDS. The aim of this study is to understand the impact of telehealth use on caregiving coordination during the COVID-19 pandemic.

This article is written as an autoethnography- a social science research method in which the corresponding author is a participant observer as an informal caregiver of a patient with hEDS. Autoethnography uses these experiential insights to inform a wider social and political understanding of a particular phenomenon (26). Two research questions guided our analysis: (1) How did the transition to telehealth services during the COVID-19 pandemic impact care coordination and inform the role of caregivers and quality of care and (2) What are the implications for health policy and practice?

## THEORY

In 2007, AHRQ highlighted relational coordination as one of four frameworks that explained the relationship between care coordination and performance outcomes (3). Relational coordination (RC) is a framework derived from organizational theory and refers to a mutually reinforcing process of high quality relationships supported by high quality communication (27). Simply put, RC is communicating and relating for the purpose of task integration (28), and as such has been found to reduce the tradeoffs between quality and efficiency, pushing the quality and efficiency boundary outwards to generate new value.





As a construct, relational coordination consists of seven dimensions through which work is coordinated. Three relational dimensions include shared goals, shared knowledge and mutual respect. These relational dimensions are supported or reinforced by sufficiently frequent, timely, accurate and problem-solving communication and are expected to support a wide range of outcomes (29) (see **Figure 1**). For example, when individuals feel respected by others who are engaged in the same process, there is a tendency to experience higher quality communication. Likewise, when individuals share goals in a particular work process, they are more likely to engage in communication that is problem-solving, and less likely to blame others for poor performance. Finally, those who share knowledge about role responsibility are more able to engage in timely communication with one another as they understand what other roles need to contribute to the work process.

Relational coordination been widely studied in health care with consistent results across organizations (29, 30). Strong RC across organizations serving the same constituents enables participants to achieve higher quality outcomes more efficiently (27, 28, 31, 32). A recent systematic review (29) identified several healthcare studies which positively associated relational coordination among interdisciplinary staff to quality outcomes including postoperative functional status, patient reported quality of care and quality of life, family satisfaction with care, patient trust and confidence with providers, and patient psychological well-being (27–29, 33–44). Despite the growing evidence of relational coordination on patient and provider outcomes, only 14% of all RC findings were based on relational coordination between providers and their clients, including caregivers (29). Thus, relative to its territory, RC remains under-explored between caregivers and providers. We extend the theory by examining RC

between a caregiver and multiple providers treating a pediatric hEDS patient. In the network map above, coordination between providers is largely facilitated by the caregiver (see **Figure 2**).

RC theory (45) also predicts that certain organizational structures can support stronger relationships and communication within and across workgroups. For instance, boundary spanners can impact performance outcomes through their ability to facilitate relational coordination. Boundary spanners are broadly defined as or roles that are dedicated to coordinating between other roles (28, 46). Bragstad et al. (47) found that caregivers in-part function as boundary spanners, and generate performance outcomes and subsequent value for the health care system through their ability to mediate the relationship between the patient and their providers. Studies found relational coordination between patient's family members and care providers to be positively associated with high quality post-surgical outcomes, greater patient well-being and patient perceived quality of care (35, 44, 48). Additionally, relational coordination between providers and family members was associated with family members' preparation for caregiving (44) as well as shared decision making with the patient (49).

Shared information systems are another structure that has been shown to reduce barriers to communication, thus strengthening relational coordination and subsequent performance outcomes (28, 29). Shared information systems are expected to support coordination when they are accessible to all stakeholders, provide visibility to the work process and used as a supplement rather than a replacement for other forms of communication (50), the research findings have shown mixed results across industries. In healthcare settings, shared information systems have been positively associated with relational coordination among care providers (36, 41). Other healthcare studies suggest that relational coordination may decrease challenges associated with lack of proximity in patient portal networks (51). Testing this theory on the introduction of clinical information systems in chronic care delivery, Cramm and Neiboer (36) found a strong correlation between the existence of clinical information systems and measures of RC as reported between clinicians. We are extending this theory to the relationship between telehealth and teams formed between clinicians and informal caregivers. In this paper we connect RC, an evidence-based framework and management tool, to the production of healthcare in informal teams composed of patients, providers, and caregivers.

## MATERIALS AND METHODS

This single-case study aims to understand how increased use of telehealth during the COVID-19 pandemic impacts caregiver perceptions of the dimensions of relational coordination. This paper uses autoethnographic methods to study the lead author's experience as a caregiver of her daughter who experiences hEDS.

Research for this paper began before the COVID-19 pandemic, at which time the aim was to study relational coordination between the caregiver/lead author and several providers involved in managing the caregiver's daughter's hEDS. This initial work was subsumed into this current research project, which was re-directed to study how relational coordination between the caregiver and providers was impacted by increased use of telehealth during the pandemic.

Yin (52) argues that holistic single-case studies are appropriate in critically testing a well-formulated theory that has a set of propositions and conditions under which the prepositions are supported or hindered, as is the case with the theory of relational coordination. This method is also particularly helpful in understanding a rare, "extreme," or otherwise exemplary case (52). In this instance the caregiver is a Ph.D. researcher, and a highly involved mother of a daughter with a rare genetic disease that requires chronic pain management. Thus, this single case study is intended to be a deep dive into the experiences of an exemplar for the purpose of extending literature on relational coordination theory to the process of caregiving using telehealth.

We used autoethnographic methods to determine the relationship between telehealth use and care coordination using relational coordination theory between the informal caregiver and the provider team. As a qualitative approach to research, autoethnography aims to describe and systematically analyze one's personal experience in an effort to understand a broader culture (53). In line with Jones' (54) definition of autoethnography, our first commitment is to explore the "dynamic relationship between theory and story" [p. 231]. Here, the corresponding author uses personal accounts reflexively to shed light on the broader context in which her experiences have occurred (55). While criticisms of this approach have centered on its "rampant subjectivism" [(56), p. 48] and lack of rigor, others have noted the benefits of integrating story and social science, bridging creative, and critical aspects of inquiry (57). Others argue that autoethnographies can be rigorous when systematically designed with well-defined research questions that allow them to be inclusive of personal and social phenomena (58), as is the case with this paper. We believe that subjectivity is a strength of this paper, allowing for more detailed and holistic observations that would not be possible if the researcher was removed from the subject.

In this study, autoethnography was accomplished through reflective journaling and participant observation by the lead author regarding her experience as a caregiver and the relational coordination that she experienced with members of her daughter's care team. Reflective journaling was used to determine (1) the tasks performed by the caregiver, and (2) how the caregiver's experience of relational coordination with providers changed as her use of telehealth increased during COVID-19 pandemic. The caregiver further recorded a count of the remote and in-person interactions that she had with members of the care team before and during the COVID-19 pandemic. In several instances the author also documented segments of conversations she had with her daughter, the patient, as well as conversations with other members of her daughter's medical and social care teams during the COVID-19 pandemic. This journaling was

supplemented with information from provider notes to confirm and elaborate clinical observations.

This research also involved several interactive interviews to provide in-depth account and understanding of the participant's lived experience (59). Development of the interview questionnaire was iterative and began with the second author developing a set of interview questions to illuminate the experience of the caregiver before and during the COVID-19 pandemic. These questions were largely divided into (1) questions about the process of caregiving using telehealth and in person visits, and (2) experience questions that asked the caregiver to explain how the shift from in-person to predominantly remote care impacted the seven dimensions of relational coordination (frequency, accuracy, and timeliness of communication, as well as the ability to problem solve, share goals, share knowledge, and develop mutual respect).

Interviews were completed after the start of the COVID-19 pandemic, allowing for a post-intervention assessment. These interviews occurred as a collaborative endeavor between the participant researcher (corresponding author) and a second researcher (co-author). The interactive interviews occurred multiple times throughout the COVID-19 pandemic and were situated in the context of a well-established working relationship between the two researchers. Content analysis was performed by both the primary and secondary researchers to capture both the emic and etic perspectives on the transition from in-person to remote caregiving (60).

## RESULTS

**Table 1** provides summary data comparing telehealth visits between 2019 and 2020. During the period between March–December, 2020, the informal caregiver used telehealth to attend several visits with a specialist and primary care clinicians (see **Table 1**). Also shown are comparison data from the same months in 2019. This data shows a substantial increase in telehealth visits from 2 telebehavioral visits in 2019 to 54 visits across specialties in 2020. We see that the total frequency of visits (telehealth + in-person visits) was greater during 2020 than in 2019. This trend is also reflected at the individual clinician level.

The caregiver used Zoom, Doximity, and her cellular phone (iPhone 10 with messaging, audio, and FaceTime capability) to communicate with providers remotely. The fact that visits could be done remotely increased flexibility that facilitated timely interactions and saved the patient and the caregiver time commuting, and made it possible for the caregiver to avoid having to schedule and pay for childcare and other expenses associated with travel, and as a result, the frequency of appointments was higher during the COVID-19 pandemic as compared to pre-pandemic levels.

## Informal Caregiver Role

Our findings reveal the unique role of an informal caregiver of a pediatric patient with a chronic, multisystem condition, and their perspectives on care coordination in the context of 54 telehealth visits between March and October 2020. During the study period,

**TABLE 1** | Comparison of number and type of in-person and telehealth visits, March–December 2019 and 2020, for a pediatric patient with hypermobile Ehlers-Danlos Syndrome (hEDS).

Provider type	March 2019–December 2019		March 2020–December 2020	
	In-person visits	Telehealth visits (phone, video)	In-person visits	Telehealth visits (phone, video)
Primary care physician	3	0	1	5
Therapist	8	2	9	10
Genetics	1	0	1	1
Functional medicine	0	0	0	3
School nurse	5	0	6	3
School counselor	52	0	16	22
Physical therapy	0	0	1	1
Psychiatry	0	0	0	1
Case manager	0	0	0	3
School IEP team	2	0	0	5
<b>Totals</b>	<b>71</b>	<b>2</b>	<b>34</b>	<b>54</b>

*Bold values represent total number of visits for each type of visit for each time period.*

the informal caregiver allocated ~20–24 h per week coordinating care and services for her daughter.

Caregiving for a patient in this case was found to involve four interrelating roles; logistics support, boundary spanner, home health aide, and cultural translator. Perhaps the most visible role was that of logistics support. The caregiver was responsible for scheduling visits, transporting the patient, and collecting medical supplies to support the patient's treatment plan (see **Table 2**).

The second role was that of boundary spanner between providers and teams. The caregiver spent large quantities of time doing things like printing/scanning/emailing information and sharing it within the team. She shared perspectives between team members, interpreting clinical findings and helping to facilitate shared knowledge. One example where this action was particularly important was after her daughter received her yearly genetics exam. The caregiver shared the up-to-date information with other providers and specialists which greatly impacted their recommendations for modifications to her treatment plan moving forward.

Third, the informal caregiver performed several functions that would otherwise be the responsibility of a home health aide. This includes helping with activities of daily living before and after school, preparing special diet and nutritional supplements, assisting with pain management strategies, and responding to acute situations that come up unexpectedly, such as GI distress, joint pain, body temperature regulation, and anxiety related to these symptoms.

The fourth role was social translator. In this role, the informal caregiver was responsible for bridging the clinical sphere with the patient's home sphere and is captured in the following quote:

*During health visits, I help to bring up and talk through aspects of my daughter's life that are either barriers to treatment, or potential*

*opportunities to improve management. I help my daughter to make decisions about adherence to a particular treatment strategy or practitioner. Even now, several years into the disease, we regularly discuss the many possible interventions and lifestyle modifications to iterate a treatment plan that will add the most value to my daughter's life.*

–Informal Caregiver

## Impact of Telehealth on the RC Dimensions

The change from in-person to remote visits initially impacted measures associated with communication more than measures associated with relationships. More broadly, the option for remote visits allowed team members to spend more time talking, problem solving, and coordinating.

### Timeliness

The most cited communication change observed during the study period was the change to the timeliness of visits. As previously discussed, the challenges around travel and child care were virtually eliminated with the transition to remote visits, allowing the caregiver to move quickly to book the first appointment with the physician that was available. This dramatically increased the timeliness of communication, allowing the patient and caregiver to iterate treatment plans at a much greater speed and is reflected in the following quote:





*Before COVID-19, we would have to schedule an in-person visit with the PCP to discuss changes to the plan of care. Now we can hop on the phone or video call to talk through changes in status and/or responses to specific interventions, including next steps for care. Something that used to take months now takes no time and we don't have to figure out childcare for our younger children or account for travel time.*

–Informal Caregiver

This was particularly impactful for multi-appointment initiatives where a meeting with the PCP indicated a need to see a specialist, which often required a follow up visit with the PCP to work the specialist's suggestions into the patient's treatment plan. Instead of multiple in-person visits, telehealth provided a mechanism for a quick follow-up and debrief of specialist appointments. Likewise, timeliness of communication between the informal caregiver and the therapist improved with access to telehealth services and is captured in the reflection below:

*Telehealth appointments have also occurred (weekly) between her therapist and informal caregivers (my husband and I). This has been incredibly valuable in saving time before and after in-person therapy appointments to communicate updates and debrief how sessions play out. The coordination with the therapist has improved greatly through the use of telehealth services – it's easy to schedule these appointments and they've morphed into more of a "huddle" now that we've been doing it for a few months- a time for us to sync up, provide highlights and for the therapist to suggest the next course of action. Before, we used to go into therapy sessions and I would do my best to provide an update in a short amount of time, unsure of what information would be most helpful to communicate to the therapist and trying not to talk about it in front of my daughter – and also trying to save time so that she could get the most of the time.*

**TABLE 2 |** Coordination role of informal caregiver for a pediatric patient by coordination area: pain management, academic accommodations, mental health support, and future planning.

Coordination area	Relevant providers	Coordination activities	Exemplar
 Pain management	Primary care physician (PCP), orthopedic gastroenterology, etc.	Schedule and prepare <sup>a</sup> for appointments; implement adjustments to care plan and home care, including medication management. Respond to acute medical needs, including emergency services.	Share new peer reviewed studies with PCP related to hEDS treatments and pain management methods which serves as the basis for discussion at the next appointment.
 Academic accommodations	School teachers, counselor, physical therapist, school nurse, PCP	Prepare for, attend and follow up on Individualized Education Plan (IEP) meetings and progress reports; provide school team with updates from medical team; problem-solve challenges that come up and which impact academic work, e.g., fatigue, pain, anxiety, etc.	Proactively reach out to core team members to share updates to plan of care, including recommendations from specialists. Schedule phone calls with individual teachers who are unable to attend team meetings to share knowledge. Send emails with home updates related to pain management.
 Mental health support	Therapist, PCP, music teacher, school counselor	Schedule and prepare for therapy sessions, including parent huddles to provide updates and debrief sessions and to iterate the plan of care.	Access private music instruction and opportunities outside of school district. Initiate discussions with multiple teachers and leaders in the school district about how to provide more supports around music and arts as a form of expressive, socioemotional learning.
 Future planning	Genetics, PCP, school, financial advisor, insurance company	Schedule, attend and follow up on meetings with financial advisor; engage with case manager to optimize access to health benefits; engage in genetic counseling and testing to identify risk factors that have potential to impact future financial and healthcare plans.	Identify, access, and engage financial planner to provide guidance on long term financial needs based on current health information and future health needs, including genetic testing results; conduct in-depth research on healthcare plans to meet anticipated future needs.

<sup>a</sup>Appointment preparation includes, but is not limited to, uploading/emailing/photocopying visit summaries or notes from other provider appointments/meetings, developing a list of discussion items, and/or questions that have come up since last appointment and having a conversation with the patient regarding the appointment itself, what to expect and any concerns she may have.

*Now, the therapist is able to count our “parent telehealth meetings” as appointments, bill for them and we aren’t rushed. Also important is that we are not in front of my daughter while we’re talking. This has provided us with the space and time to build shared goals and co-produce a course of treatment for my daughter. It’s extremely efficient and feels aligned and collaborative.*

-Informal Caregiver

Overall, the remote care appointments were used for follow up to in-person visits and to seek advice when adapting a treatment plan to the constraints of the patient’s life. Using telehealth to provide opportunities for coordination to support the in-person clinical procedures reduced the number of duplicative visits and improved timeliness of care.

## Frequency

The frequency of visits with the care team increased during the pandemic as a direct result of the option to schedule remote visits. This reduced the time allotted for the informal caregiver to attend remote visits from several hours to ~30 min. The increased frequency of care delivery using telehealth during the COVID-19

pandemic allowed the caregiver to move more quickly and build momentum with different interventions.

*We’ve had more communications with our daughter’s PCP and therapist specifically since COVID-19. Part of this is due to the ease at which we are able to schedule telehealth appointments versus in person appointments. Also, providers can now bill for phone and web-based appointments so they have blocks of time carved out to touch base with patients who need the extra support. More frequent communication, especially with the PCP and therapist, has resulted in more efficient communications that take less time overall.*

-Informal Caregiver

The decrease in time commitment (finding child care, driving, etc.) required for each individual visit made it possible to meet with specialists and the PCP in the same week to incorporate the new insights into the treatment plan. For instance, during one appointment, our PCP recommended a medication consultation with a specialist. That same day, the PCP coordinated the consultation and within the same week, we had met with the specialist via telehealth to discuss medication management. This



type of iterative meeting schedule is common in the treatment of patients with hEDS. Telehealth made it possible for treatment to be iterated in a much more condensed manner, allowing the team to meet a specific goal in a matter of weeks, where it would previously have taken months.

### Accuracy

The adoption of telehealth both positively and negatively impacted the accuracy of communication. The limited window and two-dimensional view offered in video applications made it challenging for the participants (patient, caregiver, and provider) to observe body language, which limited the perception of social cues. Physical exams, orthopedic tests, and other sight based clinical procedures often had to be repeated in-person or were not attempted remotely. This is consistent with the notion that telehealth is not appropriate for some procedures.

Interestingly, the frequency and timeliness of communication appeared to positively impact the accuracy of communication being shared, though this appeared to be a secondary outcome. This was especially true in the case where the caregiver was responsible for transferring information between providers. The fact that meetings with the primary care provider could happen in the same week as a meeting with a specialist meant that the information from the specialist was fresh in the caregiver's memory, which facilitated accuracy of information transfer. Additionally, having the option for brief follow up calls with providers was an opportunity to clarify details and next steps:

*The ability to follow up with healthcare providers after an appointment has been very helpful. We recently had an in-person genetics appointment which was followed by a telehealth appointment to clarify next steps for genetic mapping, physical therapy, and at-home management of symptoms. For anyone who has attended a genetics appointment, even the most educated among us can be easily overwhelmed by the technical details communicated by these providers, making follow up appointments critical to clarifying important details about the plan of care.*

*During another telehealth appointment, the PCP coordinated with a specialist to gain up-to-date information on a pain medication. These follow up telehealth calls have allowed us to update and implement the plan of care more efficiently and effectively.*

-Informal Caregiver

In some instances, the caregiver was able to organize phone calls or video-conferences where both specialists and the primary care provider attended the meeting, which also increased the fidelity of information sharing between groups. As a last point, the option to meet with providers remotely made it possible to meet with new specialists who were too far away to visit in-person. This made it possible to access providers with more specific knowledge about the condition.

### Problem-Solving

Telehealth provided the space and opportunity for more problem solving communication. As previously discussed, telehealth works for some clinical needs and not for others. The increased frequency of appointments gave the caregiver more

time with providers, allowing for a shift from information sharing to problem solving communication. By comparison, the caregiver described pre-COVID in-person visits as being quick, unidirectional, and clinically oriented to facilitate sharing large amounts of information in discrete windows of time.

The convenience of telehealth allowed the patient and the caregiver to have a follow up appointment with the geneticist after the annual in-person exam. The additional time made it possible to solve problems related next steps for genetic mapping, school services, physical therapy, and at-home management of clinical symptoms. Similarly, the caregiver began scheduling remote visits with her daughter's therapist to debrief and communicate updates between sessions:

*Before COVID-19, we'd have to hope that there was a few minutes in between patients for us [caregivers] to provide any updates to the therapist. The same issue happened at the end of the appointment. Sometimes we wouldn't have time to debrief with the therapist and would have to figure out how to have a quick conversation before the next appointment. It didn't always happen. Since COVID-19, we've scheduled parent huddles between our daughters' appointments. They aren't rushed but also aren't very time consuming and allow us to problem solve around specific challenges that come up. We've seen more progress since the parent huddles.*

-Informal Caregiver

### Shared Knowledge

The increase in frequency of visits created more opportunities to share knowledge between the caregiver and providers, which impacted both the volume and quality of information shared. This increase in communication impacted the provider/caregiver dyad, but also impacted the ability for providers and other members of the team to share information through the caregiver as a boundary spanner:

*There's just been more time to connect with providers related to day-to-day management of hEDS symptoms and our daughter's response to specific interventions. It also seems like our providers have more time to understand the daily impacts of the disease. I'm not sure if that's because they aren't spending time on other things and have more time to spend with patients but there's definitely been a shift. Our PCP, therapist and other specialists appear to be less rushed and have more capacity to coordinate with us and other providers.*

-Informal Care Provider

### Shared Goals

Goal setting for the patient is iterative and is driven by annual genetics, PCP and therapy appointments, which provide data and insight for how to prioritize care. Additional facetime between the caregiver and providers gave them space to discuss these goals and how they impact and are impacted by the treatment plan. What's more, this additional time allowed the caregiver to work with the primary care provider to come up with strategies to align these goals with the goals of the patient. From a more clinical perspective the extra time allowed the caregiver to work with the primary care provider to synthesize and prioritize the various goals of the clinical specialists. This is especially important in



the case of multi-systemic diseases like hEDS, where attending to all of the goals of each specialist (cardiologist, orthopedist, geneticist) is not realistic or feasible.

### Mutual Respect

Mutual respect between the informal caregiver and providers remained largely unchanged during the transition to telehealth visits, as indicated by the following quote:

*There's a high level of mutual respect that hasn't changed since COVID-19, but a higher quality of communication has emerged and it's strengthened our shared goals for the patient, our daughter.*  
-Informal Caregiver

hEDS is associated with a wide range of other co-occurring diagnoses, which are often eclipsed by the principal diagnosis. Reporting symptoms of the patient, which interventions are working, and which are not, is important to our understanding of the disease pathology. The frequency of interacting with providers, especially the primary care provider, allowed a lot of the more subtle observations of the caregiver to be fleshed out in full. Additional time only amplified the pre-existing willingness of the PCP to help the caregiver think through how best to manage symptoms and co-produce a treatment plan:

*The uncertainty of the path of treatment felt okay because we were navigating these uncharted waters together.*  
-Informal Caregiver

## DISCUSSION

U.S. national and state level policies during the COVID-19 transformed the landscape of healthcare payment and delivery in two important ways. First, providers were authorized to conduct telehealth visits which were reimbursed at parity with in-person visits (1, 20, 63). Additional payment structure changes allowed providers to utilize check-in codes for telehealth visits delivered via phone, web-based platforms and/or email communication (64). Second, the Office of Civil Rights provided flexibility around HIPAA laws with respect to patient privacy and confidentiality in accessing telehealth services (18). This offered opportunities for providers to communicate with patients and/or caregivers via phone and/or other less-secure mechanisms. The healthcare payment and service delivery policy changes have impacted the ways in which patients and caregivers interact with providers and in some cases, has reduced barriers to accessing services which has resulted in a more efficient and effective plan of care.

This study investigated the care coordination of a pediatric patient in Massachusetts with a complex chronic condition from the perspective of her mother, an informal caregiver, in the context of the healthcare policy changes to telehealth service delivery. Overall, communication and coordination were observed to have improved over the course of the study period, allowing for the patient plan of care to be implemented and adjusted more efficiently and effectively. These findings extend the current body of research by pointing to the importance of care coordination and the critical role of relational coordination

in the provision of care. Specifically, our findings support the notion that productive collaboration between informal caregivers and healthcare providers is likely due to a combination of communication frequency, accuracy, problem solving, and timeliness supported by shared goals, shared knowledge, and mutual respect (48).

We interpret these findings around care coordination between the informal caregiver and healthcare providers in several ways. First, we view them from a broader context by recognizing the informal caregiver as a co-producer of patient health and well-being. Because more medical care is provided at home than in formal health care settings, there is a need for informal caregivers to be viewed as formal members of the health care team (44). Arguably, this may be more important for patients who have rare, complex diseases for which shared knowledge from the caregiver is crucial to assessing the patient and developing and adjusting the plan of care. Thus, the increase in timeliness and frequency of communication in addition to shared knowledge via telehealth visits between the caregiver and providers is important in the shared planning and execution of care (65).

Second, accessing telehealth services through video conferencing and phone calls highlights the importance of shared information systems in the delivery of health care services. In the case of this study, the shared information systems included a web-based platform for engaging in video conferencing and use of phone lines. Together these supplemental forms of communication reduced barriers to access to care and supported key components of relational coordination. This finding supports the structure/process/outcomes model of relational coordination proposed by Gittell (45).

Third, this case study provides insight into several caregiving functions that have been impactful in the care for this patient. A resounding theme of the caregiving role is that of boundary spanner and coordinating work among providers (66). These findings concur with a growing body of literature that highlights the need to develop and study tools to support caregivers as boundary spanners (47, 67). This role can be further augmented with management tools, like stakeholder charts and information sharing platforms offered by telehealth that are designed to help caregivers accurately and effectively coordinate care (68). That being said, building checklists for patients, like other means of explicit accountability, is a double-edged action. While it can give welcomed structure to caregivers who are able and willing to provide care, it has the potential to lock other caregivers into roles that they can't perform or are inappropriate. In the case of caregivers who are already receiving social pressure to give labor to the patient, this can put additional strain on that relationship, which has the potential to create unintended consequences for the health of the caregiver (69) and the quality of care provided to the patient (70). Gage and Albaroudi (71) instead argue that an appropriate tactic is to measure the capability of caregivers and co-produce one or more responsibilities according to the characteristics of their specific involvement. From a practical standpoint, it may be helpful to equip caregivers with the knowledge, skills, and abilities needed to prepare for appointments, utilize time during appointments and follow up in between appointments.

We highlight policy and practice implications including continued access to telehealth services and systematically assessing the strength of relational ties between caregivers and providers. Caregiver access to telehealth through videoconferencing, phone and/or email communications has potential to improve care coordination and result in more efficient and effective implementation of the plan of care. Providers may consider increasing the adoption of newly created check-in codes (64). This incentivizes the use of shorter visits that can be synchronous (phone or video) or asynchronous (secure message). This nimble medium for coordination of care increases timeliness and frequency of communication without requiring the time or financial expense of a full-length visit. This study found that check-in and other billing codes were often used to reimburse providers for interactions with caregivers. This practice requires support of insurance payers and health systems in the form of explicit policies indicating that providers can bill for the time that they spend with caregivers. This limits uncertainty around what actions are billable and allow providers to feel confident that their time spent communicating and coordinating with caregivers is within their scope of practice and will be reimbursed.

Additional research is needed to understand the generalizability of the findings of this single case study of an exemplar. Subsequent studies with larger sample sizes are needed to assess the relationship between telehealth and care coordination between providers and caregivers for the treatment of complex patients. Relational coordination, in particular, can be measured quantitatively through the use of the validated Relational Coordination Survey, which makes it possible to do a follow up survey to determine generalizability (29, 72). It may also be valuable for providers to ask open-ended questions to informal caregivers related to goal setting and treatment plan strategy, something that can further increase patient value (73). This paper links telehealth to process measures (relational coordination, co-production, goal setting, etc.). Future research is needed to connect these process measures to performance outcomes, such as hospitalizations, health measures, and other measures of cost of care. Making this connection from process to outcome enhance our understanding of how the discussed practices impact the efficiency and effectiveness of care.

This paper focused on how telehealth impacted the caregiver's ability to provide care in their role as a boundary spanner. Research is needed to understand how this support impacts caregiver burden, which has been associated with caregiver anxiety and depression in other contexts (74, 75). A secondary benefit of this investigation is that we found that telehealth reduced time and expense of caregiving by decreasing travel and the need to coordinate childcare. Additional research is needed to explore these findings more rigorously and understand how telehealth impacts the cost of caregivers for rare disease. These findings will help insurance organizations to understand the value of caregiving, which will inform a conversation about caregiver compensation and other forms of support for the caregivers.

From a broader systems perspective, this case study suggests that the use of telehealth services are a mechanism to facilitate

and support high quality relationships between providers, caregivers, and patients. Particularly for patients with chronic conditions, the convenience of telehealth services for clarifying important details in the plan of care, medication management and problem solving around specific interventions offers the potential for timelier implementation and/or iteration of the care plan. Implementing telehealth in this way has the potential to support the caregiver's role and simultaneously reduce caregiver burden. We do not suggest telehealth as a solve-all solution for improving care coordination. It must be aligned with broader efforts to build team performance and add value for patients and caregivers. To that end, healthcare providers seeking to utilize telehealth services as a supplement to in-person visits and to improve care coordination may benefit from relational coordination training and other methods to build collaborative team cultures. Within this context, training may focus on communication and facilitation skills as well as building shared goals, shared knowledge and mutual respect within and across stakeholder groups. Training may also include best practices for coordinating with caregivers, creating care planning guidelines, understanding and respecting caregiver's preferences and capacities and developing shared goals for the patient.

## CONCLUSION

The unique role of the contributing author as both participant in her daughter's medical care and member of the social community has put her in the position of being able to bridge these two cultures, identify opportunities for them to work together, and point out misalignments.

This study has several limitations. While the autoethnographic style helped to nest the observations directly in the lived experiences of the corresponding author as an informant without interpretation, it introduced a specific type of researcher bias where there is no second party to check her portrayal of a desired outcome. That said, it can be assumed that her inherent bias is at least in part influenced by her lived experience, making it a signal in its own right. Further, the collaboration with a second researcher helped this study to be carried out systematically, using multiple methods to inform the analysis.

Perhaps more impactful are the limitations to sample size of one patient and external validity. The corresponding author is a highly educated researcher and confident in her ability to correctly interpret and explain information. She understands the pitfalls inherent in patient/provider power dynamics, and knows how to advocate for herself and for her daughter. Moreover, she has the capacity to devote time and the resources to her daughter's care. These limitations speak to a larger challenge of variation between informal caregivers, which affects their abilities to perform a single defined set of functions. Moving forward, this means that support and measurements of quality must be broken down into specific caregiving functions, allowing caregivers to define the bounds of their contribution. This itemization can maximize performance of individual tasks, while minimizing pitfalls associated with assuming caregiver ability.

## AUTHOR'S NOTE

The goal of this research is to understand where telehealth adds value for patients and their families to inform policy that expands access to remote health care. Because the corresponding author is the instrument in this qualitative study, it is beneficial to provide a brief explanation of the researcher's positionality as it relates to the research (61, 62). She holds a Bachelor of Arts degree in psychology, a Master of Public Administration and a Ph.D. in Social Policy—an interdisciplinary background that has informed a research agenda centered on organizational change and relational practices that support high performing teams, organizations and communities. Using both quantitative and qualitative approaches, she has studied team dynamics in multiple healthcare contexts. Her familiarity with theories and frameworks that support high performance, such as relational coordination, have provided the foundation for which the analysis in this study is based on. The author's perspective as an informal caregiver is also informed by her positionality as a privileged white female with high digital literacy.

The second author is a Ph.D. candidate in Social Policy, and is simultaneously working on a Master's in Business Administration. He studies caregiving and patient adoption of telehealth. The second author's perspective on both topics is informed by his positionality as a white male with substantial privilege and high digital literacy. His background and training in social policy has helped to inform a perspective that telehealth has the potential to be beneficial as a supplement communication medium to in-person visits for specific procedures. These

benefits, however, are lost on those who lack the technology, internet bandwidth, and/or high digital literacy needed to effectively make use of the technology. This framing has led him to explore different contexts for telehealth use to identify strengths and weaknesses of the medium.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Brandeis University Institutional Review Board.

## AUTHOR CONTRIBUTIONS

The unique role of the corresponding author as both a social science researcher and participant in her daughter's medical care and member of the social community has put her in the position of being able to bridge these two cultures, identify opportunities for them to work together, and point out misalignments to inform research, policy and practice. BK contributes his knowledge and expertise in qualitative methods, healthcare coordination and delivery and informal caregiving to systematically understand and evaluate value-driven approaches to care. All authors contributed to the article and approved the submitted version.

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# Value and Cost Savings From Access to Multi-disciplinary Rehabilitation Services After Severe Acquired Brain Injury

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Acquired brain injury (ABI) is a major global public health problem and source of disability. A major contributor to disability after severe ABI is limited access to multidisciplinary rehabilitation, despite evidence of sustained functional gains, improved quality of life, increased return-to-work, and reduced need for long-term care. A societal model of value in rehabilitation matches patient and family expectations of outcomes and system expectations of value for money. A policy analysis of seven studies (2009–2019) exploring outcomes and cost-savings from access to multi-disciplinary rehabilitation identified average lifetime savings of \$1.50M per person, with costs recouped within 18 months.

**Recommendations:** Increase access to multi-disciplinary rehabilitation following severe ABI; strengthen prevention focus; increase access to case management; support return-to-work; and systematically collect outcome and cost data.

**Keywords:** health policy, cost-effectiveness, shared decision-making, societal model of health, lifetime savings, traumatic brain injury, stroke, post-acute rehabilitation

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## INTRODUCTION

Acquired brain injury (ABI) from traumatic brain injury (TBI), stroke, infectious disease, metabolic disorders, and brain tumors is a major global public health problem (1). A severe ABI (sABI) is any injury to the brain that occurs after birth, disrupts brain function, and has serious consequences (functional, cognitive, psycho-social) for the injured individual. Clinically, severe traumatic brain injury is defined as resulting in loss of consciousness for 6–24 hours or more (2). In the chronic phase of ABI from any cause, lifelong disabilities may affect the ability to work, perform activities of daily living (dressing, paying bills), participate in community life, and/or fulfill a family role. An sABI impacts the life of an individual and their family, and also has a large community, societal and economic toll (3).

The lifetime economic cost of TBIs that occurred in the United States in 2010, including direct medical costs and indirect costs in lost wages, lost productivity, and non-medical expenditures, was estimated to be ~\$76.5 billion (in 2010 dollars) (4). Ninety percent of the U.S. economic cost of TBI stems from fatal TBIs and those requiring hospitalization (4, 5). Lifetime costs have increased significantly because advances in emergency medical care and neurosurgery enable more people to survive a hospitalization for brain injury (6, 7). A severe brain injury no longer means an “end” to life for many, but it does mean life changes. Currently, an estimated 47.4% of people who experience a TBI incur lifelong disability in at least one area of function (8, 9). For example, a man hospitalized for a TBI at age 40 could be expected to need assistance with one or more activities of daily living for 23–32 more years (10).

In the U.S. some 20 million Americans are living with disabilities from TBI (from a blow or jolt to the head) and stroke (11, 12). Lack of access to appropriate multidisciplinary post-acute rehabilitation services increases the disability rate, despite evidence that access can increase functional gains (13, 14), quality of life, rates of return-to-work, and savings in long-term care (15). Access to multi-disciplinary rehabilitation can be limited by lack of insurance, coverage limitations, services unavailable close to home, and low understanding of the benefits. Payment through insurance, however, is essential to insuring availability of multi-disciplinary, post-acute rehabilitation services.

One way to conceptualize value in access to multi-disciplinary rehabilitation after sABI, is to consider three different value models for the provision of healthcare: the market, lifetime, and societal models. The market model informs access to rehabilitation in the market-based health-care system in the U.S. The lifetime model informs healthcare in countries with global healthcare budgets and a universal system of coverage, such as the U.K. (16). The societal model takes into consideration broader population health and wellness goals inside and outside the healthcare system (17). All three models manifest different values, decision-makers, and approaches (see **Figure 1**).

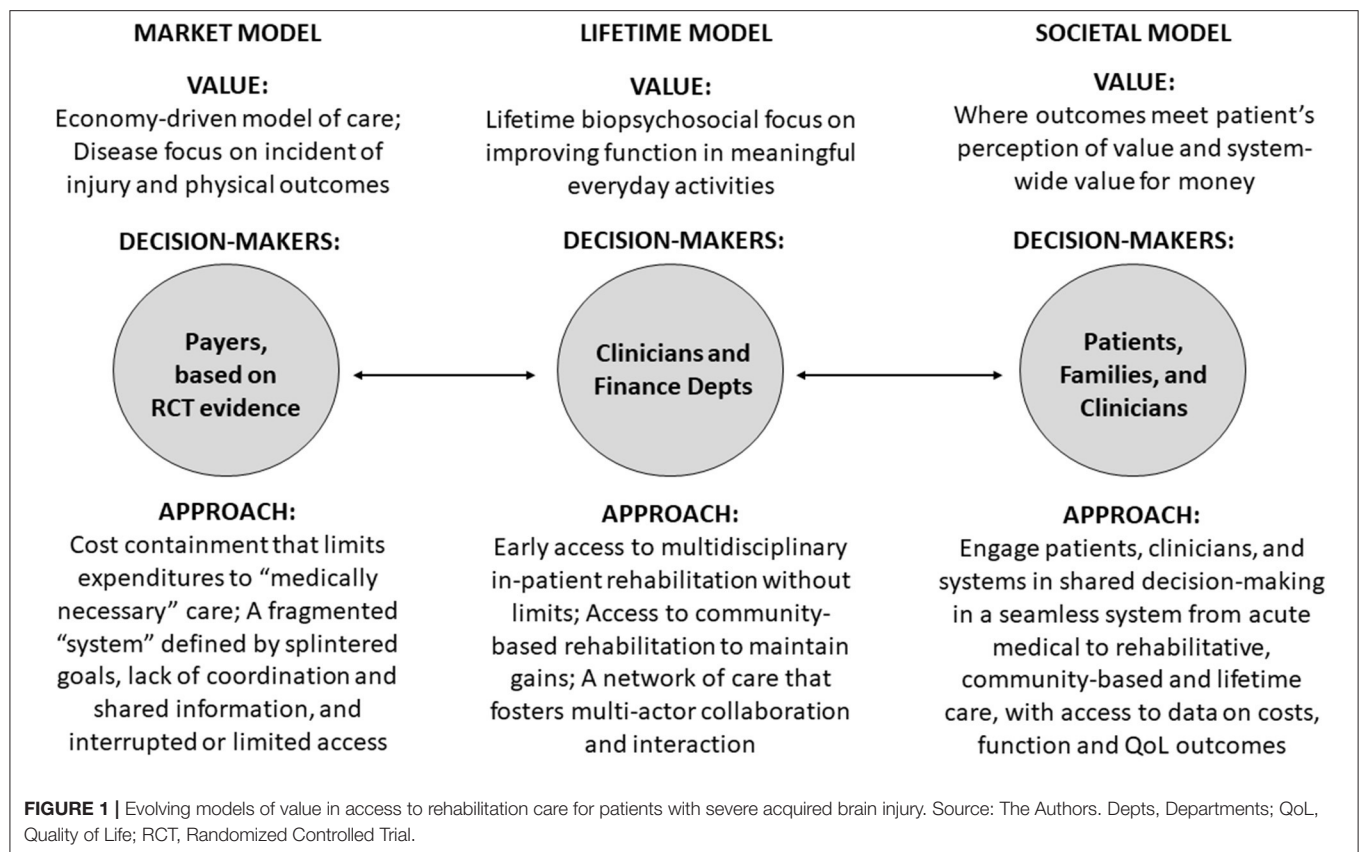
For the market model value is determined by health payers (17). When payers determine access, rehabilitation care is frequently denied unless the care is “medically necessary” to improve physical function (i.e., walking) and return-to-work (18). Employers are large purchasers of insurance and value low premiums and services that address immediate health needs. Insurance companies have short-term value propositions and are less likely to provide access when health and cost-savings benefits have a long-time horizon and accrue to others. Under the market model, access to rehabilitation services is interrupted or limited and delivered by a fragmented system whose actors have different goals (e.g., free up beds) and little incentive to coordinate across levels (19–21). An example of the market model is the U.S., where different payer systems, including Medicare, Medicaid, Employer-Sponsored Insurance, worker compensation and other options are available—or not available—on a state-by-state basis, and payers play a dominant role in determining access to multi-disciplinary rehabilitation after sABI. In the fragmented U.S. system, worker compensation is the insurance modality most likely to provide access to multi-disciplinary rehabilitation after sABI. The challenge of a compartmentalized system has been noted in the Netherlands, where different entities fund health and rehabilitation care vs. long-term care (22).

For the lifetime model of rehabilitation services, common in countries with integrated, single-payer health systems (16, 23), clinicians determine access based on evidence from research and system data. The lifetime model is concerned with ABI patients’ biopsychosocial outcomes and seeks to increase patient independence and participation in life (16, 23). The lifetime model bases decisions about access on clinicians’ expert opinions and on rehabilitation savings, projected or actual (16). The goal

is to maximize lifelong health benefits across the system in the most cost-effective manner. The lifetime model supports post-acute multi-disciplinary rehabilitation services after an ABI when function can be improved and long-term use of health and social care is reduced, and systematic collection of longitudinal data on services and outcomes to support clinical decision-making (16). Two examples of the lifetime model are Ireland and the U.K., which have integrated, single-payer health systems. In the U.K., regional networks deliver specialist rehabilitation for patients with more complex rehabilitation needs (19). Long-term services and supports are provided by the same single-payer health system. Service utilization and outcomes are tracked longitudinally to inform decision-makers – clinicians – about value and cost-savings vis-à-vis the public investments being made (19).

The societal model considers total societal costs and benefits inside and outside the medical care system. It places a high value on prevention and providing a range of effective services to support independence for individuals. Value in access to multi-disciplinary rehabilitation is determined through shared decision-making by patients, families, and clinicians (17, 21). The societal model relies on a seamless healthcare system from acute care to post-acute rehabilitation to community-based care and coordination with social supports such as vocational training, transportation, and respite care. An example of the societal model is sTBI rehabilitation in Victoria, Australia when the injury occurs due to a transport accident. Victoria’s Transport Accident Commission (TAC), established in 1986, is a “no fault” social insurance scheme funded by vehicle registration/insurance fees and returns from investment of unused funds (24). TAC programs fund injury prevention (including road improvement), rehabilitation, case management/coordination of services, income support, return to work, home care, research, and long-term (disability) services and supports for individuals injured in transport accidents (road, train, boat, etc). TAC is notable for engaging youth, patients, families, clinicians, researchers, non-profit organizations, local government entities, and the public in the program (24). TAC services are only available to individuals injured in transport accidents, not for stroke or other acquired brain injuries. There is no comparable sTBI cost-effectiveness study from Victoria to include in our analysis, although the study protocol for an evaluation of the overall injury claims management intervention has been described (25).

In this policy brief, we examine evidence from seven studies in three countries of savings in lifetime care costs from access to multi-disciplinary inpatient rehabilitation supporting physical, cognitive, and social skills after sABI. We provide a model of the continuum of care for sABI and note where policy investments can generate long-term savings. We provide actionable recommendations for policy options at the state and federal level intended to increase access to rehabilitation services after sABI. The analysis uses insights from the lifetime and societal models of healthcare to inform efficiency gains in the market model.



## POLICY ANALYSIS

### What Is Known About Rehabilitation Savings After a Brain Injury Requiring Hospitalization

Our policy analysis of seven studies published between 2009 and 2019 explores outcomes and cost-savings from access to rehabilitation services within 12 months of an ABI requiring hospitalization. Study inclusion criteria were (a) published between 2009 and 2019; (b) a TBI or mixed ABI sample of patients with high dependency on admission, which indicated sABI; (c) admitted within 12 months post-injury; and (d) provided access to multi-disciplinary, inpatient rehabilitation services for up to 6 hours per day, 5 or 6 days per week. Study sample size ranged from 33 to 3,289 (median 133). Patient age averaged 42 years (39–49 years). Length of stay in multi-disciplinary inpatient rehabilitation averaged 151 days (89–227 days).

Our calculations of lifetime savings involved several steps. First, we calculated minimum and maximum life expectancy for each sample using a standardized approach for people with TBI (10). Second, for studies that showed savings per week or month we calculated annual savings. Third, to determine lifetime savings, we used (a) an exchange rate approach to transform currencies to dollars and (b) a Purchasing Power Parities (PPP) approach for more accurate inter-country comparison (26) of

rehabilitation costs and savings. Fourth, for each study we multiplied annual savings by the minimum and maximum years of life expectancy for each cohort and averaged the two. Finally, we calculated an average savings across all studies by summing their average lifetime savings and dividing by seven.

Across the seven studies lifetime savings from access to multidisciplinary rehabilitation services within 12 months of a severe brain injury averaged \$1.58M (SD\$.36M) per person using an exchange rate method and \$1.50M using a PPP approach (SD\$.35M). The cost of services was recouped within 17.2 months (12–27.6 months) on average. Lifetime savings were realized due to patients' increased independence and decreased reliance on services and supports for activities of daily living following discharge (14, 16, 23, 27–30).

The studies calculated rehabilitation savings by comparing the cost of rehabilitation (per person, based on length of stay) and a reduction in post-discharge supervision costs (e.g., care hours) based on reduced dependency or need for supervision (14, 16, 23, 27–30). Typical dependency issues after a severe brain injury include lack of executive function and self-awareness, and increased attention deficit, impulsiveness, disinhibition, irritability, aggression, and mood disorder (14). For all studies, rehabilitation savings were greatest for patients initiating rehabilitation 3–12-months post-injury, though lifetime savings were also noted for patients admitted 2–5-years post-injury (14, 16, 27).

In a U.S. study (30) three independent certified life care planners reviewed anonymized patient reports describing cognitive, communication, mobility, self-care, psychosocial and medical areas at admission and discharge. Each care planner generated a projected cost of care for each patient report. The projected costs from the admission reports were then compared with projected costs from the discharge report file. Savings calculations included costs of long-term care, medical care, equipment, and housing. In Ireland, a study of in-patient rehabilitation cost-effectiveness found that brain-injured patients with greater dependency on admission to rehabilitation achieved the estimated per person cost-savings offset of \$56,000 in <16 months (23).

Patient gains in independence were maintained over time. In Great Britain, three intervention studies compared dependency measures at intake, discharge, and 6-months (14, 27, 28). Examples of dependency measures collected at 6-month follow-up were: independence, overnight supervision, part-time supervision, full-time indirect supervision, and full-time direct supervision (27). On average, lifetime savings identified by these U.K. studies ranged from \$1.33 to \$1.37 million per person. The cost of rehabilitation was recovered within 1–5 years for patients admitted to rehabilitation within 12 months of injury. Calculations used a discounted life expectancy approach for people with brain injury.

A 2019 study in Great Britain (16) used the U.K. Rehabilitation Outcomes Collaborative (UKROC) database to estimate life-time savings in ongoing care after access to tertiary specialist rehabilitation (intensive, in-patient, multi-disciplinary) for brain-injured patients with complex needs. The sample was 3,289 adults (age 16+) with TBI and a length of stay between 8 and 400 days. Mean estimated net lifetime savings averaged \$.83 million (\$.49M–\$1.18M). This study is notable for its sample size, which was 16 times greater than the next largest sample in our analysis.

### Limitation

A weakness in the studies included in **Table 1** is that they do not calculate any decrease in societal costs gained from less reliance on other government programs, improved return-to-work rates, and benefits to families and society through easing of family caregiving and economic burdens. In The Netherlands, researchers conducted a cost analysis of a residential community reintegration program for people injured at least 2 years prior (31, 32). They used Dutch national guidelines to identify the costs of healthcare, informal care, and productivity losses related to participation in the rehabilitation program (31). Societal costs were significantly reduced after participation in the program, and work, education, emotional/behavioral, and independent living outcomes were maintained 3 years later (32). The Netherlands studies indicate that initiating access to rehabilitation later than 12-months post-injury also leads to savings. We recommend that future research study societal costs and benefits from access to multi-disciplinary rehabilitation after an sABI.

## Where Savings From Investments in Rehabilitation Can Be Realized

The continuum of care for severe brain injury includes prevention, hospital-based services, post-hospital services, and community-based programs. Traditionally the emphasis has been on acute medical care with less attention on post-acute rehabilitation or community-based care, where most survivor time—and public costs—are spent. Our depiction of the continuum of care for severe brain injury (see **Figure 2**) illustrates the fluid nature of need as people with severe brain injuries access medical and social care throughout their lives. **Figure 2** also illustrates that family support is vital across the continuum to facilitate access to services, support recovery, maintain function, and improve quality of life for people with severe brain injury. The continuum of care provides a context for the services being discussed and our analysis.

In the U.S., the Medical Care phase after a brain injury is largely covered by an individual or a families' health insurance, or by worker compensation if the injury occurred when working. Delays or interruptions in access to rehabilitation services can mean lower gains in function, quality of life, independence, and vocation (34). Within 6 months of their injury, over 30% of U.S. residents who survive sABI lose their private or employer-based health insurance (35). Many with severe injuries incur major debt and are forced into bankruptcy (36). The studies examined demonstrate that improved access to rehabilitation after sABI can lead to savings in medical care at the post-acute care level through reduced length of stay when the care is not interrupted (37, 38) and savings for individuals, families, and society when independence is increased and the need for supervision reduced (39).

## RECOMMENDATIONS

While not explored in this paper, prevention policy to reduce the number of brain injuries would maximize population health and minimize total social costs (4, 40). Enhancing prevention is in keeping with the societal model. Prevention efforts include automobile enhancements to prevent crashes; efforts to reduce distracted, drunken, and drugged driving; sports safety measures to reduce multiple concussions; and fall prevention programs for seniors. One prevention example is Victoria, Australia's efforts to reduce transport accidents through public education campaigns and investments in road infrastructure making high-risk roads and intersections safer for cyclists, pedestrians, and vehicles (41).

The second recommendation is to improve access to rehabilitation after sABI to generate value within the lifetime and societal models of value in healthcare (see **Figure 1**). The greatest health benefits and savings would accrue from ensuring consistent rehabilitation within the first 12 months of injury. Providing access two or more years post-injury would help to maintain function, maximize independence, and reduce the need for services and supports. One approach to improve access would be to mandate rehabilitation service access nationally as part of mandated coverage requirements under the Affordable Care



**TABLE 1 |** Analysis of average, lifetime, per-person rehabilitation cost-savings for patients with sTBI or Mixed sABI (High-Dependency) admitted to multi-disciplinary inpatient rehabilitation <1 Year Post-Injury in Ireland, United Kingdom, and United States (7 studies) (1999–2019).

Source	Sample	LOS	Measures	Costs Measured*	Lifetime savings (Exchange)*	Lifetime Savings (PPP)**	Cost Offset (Time to savings)***
Cooney, <i>Clinical Medicine</i> , 2016/Ireland	41/mixed sABI/43.5 yrs	93 days	DRS	Direct costs of post-acute rehab care	\$1.517M (\$2.011M–\$1.023M)	\$1.310M (\$1.737M–\$0.884M)	15.6 mo
Griesbach, <i>Journal of Neurotrauma</i> , 2015/USA	33/sTBI/40.1 yrs	227 days (sTBI)	CIQ CNS DRS LSS MPAI-4 OSS	Projected lifecare costs (pre-rehab vs. post-rehab)	\$2.268M (\$2.949M–\$1.587M)	\$2.268M	(not studied)
Oddy, <i>Brain Injury</i> , 2013/UK	196/sTBI and stroke/ 41 yrs	183 days	MPAI-4 SRS	Direct costs of post-acute rehab care	\$1.502M (\$1.940M–\$1.064M)	\$1.430M (\$1.847M–\$1.013M)	12 mo
Turner-Stokes, <i>Brain Injury</i> , 2007/UK	51/sTBI/39 yrs	183 days	NPDS NPCNA UK FIM+ FAM	Bed-day cost X LOS	\$1.926M (\$0.393M–\$2.238M)	\$1.835M (\$2.329M–\$1.341M)	14.2 mo
Turner-Stokes, <i>BMJ Open</i> , 2016/UK	190/mixed sABI/46 yrs	103 days	RCSE-M UK FIM+FAM	Episode cost per patient in the rehab unit	\$0.685M (\$0.937M–\$0.432M)	\$0.652M (\$0.892M–\$0.412M)	27.6 mo
Turner-Stokes, <i>JHTR</i> , 2019/UK	3,289/sTBI/49 yrs	89 days	NPDS NPCNA UK FIM+FAM NPDS NPSPCNA	Cost of rehab	\$0.833M (\$1.176–\$0.490)	\$0.793M (\$1.120M–\$0.467M)	15.9 mo
Worthington, <i>Brain Injury</i> , 2009/UK	133/mostly sTBI/36 yrs	183 days	ARS FAQ OERS SRS	Direct costs of post-acute rehab care	\$2.310M (\$2.868M–\$1.753M)	\$2.200M (\$2.731M–\$1.669M)	12–24 mo

\*Exchange rates: \$1.5/£1 (2006–2013); \$1.82/€1 (2005 and 2011); \*\*Eurostat, Organization for Economic Cooperation and Development (OECD), Purchasing Power Parities (2012);

\*\*\*Time point when rehabilitation costs are recouped by rehab savings. Monetary symbols: £= British pound; € = Euro; \$ = U.S. dollar. ABI, Acquired Brain Injury; ARS, Accommodation Rating Scale; CIQ, Community Integration Questionnaire; CNS, Center for Neuro Skills Independent Living Scale; DRS, Disability Rating Scale; FAQ, Functional Activities Questionnaire; LOS, Length of Stay; LSS, Living Status Scale; M, million; mo, months; MPAI-4, Mayo-Portland Adaptability Inventory – 4th edition; NPDS, Northwick Park Dependency Scale; NPCNA, Northwick Park Care Needs Assessment; OERS, Occupational Engagement Rating Scale; OSS, Occupational Status Scale; RCSE-M, Rehabilitation Complexity Scale, including medical support; PPP, Purchasing Power Parities; rehab, rehabilitation; SRS, Supervision Rating Scale; sABI, severe acquired brain injury; sTBI, severe traumatic brain injury; TBI, traumatic brain injury; UK FIM+FAM, Functional Independence Measure, version 4 plus a derived Barthel Index; yr, year.

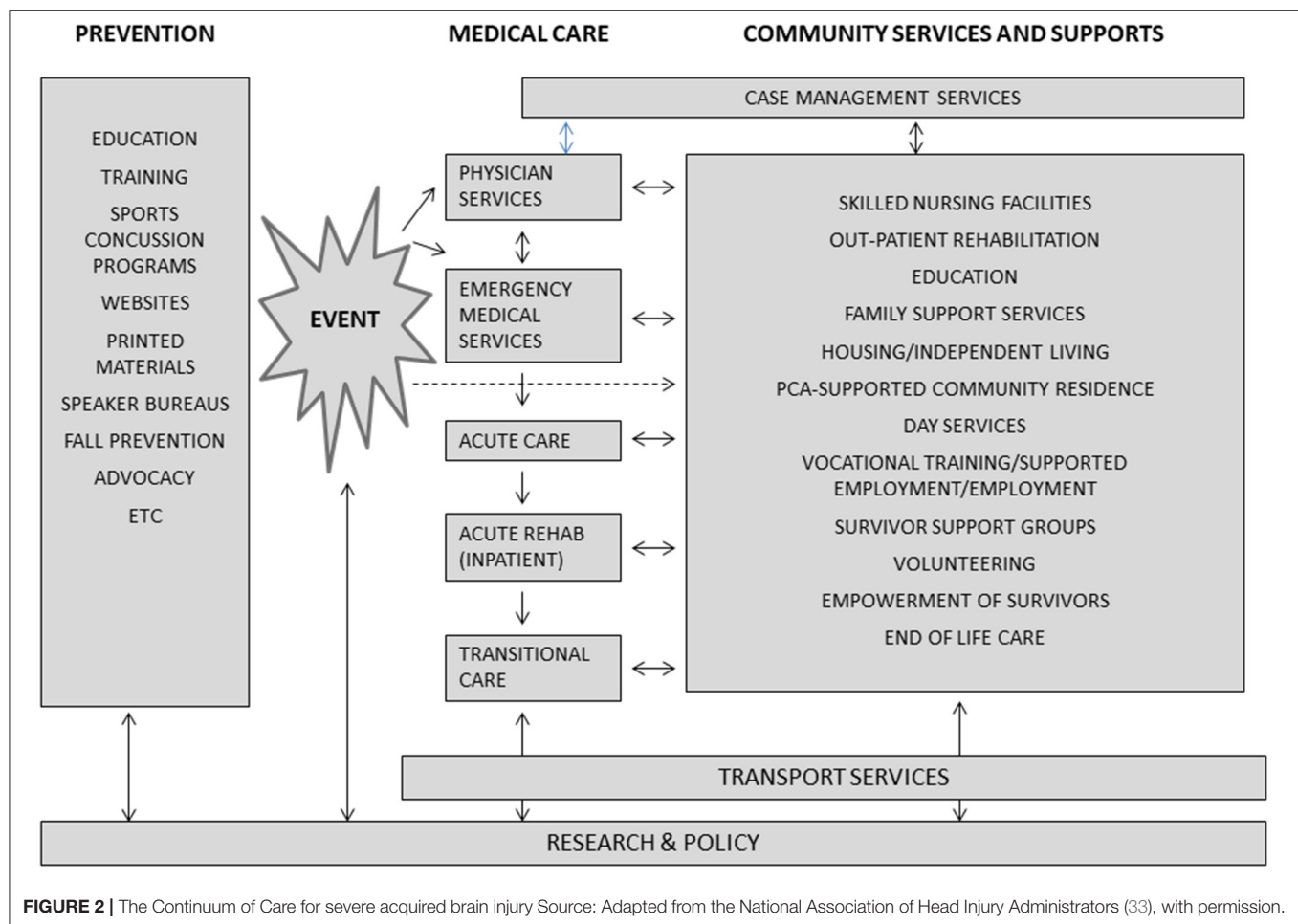
Act (ACA). Access would then also be required under Medicare and Medicaid, which are the largest providers of services for people with TBI. Alternatively, states could mandate post-acute rehabilitation services through state insurance regulation. Texas has done this since 1995 (42), although the regulation does not apply to all insurance products sold in the state. Large companies that provide health insurance under the Employment Retirement Income Security Act of 1974 (ERISA) for example are exempt from state insurance regulation as is the Medicare program. State action in multiple states, however, would increase the probability of national legislation (43). Implementing these recommendations would adjust the market model to create a level playing field across all insurers and achieve some of the benefits of the societal model.

The third recommendation is universal case management from the time of injury to recovery or end-of-life. It is not enough to have services covered if people do not know what is available and how to access the appropriate care. TBI is, by definition, traumatic causing sudden and massive changes in the lives of individuals and families. Independent case managers

provided by state-sanctioned entities not tied to providers or insurers would be provided to all patients regardless of income (24). Case managers would assist patients through the complex medical, economic and social supports necessary to optimize health and independence (44). In addition to medical care, case managers would help provide access to social services such as housing, day programming, and vocational rehabilitation (7, 45, 46), thus increasing the possibility of returning to work, family engagement, community participation, and increased annual earnings (7, 46, 47). Examples of successful case management for people with disabilities from severe brain injury can be found in Missouri, Victoria, Australia, and the U.K. (24, 41, 48). Informing patients, families and providers about the best available care would limit asymmetric information and lead to efficiencies in the market model.

The fourth recommendation is to support back to work efforts. Vocational rehabilitation has been shown to help move people toward greater independence and improved quality of life and save money. Indiana's program "Resource Facilitation," led to significant cost savings to that state through improved





long-term function, reduced annual lost wages, and increased annual earnings (7, 47), identified through research supported by a collaboration of providers, state agencies, advocacy groups, and federal and local funders. Here the societal model informs opportunities for people to engage in communities including the economy.

The final recommendation is to systematically collect service utilization, outcomes, and cost data to better document the costs and savings of rehabilitation services and social supports. The evidence we presented shows unequivocal society and even medical care rates of return from access to rehabilitation after sABI. Having longitudinal data can help to identify where and how savings are achieved and could be maximized, and can help to make an even stronger political case for the upfront investment in multi-disciplinary rehabilitation services after sABI. One approach to data is to create a national brain injury or trauma registry (49), which could be informed by the Traumatic Brain Injury Model System (TBIMS) (50), the OutcomeInfo database (51), and the brain injury registries that already exist in 24 U.S. states. Including demographic and functional measures will help point out where and how optimal health and efficiency goals can be achieved. Longitudinal data are essential for market efficiency.

## CONCLUSION

Acquired brain injury is a major global public health problem and source of disability. Greater access to multi-disciplinary rehabilitation after a severe ABI will improve lives and save money. Savings are achieved through sustained functional gains, improved quality of life, increased return-to-work, and reduced need for long-term care. The societal and lifetime models of healthcare perceive long-term function of sABI patients as providing value. A societal model centers patient and family needs and promotes public health approaches to prevention and care. Insights from this model can be used to adjust the market model to achieve greater efficiencies and this is reflected in our recommendations. An analysis of seven studies (2009–2019) exploring outcomes and cost-savings from access to rehabilitation after a brain injury requiring hospitalization identified average lifetime savings of \$1.50M per person, with rehabilitation costs recouped within 18 months. Our recommendations are to promote prevention, require public and private insurers to provide the range of post-acute rehabilitation services, facilitate access through case management, support back-to-work efforts, and systematically collect and analyze data

to better pinpoint where additional health and costs savings can be realized.

The models presented here are informed by work on ethical frameworks to promote health systems change related to access to care for persons with brain injury (21) and on the concept of value in the healthcare system (17). The multi-disciplinary lens' of ethicists, researchers and clinicians in the field of health service research hold promise for evidence-based action that will improve health and save money.

The continuum of care shows the types of care being provided (or not being provided) after a severe acquired brain injury and their typical sequence over an individual's lifetime. Individuals hospitalized for a severe acquired brain injury are not denied

acute care, and while saving someone's life can be a heroic act, we argue it is access to multi-disciplinary rehabilitation that can help the individual have better function and quality of life in both the short- and long-term.

## AUTHOR CONTRIBUTIONS

LSL and MD developed the conceptual framework for the paper. LSL took the lead on the analysis and computations in the piece. MD took the lead on applying the theory to the analysis and drafting the policy recommendations and conclusions. All authors contributed to the article and approved the submitted version.

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# Challenges and Opportunities for Public Health Service in Oman From the COVID-19 Pandemic: Learning Lessons for a Better Future

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Despite the apparent challenges inflicted by COVID-19 globally, the pandemic provided an opportunity to utilize and expand existing public health capacities for a more adaptive and resilient system during and after each wave of the disease. This paper provides a narrative review of Oman's public health response to the COVID-19 pandemic from January 2020 to July 2021, and the challenges it faced for a more rapid and efficient response. The review demonstrates that the three main pillars influencing the direction of the pandemic and aiding the control are Oman's unified governmental leadership, the move to expand the capacity of the health care system at all levels, and community partnership in all stages of the response including the COVID-19 vaccination campaign. The opportunities identified during response stages in the harmonization of the multisectoral response, streamlining communication channels, addressing vulnerable communities (dormitories, residences at border regions), and providing professional technical leadership provide an excellent precursor for expediting the transformation of Oman's health care system to one with a multisectoral holistic approach. Some of the major challenges faced are the shortage of the public health cadre, lack of a fully integrated digital platform for surveillance, and the scarcity of experts in risk communication and community engagement. A future health system where the center for diseases surveillance and control acts as a nucleus for multisectoral expertise and leadership, which includes community representatives, is crucial to attain optimum health. The destruction inflicted by this prolonged COVID-19 pandemic at all levels of human life had valued the importance of investing on preventive and preparedness strategies.

**Keywords:** COVID-19, Oman, public health, disease surveillance, One Health, health care system, pandemic

## INTRODUCTION

The unprecedented events of the COVID-19 pandemic have placed enormous strain on public health systems worldwide, exposing numerous opportunities for improvement and future preparedness. The ongoing impact of the COVID-19 pandemic since the World Health Organization first declared it emphasizes the need to change, in terms of a pandemic combating strategy, from unidirectional short-term solutions toward a holistic, integrated, and multisectoral approach (1).



Experts in global health have been advocating for a “syndemic” or synergistic epidemic approach to the management of communicable and non-communicable diseases, recognizing that diseases occur alongside social and ecological conditions (2–5). Looking at COVID-19 from a syndemic perspective through multisectoral approach may add more value to individuals and communities.

Oman is a Middle Eastern country with a population of 4.6 million of which 41% are migrants.<sup>1</sup> The country has made efforts to meet the needs of International Health Regulations (2005) (IHR) (6). In April 2017, Oman underwent a Joint External Evaluation (JEE) of the IHR core capacities which included a measurement of public health capacities. The JEE found that the collaboration between different response sectors is a strength for Oman (7). However, despite magnificent effort and steps made in the field of public health in Oman recently, the pandemic revealed that the country was fit to make it through a short event but unprepared for a pandemic of the magnitude of COVID-19.

The current article describes COVID-19 pandemic public health management in Oman from January 2020 to July 2021. During this time, Oman faced multiple unique challenges including transition to a new government, financial crises, presence of multiple borders, and socio-economic connections with neighboring countries, large extended families and the dormitories of migrant workers, as well as challenges within the healthcare system. This review addresses how the COVID-19 pandemic has generated opportunities that position Oman to make steps to align their various efforts in health care adding value and minimizing destruction in future similar situation and the ongoing public health care services.

The framework of this review is designed to cover three periods in relation to the COVID-19 pandemic: before, during and the desired way forward in post-pandemic. This framework highlights the opportunities generated by the COVID-19 pandemic in the field of public health in Oman (Figure 1).

## PRE-COVID-19: OMAN'S GEODEMOGRAPHIC AND PUBLIC HEALTH STRUCTURE AND SERVICES

There were many challenges encountered in Oman during the combating of the COVID-19 pandemic that generated opportunities for improvement (Supplementary Material 1). Oman, with its unique location in the Middle East, shares land borders with three countries, and is connected closely to other countries by sea and air travel. These connections serve social, commercial, religious, touristic, and educational purposes. The diversity of Oman's geography with its many border crossings, and the collectivist culture of large Omani families and extended social connections, create an environment with a high risk of importing the disease and increased risk of transmission within the community. Furthermore, the migrant working class with their need for medical care along with an underdeveloped health insurance system have posed difficulties, including establishing

free testing and clinical care and vaccination during COVID-19, to achieve universal health coverage. Consequently, during the COVID-19 epidemic, outbreaks in high-density communal residences of migrant workers (dormitories) largely from the Indian subcontinent were challenging to control, not unlike settings in Singapore (8).

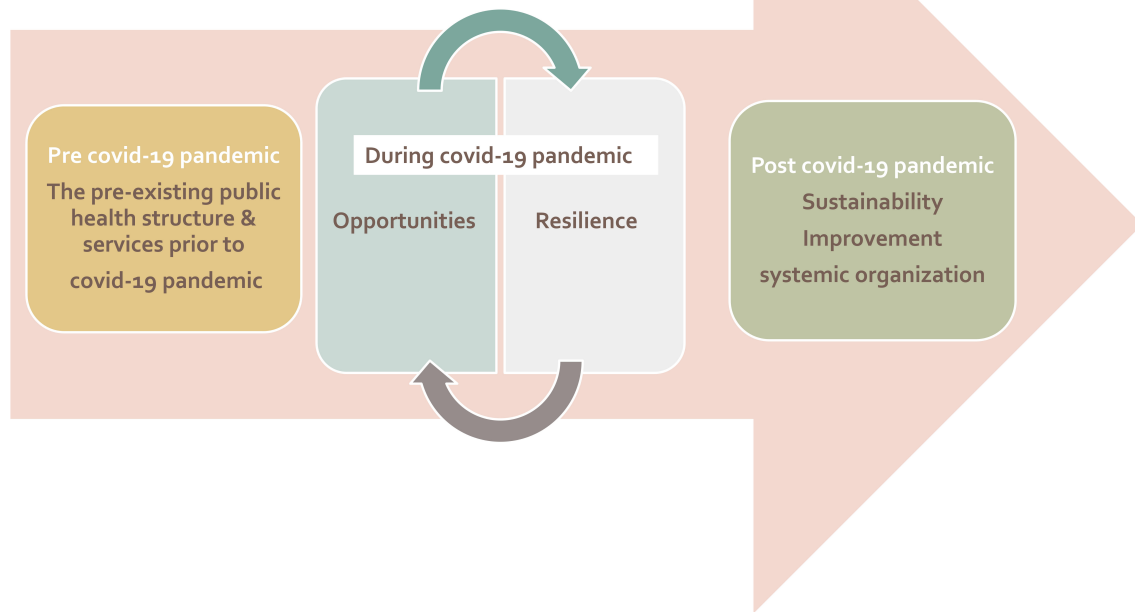
Health care services in Oman are widely distributed and mainly led and financially supported by the government in collaboration with the private sector. At a national level, the Directorate General for Disease Surveillance and Control (DGDSC) is considered the responsible body to run and monitor day-to-day public health work as well as during emergent events and public health crises via its different departments including surveillance, communicable diseases, central public health laboratories, infection prevention and control, environmental, port health and International Health Regulations, and occupational health. However, the DGDSC has no functional arm by itself except through the directorates general for health services in the different governorates. The functional arm which implements and runs the clinical as well as the public health services are the primary, secondary, and tertiary health care facilities, private health establishments and other non-Ministry of Health (MoH) health care facilities.

The scattered structure of public health services with limited resources for detection, response and prevention, necessitated a huge effort to mobilize and train health care workers for the implementation of public health interventions during the pandemic. Additionally, maintaining essential health services, especially during surge periods, was a leading challenge during the pandemic. For example, the primary health care staffs were utilized in COVID-19 response at community level as well as in acute care services at the hospitals.

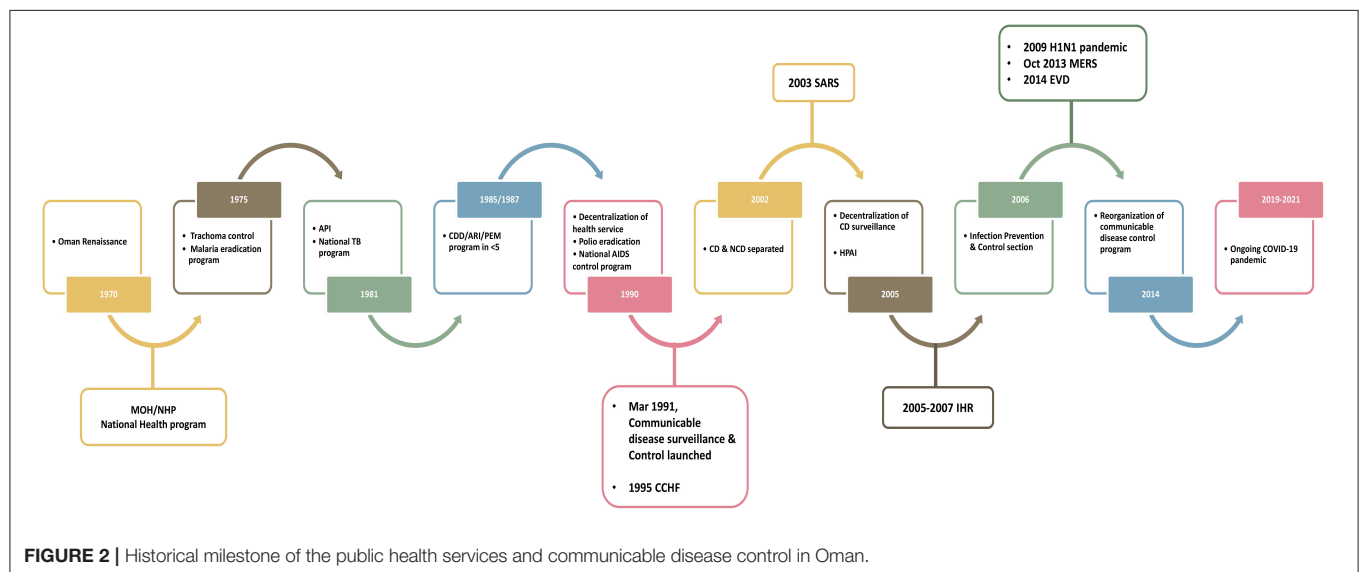
Over the years, Oman experienced different outbreaks such as Crimean-Congo hemorrhagic fever, dengue fever, measles and Middle East respiratory syndrome coronavirus (MERS-CoV) (9–11) (Figure 2). Although Ebola did not evolve into a pandemic in 2014, the preparedness experience for it at Oman's PoEs and in building infection prevention and control capacities was of immense value thereafter (12). Ebola preparedness allowed the involvement of public health in designing the country's new international airport in Muscat with a health care facility linked to the arrival pathway before immigration with six airborne isolation rooms and an exit pathway away from passengers to avoid exposures from potential infectious cases. The management of dead bodies from infectious cases was addressed as a public health hazard during Ebola and MERS-CoV outbreaks where infection control policy was brought forward through scientific risk assessment with religious approval (12). The experience with malaria, CCHF, MERS-CoV, and the later importation of dengue triggered multisectoral collaboration with other sectors—animal health, environment authority, and municipalities—through a committee for integrated vector management and zoonotic diseases. Previous experience from management of local and international threats as well as the JEE were useful in showing Oman's unique capabilities and weaknesses. However, these events have proven

<sup>1</sup><https://data.gov.om/search?query=Population>





**FIGURE 1** | Framework scheme of the review.



**FIGURE 2** | Historical milestone of the public health services and communicable disease control in Oman.

the effectiveness in management of short-term crises, but they are limited when it comes to long-term crises such as the COVID-19 pandemic.

For surveillance and reporting of notifiable diseases, an electronic surveillance system (Trassud) was established in 2017 but was only accessible to MoH health institutions. In

addition, a national incident command chain existed prior to the COVID-19 pandemic to ensure abrupt reporting and response to acute public health events (**Supplementary Material 2**). Nevertheless, there was an unclear implementation framework and responsibilities despite the presence and involvement of different stakeholders.

## DURING THE COVID-19 PANDEMIC: CHALLENGES, OPPORTUNITIES, AND RESILIENCE

Preparedness for the COVID-19 pandemic in Oman started with the announcement of initial cases of SARS-CoV-2 infection in Wuhan in December 2019. For the DGDSC team, this was regarded as a significant public health threat and the existing national incident command chain was activated. Pandemic management was based on risk assessment at national and district levels during the various stages of transmission using the existing all hazard plan, setting guidelines and preparation plans, conducting risk assessments at PoEs, and making field visits to PoEs and health care institutions.

There were daily virtual meetings with all public health officers from each governorate in the country for the first 7 months of the pandemic, until July 2020, and then twice weekly until December 2020, currently, meetings occur on a weekly basis. Discussion included the day-to-day situation analysis of the pandemic and troubleshooting, any new national guidelines or policies, the global situation and travel related issues, strategic plans, and implementation approaches.

Capacities increased to fulfill the needs for detection, response and prevention as described below while observing and maintaining other essential health care services. For example, the primary health care visits in Muscat governorate came down from 115,324 in January 2020 to 109,719 in March 2020 when the epidemic started but the essential health services were ensured for vulnerable groups, women and children (13). During the phase of increase in capacity, several challenges surfaced. This included the lack of infrastructure and trained human resources that played a major challenge in detection, management, contact tracing, and vaccination. Furthermore, the re-organization of health care workers between institutes as well as attitudes and practice toward intervention implementation processes were additional challenges. Moreover, there was a lack of operational plans, governance, and technicality at the workplace due to lack of occupational health experts in institutes including health care institutes.

### Detect

Despite limited human resources, poor logistics, and the scarcity of laboratory tests due to the increased global demand at the start of the pandemic, the central public health laboratory (CPHL) managed to provide the country with the national base of pandemic data. At the beginning of the pandemic, there was limited human resources, shortage of experienced staff in molecular microbiology, limited supply of kits and consumables, limited laboratory and storage space that could accommodate a large number of samples and the lack of integration in the electronic lab information system. In order to tackle these challenges, detection services expanded to cover all health care facilities in both government and private sectors that increased the capacity from the originally available two laboratories at the beginning of the pandemic to 44 laboratories countrywide. Reverse transcription polymerase chain reaction (RT-PCR) and

point of care PCR rapid testing were provided to all COVID-19 admission health facilities. Later, rapid antigen testing was also introduced in hospitals, primary health care, workplaces, and communities.

The CPHL, as part of DGDSC, played a pivotal role in the decentralization of testing, training of laboratory personnel, evaluation of kits, auditing the newly established laboratories, and providing quality assurance samples to all testing facilities. With the emergence of COVID-19 variants, CPHL began to establish and build capacity for whole genome sequencing and establishment of a fully functioning bioinformatics system. The role of CPHL was upgraded from testing, training, and building the diagnostic capacity of the other laboratories at the beginning of the pandemic to supervising, auditing, validating, and verifying laboratory processes and tools. Since June 2020, the DGDSC expanded the influenza-like-illnesses (ILI) sentinel sites from two to 13 sites nationally and integrated the sentinel surveillance of influenza and SARS-COV-2 in the ILI and severe acute respiratory infections surveillance programs.

### Respond Unified Government Leadership

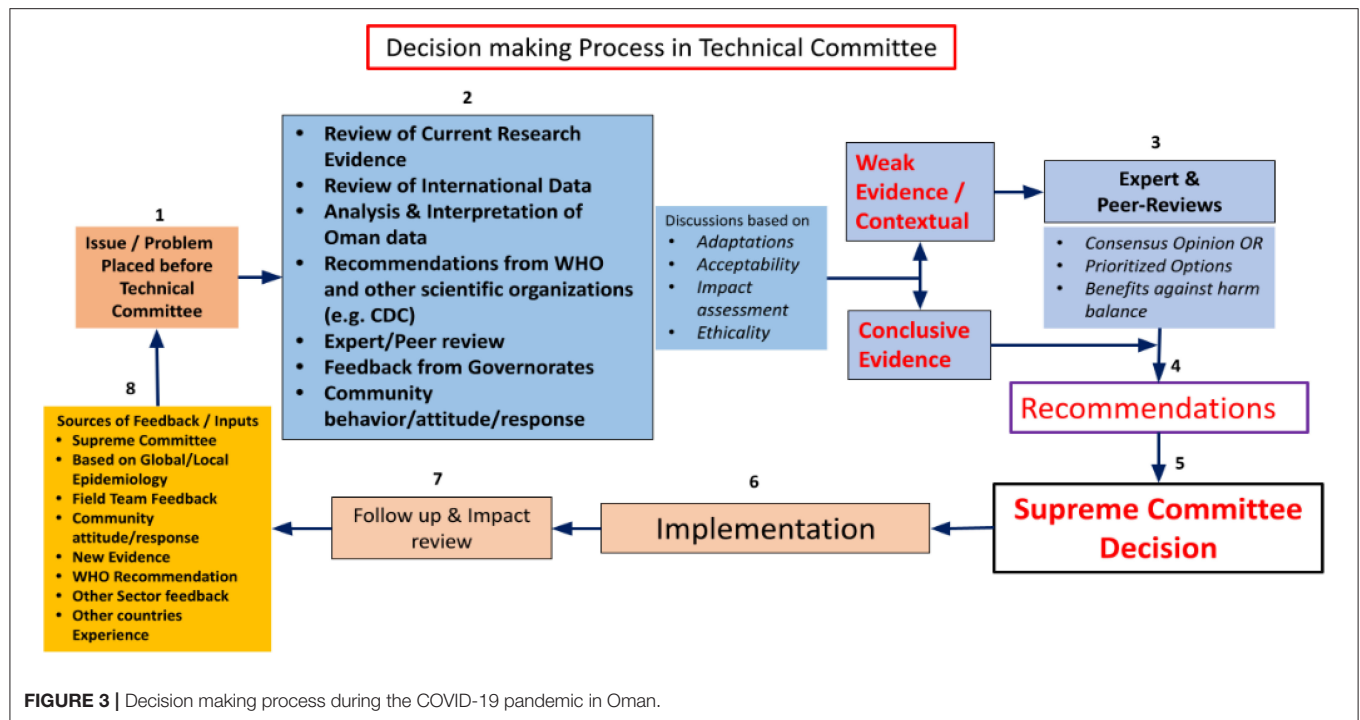
Despite Oman going through a political transition with the appointment of the new sultan, the incoming government committed to provide full support for the pandemic response. Thus, a Supreme Committee, including all relevant stakeholders from different sectors, was formed to deal with COVID-19 pandemic disease progression in March 2020.<sup>2</sup> This was a national priority in response to the pandemic threat to harmonize the response and minimize the impact of the pandemic on life, health, and social, and economic aspects.

The DGDSC was the technical advisory body for the Supreme Committee during the pandemic and oversaw monitoring the national epidemiological data tasked to design models to assess progression of the pandemic that aided decision-making processes of the Committee. The algorithm in **Figure 3** illustrates the mechanism of decision making by the technical team.

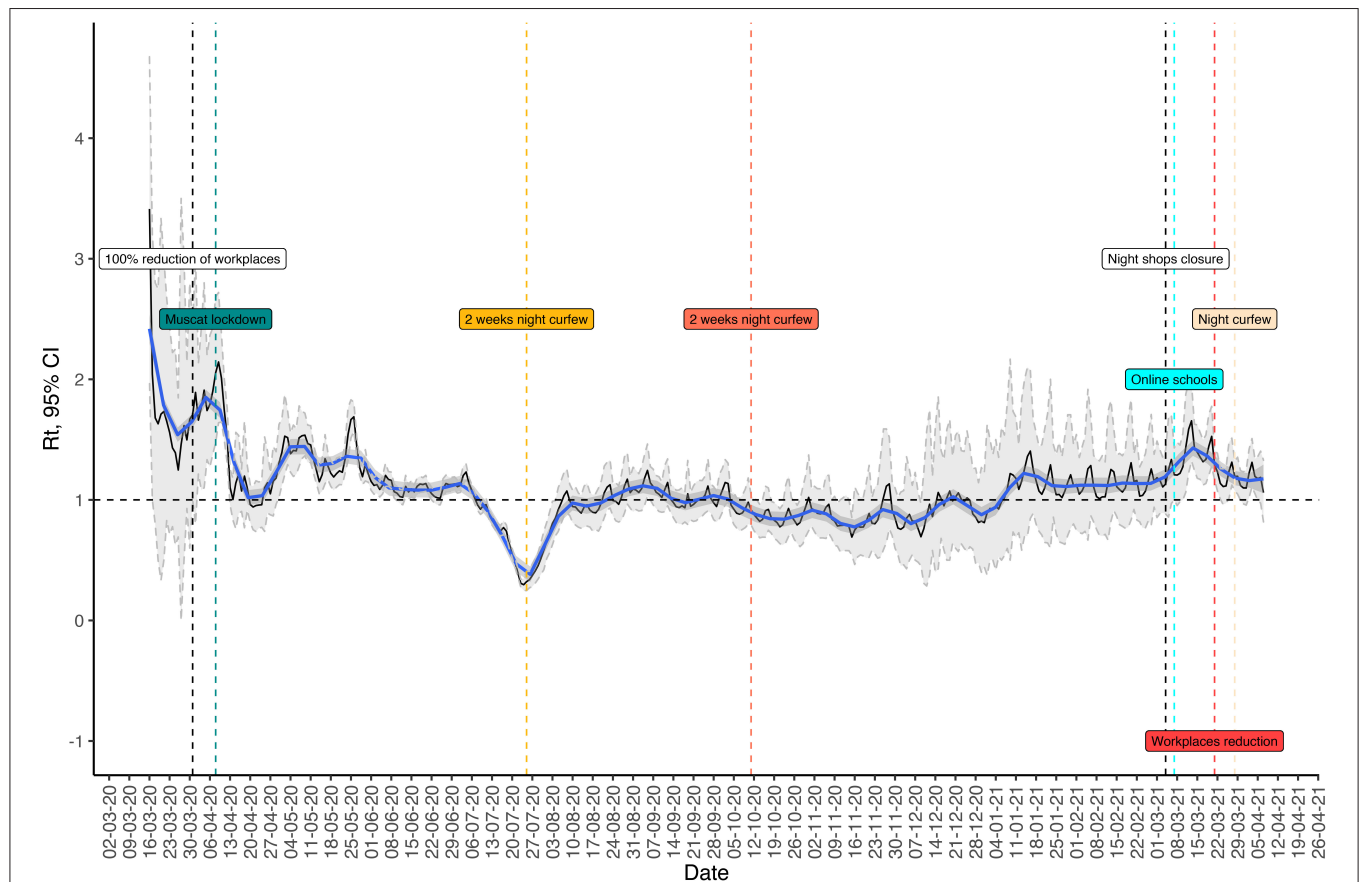
An example of the work of the technical team is the development of a color-coded alert system (**Supplementary Material 3**) to monitor the capacity of the health care system for COVID-19 case admission in general and intensive care units based on the peak capacities during different disease waves at national and governorate levels. This was utilized to guide population mobility restriction and other public health measures besides other indicators.

Organizing the hierarchy of mega intersectoral collaboration required during such a pandemic is crucial. As time passes, the lack of governance and legal framework, unclear implementation body and lack of risk communication and infodemic control become clear as one of the major challenges. In addition, establishing a balance between the economic, financial, and social impact of the pandemic while implementing restricted measures remained a primary challenge throughout the pandemic.

<sup>2</sup><http://omannews.gov.om/Local/ArtMID/416/ArticleID/9985>



**FIGURE 3 |** Decision making process during the COVID-19 pandemic in Oman.



**FIGURE 4 |** The relationship between the reproduction number and different public health measures during COVID-19 pandemic in Oman.

## Upscaling Capacities in Surveillance, Artificial Intelligence (AI), and at PoEs

### Surveillance

The Tarassud Plus platform is used as a hub to collect a huge amount of data including all laboratory results for COVID-19 from governmental and non-governmental centers on a daily basis. In this platform, the confirmed, probable and possible cases as well as contacts are digitally monitored. From this, and the monitoring of the daily reproduction number ( $R_t$ ) curve, which is an indicator of the spread of the disease in the community, the DGDSC generates daily reports on Oman's epidemiological situation (**Figure 4**). Such monitoring allows for proper evidence-based reports, such as the explanation that the actions taken during the pandemic last year proved effective in reducing  $R_t$  (e.g., a 7 p.m. curfew, implementation of the business continuity plan to reduce numbers of non-essential workers at workplaces by at least 70%). The same surveillance system was utilized by the national infection control team to report COVID-19 infection in health care workers and identification of health care associated outbreaks. Nevertheless, monitoring the input from non-governmental institutes and private centers required additional staff and the deficiency of information technology personnel were the main challenges for surveillance.

### AI

The role of AI in the COVID-19 response has been evident by expanded utilization of different tools by many countries (14–17). In Oman, AI was introduced early as part of the pandemic response, e.g., surveillance, contact tracing, laboratory testing, and public-private mix. The Tarassud platform has been used to register and monitor travelers in regard to receiving COVID-19 vaccines, track vaccine related adverse events and provide digital health passports (**Figure 5**). Contact tracing and geofencing in the form of electronic bracelets were used to track confirmed cases, contacts of positive cases and travelers on quarantine. However, as the number of positive cases were growing, sustaining the use of electronic bracelets for contacts was a challenge. Additionally, the availability of good networks and presence of geographical factors, e.g., districts in the mountain, were another challenge in the use of geofencing. High costs of the digital infrastructure and limited funding, the need for around the clock IT support, difficult sustainability, data protection, privacy of personal data, and cybersecurity were some of the challenges in utilization of the AI. Additionally, community acceptance of some AI interventions, e.g., chatbots for risk assessment and follow up, was a challenge. The AI future value as a tool for monitoring other communicable and non-communicable diseases such as individual's compliance with anti-tuberculosis treatment and/or prophylaxis will reduce the pressure on service providers and will be more convenient and time saving for the consumers.

### PoEs

Controlling and monitoring the travelers at PoEs during the pandemic is a major pillar where preparedness, policymaking, and intersectoral collaboration is established. This includes working with the Civil Aviation Authority, the Ministry

of Transportation and Telecommunication, Oman Airports Company, other civil aviation airlines, and land services. Enhancement of public-private mix at PoEs facilitated the establishment of PCR testing facilities at international airports, compulsory pre-registration through Tarassud Plus before arrival to the country and testing on arrival and isolation monitoring through Tarassud Plus. The main challenges at PoEs were the lack of public health services and collaboration between different civil aviation sectors, which were introduced and monitored by different stakeholders during the COVID-19 pandemic. Thus, the operational plan was unclear, and this led to differences in the implementation of required health and safety measures. Moreover, the conflict of interest between stakeholders regarding travel restrictions and its effect on the business was a challenge.

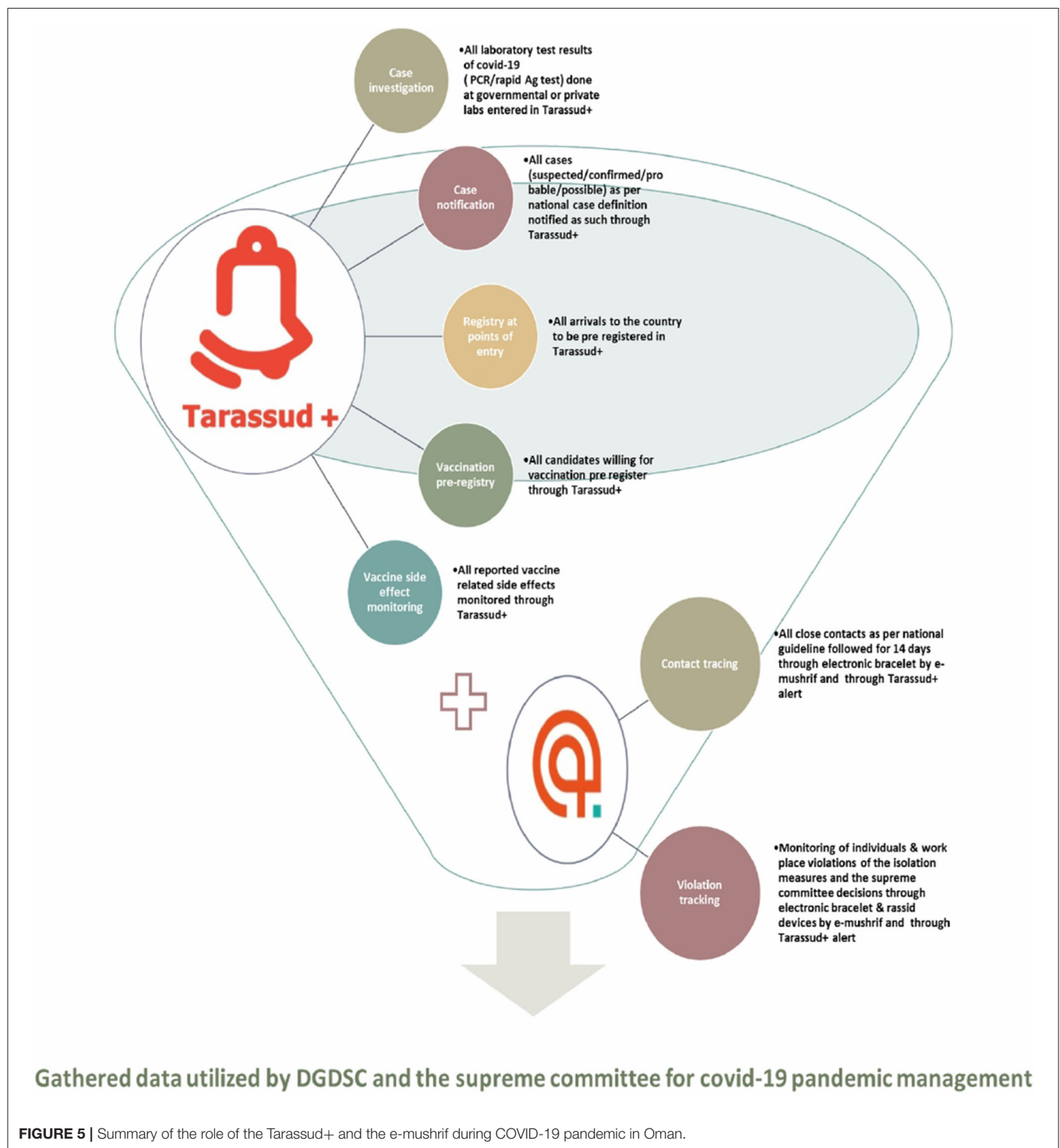
## Risk Communication and Community Engagement

The participation and mobilization of communities was one of the key components of the national preparedness and response plan. To encourage this, there was collaboration with community organizations such as the Healthy Cities and Villages Initiative, wilayat (district) health committees, and community volunteers (18). Awareness activities were implemented at all levels, specifically for infection prevention and control through guidelines that were drafted for places like schools, nurseries, airports, seaports, and dormitories with training and support on implementation and monitoring.

Many efforts were made to raise community awareness and unify media messages to combat COVID-19 including:

- weekly live press conferences of the Supreme Committee were broadcasted live on national TV. The conference updated the public regarding epidemiological situation and any new or change in the national response strategy. The Minister of Health and other members of Supreme Committee addressed questions from public (questions posted in MoH Twitter prior to conference) and media representatives;
- strategic awareness media plans were implemented in collaboration with the Ministry of Information;
- an MoH call center was used to respond to public queries 24/7 throughout the pandemic.

The infodemic at global and national levels has been an additional burden that was reflected in social media as criticism toward the different pandemic interventions. For example, the public's frustrated response to paying for testing through private sector for travel and other screening purposes, the conflicting opinion regarding home vs. institutional quarantine for return travelers, the demand of lockdown and working from home by employees with stable salaries, and the frustration of businesses from the accompanied financial impact. Addressing the many challenges spurred by the infodemic and open access media was limited at many instances by the high cost of producing media and health promotion materials, the lack of training in risk communication and community engagement, the lack of behavioral scientists who could guide the different approaches to reach the community at different levels of the pandemic.



## Prevent Infection Prevention and Control Capacity

The shortage of personal protective equipment (PPE) was a threat for all healthcare facilities during the COVID-19 pandemic which further stressed frontline health care workers. The involvement of the infection control team in early planning and preparedness at

a national level assisted in mitigating this risk and providing safe care throughout the crises by:

- centralizing PPE supply and distribution based on intensity of work and type of care;
- monitoring of utilization and stock of different PPE in all health care facilities on a weekly basis;



- producing risk-based guidelines for use of different types of PPE including N95 respirators;
- providing local supply of PPE through collaboration with local factories and under monitoring of product evaluation team to ensure quality and safe compatibility of products; and
- sourcing medical N95 respirators from firefighters' half face masks

The ongoing communication and feedback between PPE manufacturers, product evaluation teams and frontline health care workers successfully supplied high quality, safe, trusted and user-friendly products even during the stormier periods of the pandemic. The central department for infection prevention and control in collaboration with the directorate of medical supplies at MoH were able to prioritize, mobilize and rapidly respond to shortages, demands or overconsumption. The utilization of private partnerships during the pandemic assisted in extending the airborne isolation facilities and environmental decontamination tools for all referral hospitals in the districts within the country, helping in managing current health care associated transmission risk and building future preparedness of health care facilities for highly communicable diseases. However, the absence of occupational health at workplaces, including in the health care sector, increased the burden on the infection preventionist to cover not only the training of the worker but also the risk assessment and management of exposure in all workplaces at a national level.

### COVID-19 Vaccination

In 2016, Oman achieved the highest effective vaccine management (EVM) score (99%) for all criteria for all levels out of the 127 EVM assessments conducted globally by World Health Organization and UNICEF in 90 countries by 2016 (19). This experience aided in setting up a national vaccination campaign that aimed to ensure quick delivery of high quality vaccines, through several consultative and negotiating channels through Gavi, the Vaccine Alliance and vaccine manufacturers. Oman has prioritized the categories that must receive the vaccine to those of at-risk groups due to the initial vaccine supply limitation and high demand. Subsequently, a strategy to cover 70% of the total population was set with a deployment plan for administering the vaccine in two phases by priority groups (30% starting in late 2020, then 40% from July to October 2021). This was achieved through an establishment of mega vaccination centers in different governorates with the partnership of the private sector. However, due to the lack of vaccine production, misleading information, and rumors regarding the vaccines, and the inactivation of the vaccine mandate, there are challenges in reaching all the target groups in a timely manner. In addition, due to the difficulty in getting pre-booked quantities of the vaccine from COVID-19 Vaccines Global Access (COVAX), Oman bought the vaccine directly from the vaccine manufacturers at much higher prices than the quantities booked through COVAX. Vaccine hesitancy was tackled through different strategies that included, showing government and community leaders taking vaccine and advocating for it, sharing information about the global and national efficacy of the vaccination *via* different media

modalities, showing success examples from other countries for controlling epidemic *via* vaccination, releasing initially daily then weekly vaccine coverage report accompanied by report of the improvement in the national epidemiology situation, and waving testing/quarantine for fully vaccinated asymptomatic individuals as a reward, mandating vaccination to attend public gathering, educational institution, and workplace.

### Operational Research and Collaboration With Different Academic Institutions in Detection, Response, and Prevention

Development in any field can only be achieved by activating the field of scientific research through which decisions are made and reviewed on solid scientific grounds. Examples of research conducted in Oman during the COVID-19 pandemic that aided decision making include a national sero-prevalence survey conducted for COVID-19 disease in the community (20), a multicenter serological study for health care worker exposure risks and infection (21), and a large population-based analysis of severity and mortality determinants (22). Additionally, a pre-campaign cross-sectional knowledge, attitudes, and practices (KAP) study of the COVID-19 vaccine was done (23). These studies aided the selection of priority groups for vaccination. Other research included a molecular epidemiology study for the early transmission of COVID-19 in the country (24), the use of time-varying reproduction number in COVID-19 epidemic monitoring after non-pharmaceutical interventions (25), a study on the impact of mobility restricting interventions during the pandemic (26), and a large population study on the role of children and adolescents in the transmission of the virus (27).

### LESSONS AND WAY FORWARD IN THE POST-COVID-19 PANDEMIC ERA

The public health crisis which ensued from the emergence of the SARS-CoV-2 virus resulting in the COVID-19 pandemic has highlighted the vulnerabilities of existing response systems and opportunities for strengthening future preparedness. The response to outbreaks and epidemics is not a new experience for the health care system in Oman but the lengthy duration this pandemic has truly tested the capacity of the current system in sustaining response while observing global development goals. The lack of health insurance for the immigrant workers in Oman, dependence on government funding for health care, the lockdown situations as a restricted mobility intervention for control of the disease spread especially before the availability of vaccines, and the burden of chronic diseases were reflected in the excess mortality rates during 1st year of the pandemic (15%) (28).

This pandemic has not only affected the United Nations Sustainable Development Goal 3 of good health and well-being but also Sustainable Development Goal 4 in the quality of education when the lockdown forced education online without a well-established platform/telecommunication infrastructure especially in the rural areas.

The process of transition to a post-pandemic health care system and building a new era is going to be challenged by grief

and exhaustion in individuals and the system itself. The role of public health will project in the recognition and guide high value reflection and empowerment of innovative health care that can withstand future public health threats (29).

The COVID-19 pandemic exposed opportunities for further resource mobilization, capacity building, and communication streamlining to achieve the optimum setting for a multisectoral holistic approach. Opportunities for improvement include the absence of dedicated public health professionals resulting in severe compromises in routine primary health programs, high staff turn-over and limited capacity to run COVID-19 tests at the beginning of the pandemic; inherent gaps in biosafety and security procedures causing challenges in laboratories, the country's multiple points of entry (PoEs) with no dedicated public health personnel to implement screening and quarantine guidelines particularly at the international airport and land crossing; and the lack of inclusivity and monitoring the quality of the private sector health institutions in testing, reporting, tracing, and patient clinical care.

Several lessons taught by the pandemic should not be let go, including the sustainability of what had already been achieved in the field of public health during the COVID-19 pandemic to make the foundation for the establishment of a comprehensive One Health approach at a national level as advocated by recent publications (1). The need for public health funding to meet the essential human capacity, risk communication and expanding implementation of AI is an investment for future national and global security. In the process of transitioning to a One Health approach and implementing value in public health care while minimize destruction, legislation and a monitoring body is crucial to ensure sustainability of local interventions and global coordination. This can be achieved through a formal national public health authority that lead and coordinate all public health services in the country.

As a community case study, this article lacks the assessment tool of the impact of the interventions applied during the COVID-19 pandemic. Additionally, mental, economic, and social effects of the pandemic were not addressed in this article. The line of logic used in the manuscript could have been biased by the personal opinions of the authors.

In conclusion, combating the COVID-19 pandemic is an integrated process. Continuous efforts from all individuals and

institutions are essential to reduce its threat. Additionally, there is a need for forward thinking for a public health strategy with empowerment by multiple resources to stand up to public health threats. The transformation of Oman's public health system to take a One Health approach has been informed by syndemic thinking. This approach should continue to be part of the fight against the COVID-19 crises and inform the future vision of a healthy population with a more holistic approach to health, encompassing physical, mental, economic, and social dimensions. A system that works on eliminating health disparities, improving health literacy, and implementing effective communication and dialogue between public health, policy makers and the community is essential to the process of improving public health.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

## AUTHOR CONTRIBUTIONS

All authors contributed to the writing and editing of the paper and approved the final manuscript.

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# The Impact of Performance Enhancement on Value of Care in Hospitals

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Hospitals are facing big challenges: decreasing reimbursements are going alongside increasing costs and the necessity of investments. At the same time occurring, excellent quality of care, and high-patient satisfaction have to be assured. The dilemma of providing both with decreasing rather than increasing resources cannot be solved only by striving for economies of scale, but by optimizing supply chain management, or reduction of overhead. Possible effects of these measures most often are already exhausted and seldom have a positive impact on the quality of care or patient satisfaction. Management is tempted to use its best-known instruments to reduce costs, while medical staff's focus is on quality of care and often battle against management as a perceived enemy. The solution to this dilemma lies in focusing on medical core processes that are directly linked to patients' treatments and, thereby improving all the parameters of Michael Porter's value equation: costs, outcome, and patient satisfaction. This approach of performance enhancement presumes understanding, acceptance, and constructive collaboration of two usually separated worlds: The medical-scientific world involved in patient care and the financial world of management. In this article, the authors explain performance enhancement for optimized delivery of care and how the dilemma mentioned above can be solved. The authors explain how performance enhancement can be achieved in daily clinical practice, which kind of obstacles have to be overcome, which changes are necessary within a hospital, how medical staff can be motivated, and how the value of care equation can be influenced.

**Keywords:** value, performance, care, hospital, quality, cost, innovation

## INTRODUCTION

Just imagine your salary is declining by small percentages every year while your costs of living stay steady or even rise. It is obvious that this development would present a real threat to everyone's living standard and contribute to an unsatisfactory personal situation. Very few of us would agree to sustain something valuable every coming year due to decreasing financial resources.

However, a similar situation can be found in hospitals of various countries: decreasing reimbursement is occurring alongside steady or even rising costs. At the same time, excellent quality of care and high-patient satisfaction have to be assured. The dilemma of providing both with decreasing rather than increasing resources cannot be solved by using the best-known management tools: economies of scale, optimizing supply chain management, reducing overhead,



further increasing the productivity of employees, or reducing spending for both the existing and new business.

So, how can this dilemma be solved, especially against the background that the economic potential concerning waste and inefficiency in the Swiss healthcare sector is estimated to be several billion Swiss Francs (1)?

## PATIENT JOURNEY AND MEDICAL CORE PROCESSES

The core competency and responsibility of a hospital and its medical staff are delivering care to the patients. Patients either enter a hospital as planned or unplanned admission, the latter most often *via* the emergency department (ED). They then pass through different stations on their “journey,” depending upon the kind of health issue and its severity, as seen in **Figure 1**.

While moving from one stage to another during their journey, patients receive a part of their diagnostic and/or therapy, planned, coordinated, and executed by the medical staff (doctors, nurses, therapists, etc.). Every single act of the medical staff for patients can be understood as a medical core process. Medical core processes, thereby, can be best described as interactions between patients and medical staff in the context of their diagnostic and/or therapeutic measures, as the following examples show:

Besides regular treatment for bacterial infection of the bladder, the evaluation of a patient’s social situation at home is a medical core process as well, executed by nurses on the ED (station “Admission,” **Figure 1**). A precise decision about the appropriateness of costly bone tissue during a spine fusion by neurosurgeons is a medical core process as well (station “Operation/Intervention,” **Figure 1**). Several blood transfusions on the intensive care unit after a long and complicated abdominal surgery can also be viewed as a medical core process. Switching intravenous antibiotics to pills on the ward while treating bacterial infections of the lungs is a medical core process that involves both the doctors and nurses. During discharge, pharmaceutical support concerning discharge medication, patient education about side effects, and information on how to take pills is a medical core process as well.

Medical core processes can be found at every stage of a patient’s journey, regardless of the medical discipline the patient is treated. These medical core processes should be systematically questioned, challenged, and—if possible—improved. By improvement of medical core processes as the very starting point of performance enhancement, we can improve performance on the one hand and make a positive impact on the value of care according to Michael Porter’s landmark article “What is Value in Healthcare” published in 2010 (2).

## IMPROVEMENT OF MEDICAL CORE PROCESSES AND THE IMPACT ON THE VALUE OF CARE

In this 2010 article and the previous publications, Michael Porter presents his central concept that the “value” of care a patient

receives should not only be measured according to the success of a single procedure or traditional outcome measures such as mortality or rehospitalization rates. Value of care should also be assessed by taking into account so-called “outcomes that matter to patients.” These can be multidimensional and also include functional status, patient’s experience, and sustainability of treatment. At the same time, care delivered to the patients should be provided at acceptable costs.

In the context of radical prostatectomy, for example, one should not only measure mortality, infection, or readmission rates but also patient-oriented outcomes such as loss of sexual function or degree of bladder function.

Value of care, therefore, is defined as the ratio of “health outcomes” on the one hand (composed of outcome measurement and patient experience) and costs on the other hand, as seen in the equation below.

$$\llbracket \text{Value of care} \rrbracket = \frac{\text{Outcome} + \text{Patient Experience}}{\text{Costs}}$$

All the parameters of this equation can be influenced by a systematic approach to performance enhancement by focusing on medical core processes. In the next sections, we discuss how the improvement of medical core processes can be achieved and what impact can be made on the value of care is discussed.

## Innovation

Innovation—in short—is about problem solving. By innovation, we usually understand a new idea solving a problem or a need.

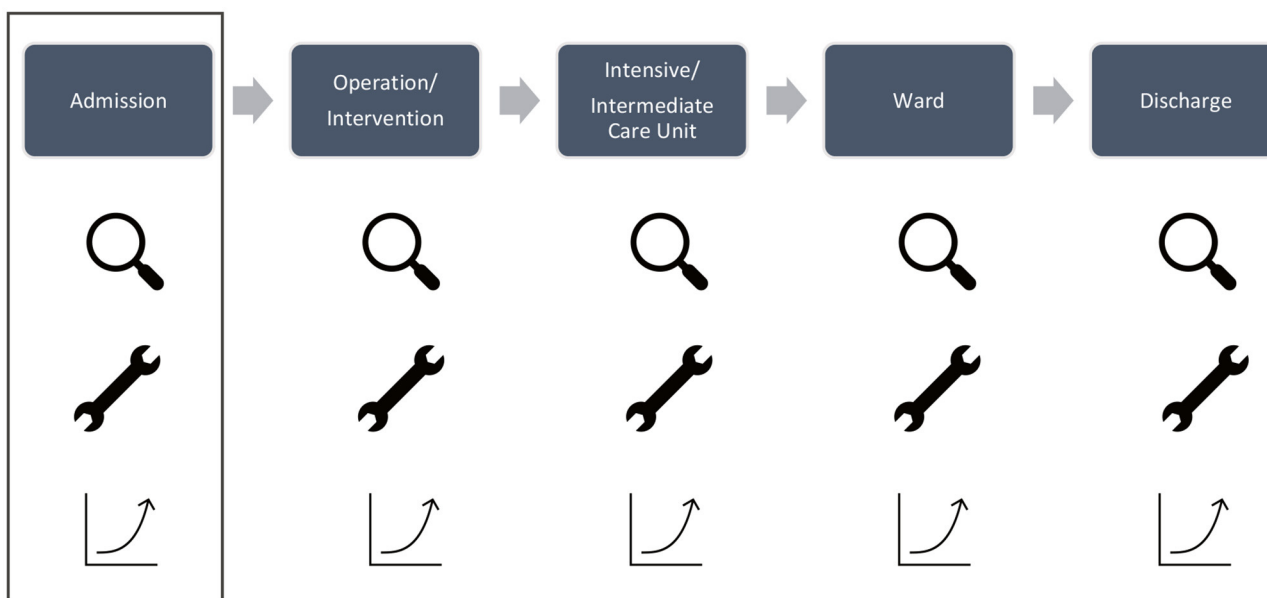
In daily clinical practice, we are confronted with various problems: hospitals are taking care of more and more elderly patients, many of whom not only have an acute medical issue but also social needs such as requiring evaluation of their domestic situation or the necessity of a post-acute care discharge solution. Most often this evaluation as a medical core process takes place later on during a stay, in the worst case shortly before discharge. However, an evaluation taking place on the day of admission could solve several problems: every hospital is dependent on timely and efficient care of patients to avoid unnecessary prolonging of the stay. Every patient needs to prepare for appropriate care after the stay as well. The so-called post-acute care discharge (PACD) score is an innovative solution that is able to solve both problems. This score is very well-established in evaluating the need for a solution after discharge within the first 24 h after admission (3). Similarly, length of stay and, therefore, costs (=denominator of the value equation above) can be reduced and the patient’s experience (=numerator of the value equation) can be enhanced, thus making a positive impact on the value of care.

In the ward, many patients are treated because of infectious diseases and receive intravenous antibiotics; prescribing and administering them are both the medical core processes. However, it is well-known that the duration of intravenous antibiotic treatment for a large group of common infectious problems (e.g., a bacterial infection of the lung or bladder) often is longer than required. Switching to pills earlier if justifiable is not only less costly but also enhances the patient’s experience because an intravenous line is no longer needed and mobilization





**FIGURE 1 |** A patient journey through a hospital. Patients enter the hospital as planned or unplanned admission. They might undergo an operation/intervention, stay at an intensive or intermediate care unit if in severe medical condition, are usually treated on a ward after that, and are discharged after their medical condition has improved. At every single stage, we can look at the medical core processes and evaluate how to improve them.



**FIGURE 2 |** Systematic approach to improve performance and value of care at each step of the patient journey—for example, “admission” by: (1) looking for medical core processes “spyglass symbol,” e.g., the evaluation of postacute care solutions; (2) improvement of medical core processes by a set of tools (tool symbol; improvement of the *status quo*, innovation, focus on quality), e.g., the use of PACD-scoring as innovation; and (3) gaining results by permanently integrating tools in daily clinical activities (analysis symbol), e.g., reducing length of stay, therefore, costs, enhancing patient’s satisfaction by providing a comprehensive evaluation of their needs and improving the value of care *via* post-acute care discharge (PACD) scoring.

is far easier without one. In addition, switching intravenous antibiotics to pills and removing intravenous lines are associated with fewer complications such as thrombophlebitis, an infection of the vein at the entry point of the intravenous line. An innovative, IT-supported solution to switch intravenous antibiotics earlier is an improvement to the medical core processes mentioned above and is able to make an impact on every parameter of the value equation and, thus, improves the value of care.

### Improvement of *status quo*

By improving on the *status quo* of a medical core process an impact on the value of care can also be achieved. Patients with acute heart failure, for example, nearly always receive so-called diuretics, which is a medication that enhances the elimination of urine and, thus, reduces water excess in the body. The earlier these medications are given, the sooner patients experience improvement of their breathing difficulties (=improvement of patient experience), the lower are mortality rates (=outcome),

and the more efficient the treatment is with further care on the regular ward instead of the ED (=lower costs). Improvement of this medical core process can be achieved by educating the medical staff and providing active feedback about the time that is passing from admission to the administration of the urgently needed medication.

During discharge, patients often find it helpful to be educated about the medication they have to take. This kind of medical core process can be improved by support through in-house pharmacists who educate patients about possible side effects of their medication and exact instructions about how and when to take them. Thus, patient experience can be significantly improved.

### Focus on Quality

More than 30 years ago, Donabedian (4) explained his understanding of three different quality dimensions. Because of rising importance, one can add a fourth quality dimension, especially through the eyes of doctors and payers: indication

quality or the question of the appropriateness of care. According to these quality dimensions, it is possible to review how care is organized around patients (structure quality), why treatment of a procedure is being carried out (indication quality), how well-certain practices are being executed (process quality), and what happened to the patient (outcome quality).

By focusing on these quality dimensions and constantly improving the quality of delivering care at the medical core processes, not only can performance be enhanced, but also an impact on the value of care can be achieved.

By using modern clinical pathways, variation of care delivered to patients can be reduced. Furthermore, clarity about treatment approaches and awareness of roles are raised and, thus, enhance structure quality. Reduction of variation commonly reduces costs in healthcare and, hence, positively influences the value equation.

By agreeing on certain indications for cost-intensive imaging procedures, e.g., for patients with a short self-limiting episode of fainting, these imaging procedures are being ordered when necessary and not to gain a certain level of security for doctors. Efficient administration of antibiotics (=process quality) in patients with severe infections in the ER has long been shown to improve survival (=outcome quality) and reduce costs due to fewer patients being treated on cost-intensive intensive care units.

By improving medical core processes along the patient journey by three different approaches, it is possible to enhance performance and generate a positive impact on the value of care. This can proceed in a generic way: first, by looking for medical core processes; second, by improving medical core processes by either innovation, improvement of the *status quo*, or focus on quality; and third, by implementation in daily practice to gain results (Figure 2).

Some of the economic results have been a reduction of length of stay of certain patient groups by 50% and more (e.g., hip and knee surgery), an increase of reimbursement/case of up to 30% (e.g., internal medicine), a reduction of lab costs of about \$15,50,000 per year throughout the entire hospital, a reduction of costs of medication of about \$3,00,000 per year in the Department of Internal Medicine, a reduction of costs of materials (e.g., implants and disposables) of about \$10,00,000 per year throughout the entire hospital and a significant rise in patient satisfaction (e.g., Department of Neurosurgery) to above Swiss average. These economic results have been monitored closely with Key Quality Indicators (KQIs), some of which could be improved as well (e.g., one of the lowest rehospitalization rates in heart failure in Switzerland), none of which getting worse (5).

However, one should be aware of several other aspects such as the change of mindset and obstacles that need to be overcome.

## CHANGE OF MINDSET: A NEW AND COMMON UNDERSTANDING

Besides striving for performance enhancement, looking for and improving medical core processes, and hence influencing the value of care, one should also seek a new and common understanding concerning healthcare delivery.

First, it is important to realize, communicate, and prove that raising efficiency during performance enhancement is not automatically associated with a reduction of quality. These changes the way by which employees feel about performance enhancement itself. It certainly helps clinicians and other staff in developing an open-minded attitude toward efficiency, cost, and quality in the highly sensitive and dynamic area of healthcare.

Second, performance enhancement has to go hand-in-hand with developing and monitoring KQIs, not only to realize quickly any deteriorating effect, but also to show improvement in the quality and, thus, the value of care, showing a positive impact to employees and, thereby, catalyzing future efforts by motivating medical staff.

Third, the power of data in healthcare, from its analysis to generating value, leads to a new understanding of their importance for daily business in hospitals. However, one has to be aware that a solid IT infrastructure and in-depth expertise of medical core processes to interpret these data are mandatory.

Fourth, assumptions—regardless of the hierarchical level they are made—have to be categorically challenged and replaced by proof or disproof. Thus, it can be shown and not only simply assumed that performance enhancement is able to generate a positive impact on the value of care and costs and quality in healthcare.

Finally, two often separately discussed worlds in the healthcare sector—the medical/scientific world and the management world—have to be viewed and understood as one world. Only by realizing that neither of these worlds can drive this kind of change by itself and full potential can be realized only through joint efforts.

## OBSTACLES, CONCERNS, AND HOW THEY WERE OVERCOME

Before and during the effort of hospital-wide performance enhancement, several obstacles and concerns have to be anticipated, addressed, and overcome.

The greatest concern often is compromising the quality of care on the journey to a highly efficient provider due to a lack of understanding that gaining efficiency does not consequently mean loss of quality (see above). These concerns have to be addressed by closely monitoring KQIs on the one hand and proof of even raising quality and, thus, the value of care on the other hand during the very first projects. These KQIs have to be discussed among all the key stakeholders in mandatory meetings on a regular basis.

An important obstacle often is a lack of understanding necessity and urgency to change. However, this problem can be addressed by clearly showing the dramatic changes in the healthcare landscape, rising regulations of the public authorities, and decreasing reimbursements over the years with the upcoming dilemma mentioned above. Management and medical staff have to understand each other's perspectives.

Another obstacle might be concerns of employees about the workload for the journey to come. Yet, by the focus on the reduction of length of stay as one of the very first measures, the

workload for medical and administrative staff can be reduced significantly. As a consequence, assigning highly motivated employees to project teams can be carried out, so that no additional personnel has to be recruited. It would, therefore, be a mistake if management would monetize the gain of a reduced length of stay by, therefore, reducing the medical workforce. This would lead many to conclude that their apprehensions were true and potentially resist further optimizations projects.

## DISCUSSION

The Healthcare landscape in recent days is changing fast and poses great challenges to healthcare providers, especially hospitals and their medical staff. Delivering a high quality of care with decreasing rather than increasing resources is one major challenge and the one the authors—medical practitioners with an experience of at least 15 years each in internal and emergency medicine—were striving for the last 6 years with the approach described in this article. However, by consequently striving for improved medical core processes through innovation, improvement of the *status quo*, and focusing on quality this challenge can be overcome with significant impact on the value of care, as the execution of this approach has shown (4). A change in mindset, awareness of obstacles, and a common understanding

of the medical-scientific world and the management world as one world are essential.

In the healthcare environment of today, we have to be prepared for changes and different requirements, may these be the evolution of new technologies such as robotics, personalized medicine, or adverse experiences such as the global COVID-19 crisis requiring expensive reserve capacities. However, ultimately, we are serving the patients as individuals when medical help is required while being obligated to society to provide our services efficiently so care will be and stay affordable in the future.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

## AUTHOR CONTRIBUTIONS

All authors equally contributed to the development of the framework mentioned in the article above, the execution in daily practice, the analysis and interpretation of data, the development of this article for publication, manuscript revision, and read and approved the submitted version.

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# Value-Based Healthcare From the Perspective of the Healthcare Professional: A Systematic Literature Review

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**Introduction:** Healthcare systems increasingly move toward “value-based healthcare” (VBHC), aiming to further improve quality and performance of care as well as the sustainable use of resources. Evidence about healthcare professionals’ contributions to VBHC, experienced job demands and resources as well as employee well-being in VBHC is scattered. This systematic review synthesizes this evidence by exploring how VBHC relates to the healthcare professional, and vice versa.

**Method:** Seven databases were systematically searched for relevant studies. The search yielded 3,782 records, of which 45 were eligible for inclusion based on a two-step screening process using exclusion criteria performed by two authors independently. The quality of the included studies was appraised using the Mixed Methods Appraisal Tool (MMAT). Based on inductive thematic analysis, the Job Demands-Resources (JD-R) model was modified. Subsequently, this modified model was applied deductively for a second round of thematic analysis.

**Results:** Ten behaviors of healthcare professionals to enhance value in care were identified. These behaviors and associated changes in professionals’ work content and work environment impacted the experienced job demands and resources and, in turn, employee well-being and job strain. This review revealed 16 constructs as job demand and/or job resource. Examples of these include role strain, workload and meaning in work. Four constructs related to employee well-being, including engagement and job satisfaction, and five constructs related to job strain, including exhaustion and concerns, were identified. A distinction was made between job demands and resources that were a pure characteristic of VBHC, and job demands and resources that resulted from environmental factors such as how care organizations shaped VBHC.

**Conclusion and Discussion:** This review shows that professionals experience substantial job demands and resources resulting from the move toward VBHC and their active role therein. Several job demands are triggered by an unsupportive organizational environment. Hence, increased organizational support may contribute to mitigating or avoiding adverse psychosocial factors and enhance positive psychosocial factors in a VBHC context. Further research to estimate the effects of VBHC on healthcare professionals is warranted.

**Keywords:** value-based healthcare, VBHC, healthcare professional, job demands, job resources, employee well-being, literature review, psychosocial perspective



## INTRODUCTION

Healthcare systems increasingly move toward “value-based healthcare” (VBHC) (1), aiming to further improve quality and performance of care as well as the equitable, sustainable, and transparent use of resources (1–3). Thus far, a globally shared definition of VBHC is lacking (4). Yet, a characteristic shared by most VBHC programs is the multifaceted approach that, on top of clinical outcomes, provides a prominent place to patient-reported quality and performance indicators. Examples of these include “Patient Reported Outcome Measures” (PROMs) and “Patient Reported Experience Measures” (PREMs) (2).

The early initiators of VBHC state that, in addition to improving health value, employee well-being should be part of healthcare organizations’ imperatives since healthcare professionals play a central role in VBHC (1). This aligns to the quadruple aim of (1) improving health outcomes for patients, (2) enhancing patient experience, (3) enhancing healthcare professional experience, and (4) reducing cost (5). In comparison to traditional care practices, VBHC may change professionals’ work by introducing new, or shifting emphasis toward, value-promoting care activities and team-based care (6). Such activities include discussing value with patients, making a shared decision, learning, and improving based on quality and performance indicators and providing care in pathways (7–9). Although these activities may not all be completely new (10), the difference is that each activity is now used as a means to generate value rather than being an end-goal in itself. VBHC is different from current care and requires new competencies of professionals (11). Psychosocial factors at work describe how work factors, such as the work environment and job content, interact with personal factors, such as a person’s competence and expectations, to impact employee experience and well-being (12, 13). Hence, we may expect changes in professionals’ well-being with VBHC currently gaining traction.

However, to date, evidence from studies taking a psychosocial perspective on VBHC, with insights about how professionals contribute to VBHC and how VBHC influences their well-being, is scattered. Most studies on VBHC understandably focus on patients and clinical results (14–16) and build on insights from implementation science [e.g., (17–19)]. Earlier reviews focusing on healthcare professionals and VBHC studied education (20) and interventions to reduce low-value behavior (21). Current literature suggests that VBHC meets the interest of professionals i.e., to deliver value for patients (1) and positively contributes to their work experience (22). However, the relation between VBHC and professionals’ interests nor the contribution of VBHC to their work experience has been convincingly established. Current literature hints at a relation between VBHC and various job demands and resources including work pressure, emotional demands, and autonomy (23). The literature further suggests both positive and negative relations between VBHC and professionals’ well-being, such as improved engagement (24) and potential fears concerning among others accountability and value-based competition on results (1).

This systematic literature review synthesizes empirical findings centering around the question “how does VBHC relate

to the healthcare professional and vice versa?”. The review aims to provide a comprehensive overview of professionals’ roles in VBHC, experienced job demands and resources as well as the impact that value-based work can have on professionals’ well-being. This work may contribute to mitigating or avoiding adverse psychosocial factors at work for healthcare professionals in VBHC and enhance positive psychosocial factors.

## METHODS

This systematic review followed the PRISMA2020 guidelines (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (25).

### Search Strategy

An extensive three-armed search strategy was developed in consultation with the Erasmus Medical Center’s Medical Library. The search string followed the PICO statement by including keywords that describe (1) the *population*, i.e., healthcare professionals, their teams or specific occupations, (2) the *intervention*, i.e., VBHC, and (3) *outcomes*, i.e., how the population impacts VBHC or vice versa (see **Supplementary Material 1**). The *comparator* is not applicable in this work.

The first part of the search string included generic descriptions of professionals or care teams, such as “professional,” “staff,” “nurse,” and “clinician,” as well as specific occupations derived from the International Standard Classification of Occupations ISCO-08 (26). Occupations both in hospital and other healthcare settings were included.

In line with terminology used by Porter and Teisberg (1), we included “high-value care” and “value driven care” in the search string as synonyms for VBHC. In the second arm of the search strategy, we searched for the use of “value-based” OR “valuebased” OR “high-value” OR “value-driven” mentioned within three words-distance of the word “care” OR “healthcare” since a Medical Subject Heading (MeSH) term for VBHC is missing. Studies only reporting on value-based payment methods were excluded, as these are beyond the scope of our work.

Third, we searched for keywords describing a relation, a characteristic or action of a professional or an outcome relevant to professionals. Examples of keywords describing a relation were “affect,” “cause,” and “benefit.” Keywords describing a characteristic or action of a professional included, among others, “attitude,” “knowledge,” and “behavior.” Keywords describing an outcome relevant to professionals were abstracted from relevant literature and lists of human values (27, 28) and included, among others, “workload,” “autonomy,” and “engagement.”

The search string was piloted by checking whether a pre-selected set of 10 relevant studies was indeed retrieved when conducting the search, which was the case for all 10 studies. **Supplementary Material 1** contains the full search string and further explanation. The search was performed on December 21, 2020 in seven databases, being Embase.com, Medline ALL Ovid., PsycINFO ALL Ovid, Web of Science (SCI-EXPANDED & SSCI),

CINAHL EBSCOhost, Business Source Premier EBSCOhost and EconLit ProQuest. Conference papers were excluded.

## Selection Process

A two-step screening process, comprising title and abstract screening and full-text assessment, was performed by two of the authors independently. Titles and abstracts screening resulted in eligible studies for full-text assessment. In both steps, studies were subjected to pre-defined eligibility criteria. Papers with inconsistent screening outcomes between the first- and second-screener during title and abstract screening were included for full-text assessment. In case of inconsistent screening outcomes in full-text assessment, authors discussed the paper and when no consensus was reached full-text assessment by the last author was decisive. This was the case for three papers.

## Eligibility Criteria

The exclusion criteria for all yielded studies were “not a peer-reviewed paper and/or journal,” “no empirical data,” “not part of/contributing to VBHC or synonym,” “no relation to the healthcare professional,” “only about VBHC education,” “only about value-based payment or synonym,” and “non-English.” In absence of consensus on a VBHC definition (4), we relied on the authors’ judgement i.e., any study in which the original author identified the intervention as “value-based healthcare” or its synonyms was assumed to be about VBHC. We identified a healthcare professional as anyone caring for, or aiming to cure, patients or clients with a formal training to do so. Consequently, consultants, administrative staff and data analyst, among others, were not considered as healthcare professionals.

## Data Extraction

Data extraction comprised two steps. First, general study characteristics were extracted. This was followed by data extraction on the relation between VBHC and the healthcare professional.

### General Study Characteristics

Elements for generic data extraction were informed by discussion among all authors and included year of publication, country, study aim, study design, healthcare setting, profession, healthcare discipline, VBHC terminology, VBHC components applied, and the degree of professionals’ involvement in VBHC. Data were abstracted by the first author.

### The Relation Between VBHC and the Healthcare Professional

First, an inductive approach was applied to analyze the relation between VBHC and the healthcare professional using thematic analysis (28). This started with familiarization with the “Results” sections in the included studies and selection of relevant quotes. Afterwards, semantic codes that closely reflected the original authors wording were attached to the selected quotes. Subsequently, repeated patterns of meaning in these codes were clustered to generate latent themes describing the underlying codes. Last, the themes were revised and possible interconnectivity between themes was indicated to

derive a thematic map. Atlas.TI software was used to facilitate this process.

The resulting thematic map showed various similarities with the Job Demands-Resources (JD-R) conceptual model (12). JD-R is a recognized psychosocial model applied to explore and design the interaction between “the job” and “the professional”. More specifically, JD-R describes that work has certain characteristics that make professionals feel engaged or strained, depending on whether these are perceived to give energy, i.e., job resources, or take energy, i.e., job demands. The level of engagement and job strain can subsequently be used to predict performance. Since JD-R allows flexible use and tailoring to fit specific contexts (29), we iteratively adapted the JD-R model by including all abstracted data regarding the relation between VBHC and the professional. Use of JD-R as an underlying conceptual model allowed for our findings to be compared to earlier scholarly work on job demands and resources.

Subsequently, the resulting modified JD-R model was used for deductive analysis. Quotes from the “Results” sections in the included studies were selected and attached to one or multiple components of the modified JD-R model using Atlas.TI software. Consistent with the eligibility criteria, data about value-based payment and VBHC education were omitted. The resulting quotes were analyzed at both a latent and semantic level. The latent approach was applied to define whether experiences were a job resource or demand as this was often not explicitly mentioned. Next, we worked from the wording as used by the original author to inductively cluster similar data within the JD-R components to form codes. The resulting codes included among others “workload” and “joy in practice.” Overall, the analysis process was iterative and evolved from description to interpretation. Throughout this process the descriptive evidence and interpretations were discussed with all co-authors to validate line of reasoning, comprehensiveness and adequate representation of the included studies.

## Quality Appraisal

Quality appraisal of the included studies was performed using the Mixed Methods Appraisal Tool (MMAT) (30), which is applicable to qualitative, quantitative, and mixed methods studies. For each study design, MMAT provides a set of five quality criteria. Mixed methods studies were assessed on both the qualitative and quantitative set of criteria and a complementary set that specifically appraises the quality of the mixed methods design. The scores resulted in a classification of each study into “high,” “medium,” or “low” research quality. **Supplementary Material 2** provides details on the scoring methodology and MMAT scores for each included study. Quality appraisal was used to provide an overall impression of the study quality. No studies were excluded based on the MMAT scores.

## RESULTS

### Selected Studies

The search yielded 3,782 records. Duplicates and literature published earlier than the introduction of VBHC in 2006 (1) were removed, resulting in 1,775 papers for title and abstract

screening. Finally, backward citation searching of the included studies resulted in inclusion of six additional papers. Based on the assessment using the exclusion criteria, 45 studies were eligible for inclusion. **Figure 1** displays the corresponding PRISMA diagram.

### Study Characteristics

Of the 45 included studies, 23 had a qualitative study design, 14 were quantitative and 8 applied mixed methods. **Supplementary Material 3** contains the full list of included studies and a summary table.

### Study Setting

Healthcare professionals from the USA ( $n = 23$ ), Sweden ( $n = 8$ ), and The Netherlands ( $n = 7$ ) were most frequently studied. No studies were performed in low-income countries. Four Swedish studies reported on the same intervention and population (24, 31–33). Hence, from the 45 studies included in this review 42 are unique.

From all studies, 24 took place in a hospital. The other studies focused on “accountable care organizations” (ACOs) ( $n = 2$ ), primary care ( $n = 2$ ), ambulatory care ( $n = 2$ ), medical laboratory ( $n = 1$ ), oral healthcare ( $n = 1$ ), home care ( $n = 1$ ), not applicable/specified ( $n = 3$ ), or different combinations of care settings ( $n = 9$ ), which included the above and new settings such as elderly care, maternity care, midwifery practice, and physiotherapy. The included studies focused on various medical specialties such as internal medicine, orthopedics and cardiovascular care. The studied populations were trained healthcare professionals ( $n = 31$ ), residents ( $n = 7$ ), or a combination of both ( $n = 2$ ). Five studies focused on other healthcare actors or did not specify the composition of professionals involved.

### Defining VBHC

“Value-based healthcare” (VBHC) has been used as term by 27 studies, followed by “high-value care” (HVC) ( $n = 12$ ) and “high-value, cost-conscious care” (HVCCC) ( $n = 4$ ). Two studies used terms interchangeably. For the readability of this review, the term VBHC will be used in the remainder of this text to refer to all of the previous.

VBHC in general, without specification of the value-enhancing interventions, was studied in 11 studies. The other studies primarily reported on team-based care models, outcome measures, quality improvement, discussing value in the clinical encounter, cost-consciousness, and care coordination within the organization’s walls as specific components of VBHC. Less frequently studied VBHC components included population health, prevention, collaboration in the full care chain and redesign of pathways and workflows. In 24 studies the population actively participated in a VBHC intervention. In 19 studies it was uncertain to what degree participants were involved in VBHC, for example studies evaluating VBHC awareness and beliefs. Two studies did not collect data directly from professionals. These studies focused on open workforce positions in VBHC and development of a framework regarding professionals’ roles in VBHC.

### Research Design and Quality

Whereas few studies explicitly investigated the implementation process of VBHC [e.g., (24, 34, 35)], the majority of studies did not clarify the time frame between VBHC implementation and data collection for scholarly work. Other than one study deploying the JD-R model (23), none of the included studies built on existing conceptual models. Five validated research instruments to study VBHC in relation to the healthcare professionals were used, containing three full-scales (36–38), one sub-scale (39), and one observer-based instrument (40).

Quality appraisal showed that 22 studies were rated as high quality, 12 studies medium quality, and 11 studies low quality. **Supplementary Material 2** provides details. Overall, qualitative studies scored highest and mixed methods studies had the lowest scores.

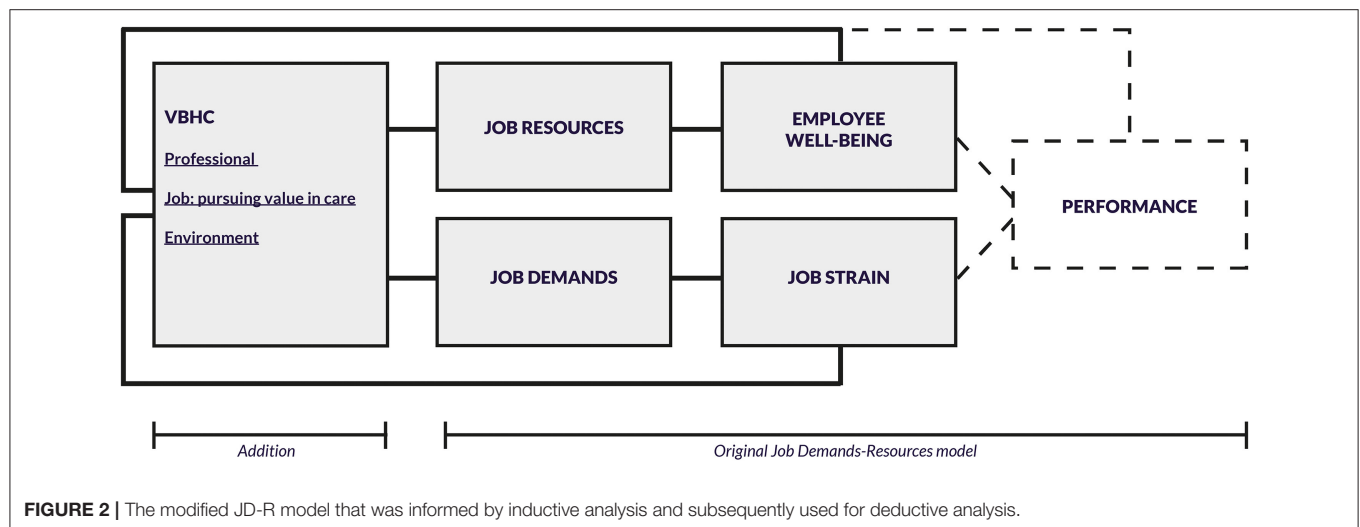
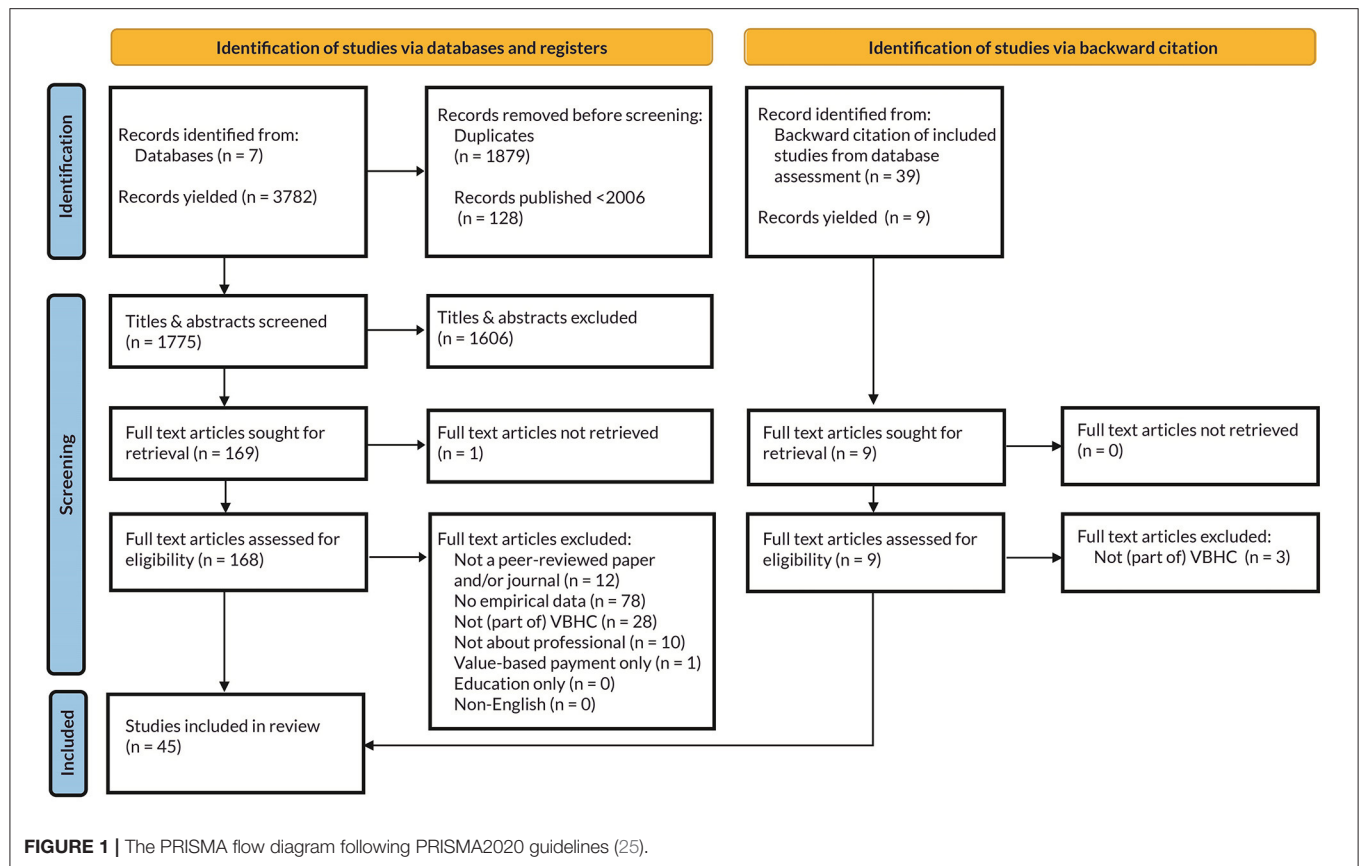
### The Modified JD-R Model

**Figure 2** presents the modified JD-R model that the authors developed based on inductive analysis, subsequently applied for deductive analysis. Two modifications were made to the original JD-R model (12). First, an additional column was added on the left-side with elements specific to VBHC. These included the “professional,” the “job” of pursuing value in care and the “environment” in which VBHC takes place. This additional column allowed studying antecedents of job demands and resources. The column in the middle reflected the demands and resources that professionals experienced when providing VBHC. These demands and resources were connected to the right column comprising the constructs of employee well-being and job strain.

Second, as outcomes of employee well-being and job strain, we distinguished between “day-to-day” performance and long-term performance. The JD-R construct “performance” at the end of the conceptual model was omitted as it suggests a long-term focus. Although work can impact professionals’ long-term performance, such as absence and intention to leave practice (41, 42), we concluded from the analysis of the included studies that VBHC needs to mature before it is possible to observe long-term effects of VBHC on professionals’ performance. Hence, outcomes related to employee well-being and job strain were linked back to the left column that described the professionals’ day-to-day performance in value-based work. Patient performance, such as health outcomes (18, 43), and organizational performance, such as operational and performance metrics (44, 45), have been studied. However, these were omitted as they are not the scope of this study.

### Thematic Analysis

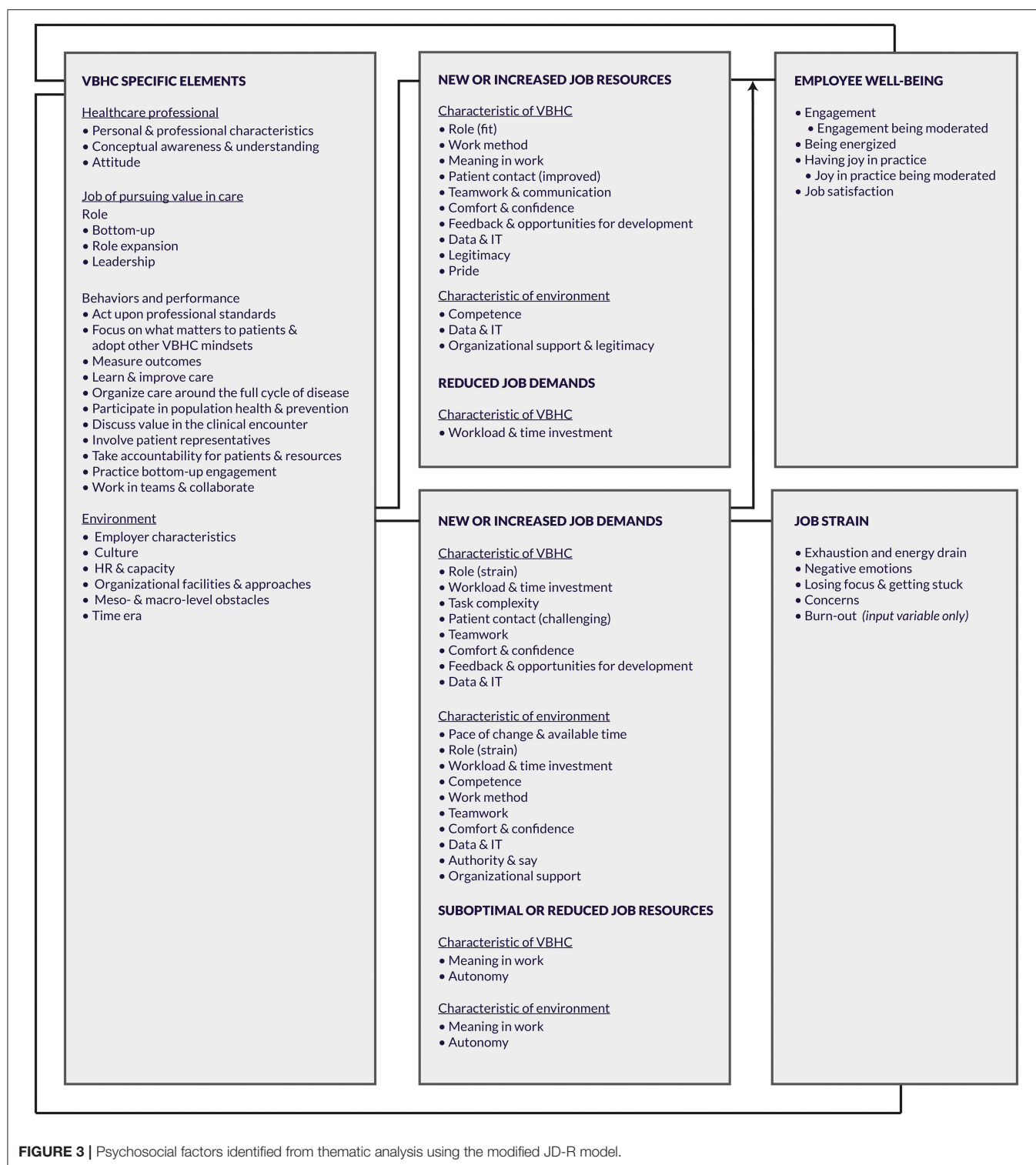
Over 800 quotes that resulted from the 45 included studies were thematically analyzed using the modified JD-R model. **Figure 3** shows that VBHC was associated with specific job demands and resources. Besides providing an overview of these factors, we distinguished between two types of job demands and resources. Namely, job demands and resources that were purely informed by the characteristics of the job, in this case pursuing VBHC, and job demands and resources



that stemmed from characteristics of the environment. These characteristics of the environment included among others organizational structures, culture, and resources, as well as how actors, such as healthcare organizations and policy makers, facilitated, and shaped the job. For example, when a professional experienced that VBHC took more effort than traditional care, this was considered a demand that resulted from the nature of VBHC. When a professional felt pressured by the pace

of implementation, this was considered a demand triggered by a characteristic of the environment. Connecting lines in **Figure 3** were based on the studies included in the review and hence differ from the original JD-R model. Except for an arrow describing the moderating effect that job demands may have on the relationship between job resources and employee well-being, arrows in the model were omitted to reflect possible bidirectionality.





**FIGURE 3 |** Psychosocial factors identified from thematic analysis using the modified JD-R model.

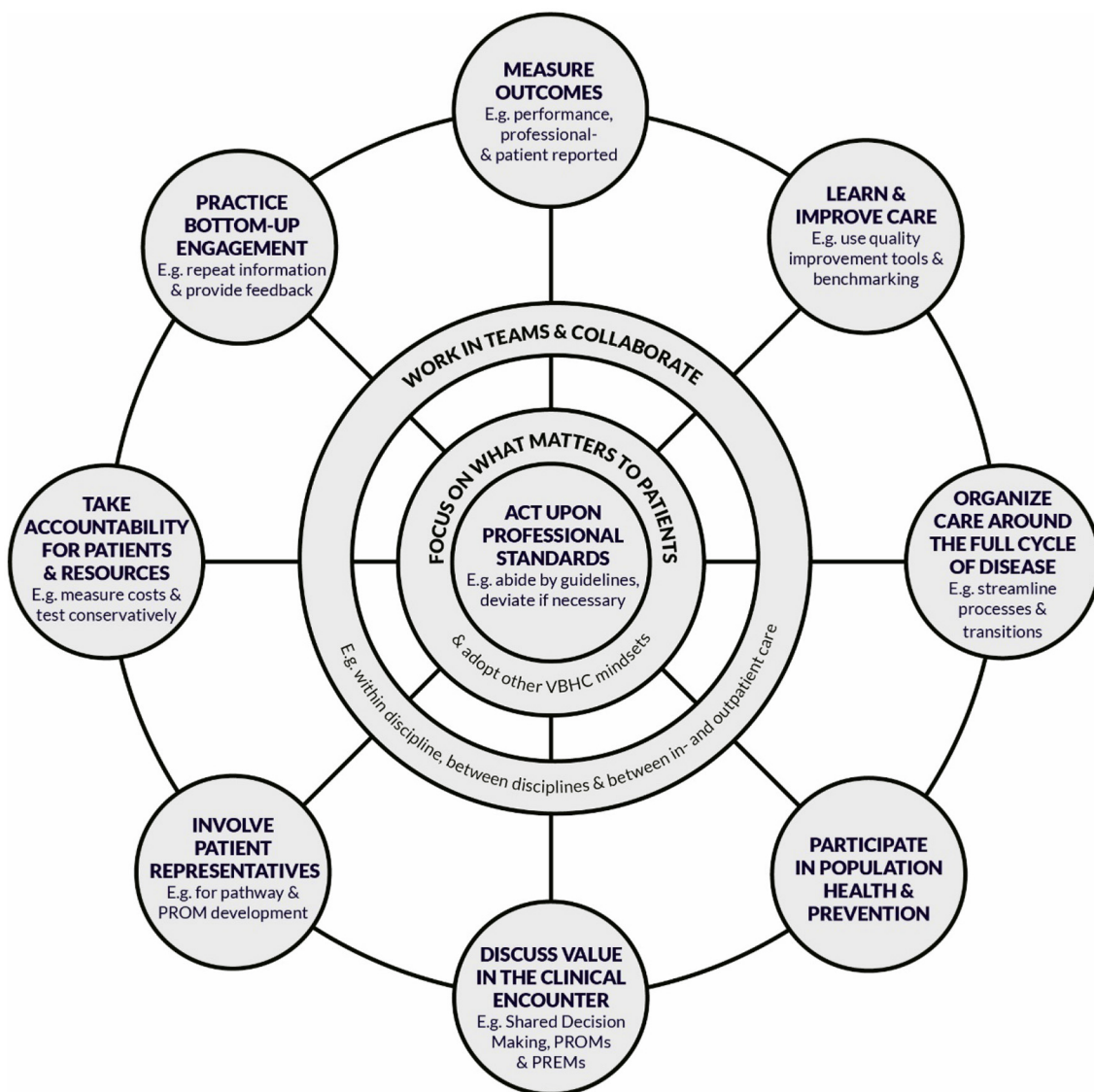
### Summary of the VBHC Specific Elements

For conciseness, the findings of the VBHC specific elements (left column in **Figure 3**) are summarized below. Details are provided in **Supplementary Material 4**. The VBHC specific elements comprised “the professional,” “the job,” and “the environment” as described from the professional’s perspective.

### The Professional

We identified three topics related to the healthcare professional, namely (1) personal and professional characteristics, (2) conceptual awareness and understanding, and (3) attitudes toward VBHC. Regarding “personal and professional characteristics” studies investigated, among others, age, job





**FIGURE 4** | Professionals' behaviors to pursue value in care identified from thematic analysis.

function, and professional values in relation to VBHC awareness (46, 47). Other studies showed mixed results regarding gender and job function in relation to VBHC attitudes and scores (23, 48, 49). Second, scholars investigated professionals' conceptual awareness (33, 46, 47, 50) and understanding (24, 31, 33, 35, 46, 49, 51–55) of VBHC, which revealed variation and possible prioritization of either patient outcomes or resource consciousness. Last, professionals' attitudes to VBHC were shown to be positive (14, 23, 24, 31, 33–35, 46, 48, 53–58) and/or negative (23, 24, 31, 33–35, 38, 47, 50–53, 55, 57–59). Positive attitudes included professionals mentioning that VBHC was received with hope (35), convincement (24), excitement and enthusiasm (33), and with suggested readiness (58). Negative attitudes included critique (53), perceived drawbacks (23) and resistance (24, 47, 51, 55), especially in the light of

considering costs (38, 52, 55, 57) and discussing costs with patients (57, 58).

### *The Job of Pursuing Value in Care*

Related to professionals' roles and behaviors, studies described VBHC as a bottom-up initiative (14, 24, 31, 32, 34, 47, 53, 54) that expanded roles and established new roles such as the “contact nurse” function (14, 24, 32, 56, 60–66). Engaged leadership was studied in terms of necessity, leadership approaches, competence, personal characteristics, as well as professions that were suggested to take up leadership roles (33, 34, 54, 66, 67). Analysis revealed 10 specific behaviors that professionals pursued in VBHC, next to acting upon their professional standards (68). These interconnected and mutually reinforcing behaviors, as visualized in **Figure 4**, are to (1) focus on what matters to patients and

adopt other VBHC mindsets (24, 31–33, 47, 50, 52, 53, 61, 62), (2) measure outcomes (14, 24, 31–35, 44, 56, 68), (3) learn and improve care (14, 24, 31–34, 47, 53, 62, 66, 68–70), (4) organize care around the full cycle of disease (24, 32, 44, 45, 54, 60, 61, 64, 66, 70–73), (5) participate in population health and prevention (24, 62, 66, 70, 72), (6) discuss value in the clinical encounter (31, 47, 50, 55, 56, 58, 63, 64, 74, 75), (7) involve patient representatives (24, 31–33, 50), (8) take accountability for patients and resources (31, 33, 38, 44, 47, 48, 54–57, 60, 64, 68, 69, 74, 75), (9) practice bottom-up engagement (14, 24, 31–35, 47), and above all (10) work in teams and collaborate (31, 34, 50, 61, 62, 66, 68, 72, 76).

### *The Environment*

Related to the perceived VBHC environment, six factors were identified, namely (1) employer characteristics, (2) culture, (3) Human Resources (HR) and capacity, (4) organizational facilities and approaches, (5) meso- and macro-level obstacles, and (6) the time era. First, studied employer characteristics included hospital type, region, health-care intensity, and number of clinicians. These factors were related to, among others, self-reported knowledge, perceived barriers, behaviors, and performance in VBHC (23, 48, 55, 63, 64, 69, 70, 74, 75, 77). Concerning culture, participants called for culture change (24, 31, 47, 56) and mentioned the need for specific cultures, particularly cultures that are transparent and blame-free (14, 31, 48, 53, 56, 66, 69, 72). Related to HR and capacity, studies discussed staffing constraints (33, 49, 59, 61), the importance of staff stability (24, 59, 66), staff composition including the use of alternative providers and medical assistants [e.g., (14, 24, 33, 35, 60, 64–66, 71, 72, 76)] and specific open job positions (33, 34, 62, 72, 78). Remarks made about organizational facilities and approaches involved professionals' desire for dedicated VBHC time (14, 59, 66), step-by-step implementation (34, 35, 56, 72, 76), and an overall supportive environment (24, 31, 53, 54, 56, 57, 59, 62, 65, 66, 72, 73) with specific attention for engaged leadership (14, 33, 35, 54, 66). Analysis revealed several meso- and macro-level impediments to VBHC (24, 35, 49, 54, 76) such as current waitlists to access specialists. Last, related to the time era, one study reported on the expected progressive impact of Covid-19 on VBHC (72).

### *Job Demands and Job Resources*

One study specifically investigated job resources and job demands in relation to professionals' attitudes toward high-value care, cost incorporation and perceived drawbacks using JD-R (23). Associations, both positively and negatively, were found for the following job demands and resources: autonomy, work pressure, opportunities for development, supervisory coaching, cognitive demands, and emotional demands.

In combination with the remaining studies, thematic analysis identified 16 job demands and resources (see **Figure 3**), namely: role fit or role strain, workload and time investment, competence, task complexity, work method, meaning in work, improved or more challenging patient contact, teamwork and communication, comfort and confidence, feedback and opportunities for personal development, pace of change and

time availability, data and IT, authority and say, autonomy, organizational support and legitimacy, and lastly, pride. Most of these constructs can both be a demand and resource depending on whether they give or take energy. All aforementioned constructs are discussed below. An overview is provided in **Table 1**.

### *Role*

VBHC itself and how organizations shaped VBHC impacted professionals' roles and interests both positively and negatively. VBHC can be considered a job resource as healthcare professionals mentioned that VBHC aligned with their interest, ethics, and nature of their work and reconnected them with their true role (24, 31, 35, 54, 55, 66, 72). Within VBHC, teams and workflows were reconfigured to allow everyone to utilize their competences to the full extent. However, when the reconfiguration was inadequate, professionals were concerned to become IT-specialists and were hindered to use their competences optimally (66). Consequently, professionals experienced job demands when their work environment did not support them to practice their role (33, 38, 55). VBHC itself also introduced role strain (14, 24, 32, 34, 51, 55, 60, 69, 74). For example, professionals found it hard to balance patient care and implementation work (33), questioned their role in discussing costs with patients (69), and experienced role unclarity due to new responsibilities in VBHC that were not yet formalized (14, 32). Residents in particular experienced specific strains related to priority-setting between VBHC and learning goals and felt uncertain about their contribution to VBHC (51, 55, 60, 74).

### *Workload and Time Investment*

VBHC was suggested to take more time and effort than providing lower-value care and hence was considered a job demand (31–33, 51, 62, 66, 71, 73). Among others, providing preoperative services and continuous work on pathways were considered time consuming. Related to organizational facilities and resources in the work environment, inadequate data-systems were suggested to increase work burden by demanding more manual work (33). However, when workflow and team compositions were adequately shaped, professionals experienced reduced administrative workload (60, 66, 72). This suggests that VBHC can also turn into a job resource.

### *Competence*

Although residents reported adequate VBHC knowledge (75) and nurses mentioned VBHC as one of their best competences (77, 79), the majority of studies revealed knowledge, skill, and experience deficits (31, 33, 38, 49, 50, 55, 57, 59, 60, 62, 75). These deficits related to, among others, tailoring care, managing case complexity, care integration and coordination, IT and data, quality improvement, interpretation and use of PROMs scores, exploring treatment options, benchmarking, knowledge about healthcare costs, and overall maintenance of knowledge.

### *Task Complexity*

Two studies reported on increased task complexity in VBHC. One study mentioned that nurses experienced

**TABLE 1** | Overview and illustrative quotes on job demands and resources in VBHC.

Job demands and Resources	Specification	Studies	Exemplifying quote
Role (fit and strain)	VBHC resource	(24, 31, 35, 54, 55, 66, 72)	<i>"It seems that VBHC appeals to healthcare professionals' closest sphere of interest"</i> (31)
	VBHC demand	(14, 24, 32, 34, 51, 55, 60, 69, 74)	<i>"Another problem was that team leaders found it difficult to prioritize their implementation work because they felt that their patients were their first priority"</i> (33)
	Environment demand	(33, 38, 55)	<i>"Adding to the complexity of learning to provide HV3C were the mixed messages that residents received at the workplace level regarding their role in HV3C"</i> (55)
Workload and time investment	VBHC resource	(60, 66, 72)	<i>"[...] medical assistants would room patients, ensure all paperwork was printed and complete, and act as scribes entering most of the information into the EHR. This allowed physicians to focus on patients, not the HER [electronic health record]. As one physician stated, 'I got to practice medicine again!'"</i> (66)
	VBHC demand	(31–33, 51, 62, 66, 71, 73)	<i>[The most common barriers to high-value care Included:] "increased time and effort"</i> (51)
	Environment demand	(33)	<i>"However, the difficulties of accessing data, especially from the internal IT system, took too much time and energy because it required so much manual work"</i> (33)
Competence	Environment resource	(75, 77, 79)	<i>"The highest measured mean scores were found in the competence areas 'Value-based nursing care' and [...]"</i> (79)
	Environment demand	(31, 33, 38, 49, 50, 55, 57, 59, 60, 62, 75)	<i>"Our experts did have the concern that [...] many lack the skills and training to take advantage of those data, whether the data were 'mined' by themselves or by a data scientist"</i> (62)
Task complexity	VBHC demand	(60, 73)	<i>"Participants shared another disadvantage of CPW [clinical pathways] is 'information overload,' where the number and length of pathways are perceived to be increasing over time. Providers find it challenging to remain up-to-date on which pathways exist and are unable to educate oneself on the content"</i> (73)
Work method	VBHC resource	(24, 31, 32, 49, 50)	<i>"Participants stated that VBHC includes improved working methods and organization of the work"</i> (31)
	VBHC demand	(14, 49)	<i>"A systematic approach for the identification of improvement potential, and the selection and implementation of improvement initiatives is lacking. Physicians explicitly mentioned that they struggle with this."</i> (14)
	Environment demand	(24)	<i>"This organizational structure was frustrating as this contributed to difficulties in tracking and following patients during the course of the disease when they crossed boundaries between departments"</i> (24)
Meaning in work	VBHC resource	(24, 31, 32, 35, 56, 60, 61, 66, 73)	<i>"The presence of medical assistants, care coordinators, and other team members, in conjunction with population management tools, created the opportunity to better understand, manage, and care for individual patients and different populations"</i> (66)
	VBHC demand	(24, 31)	<i>"Engagement for VBHC also decreased when participants did not see any actual activity or result of their implementation work"</i> (24)
	Environment demand	(24)	<i>"Being forced to make cancellations caused frustration among participants. They then lost their confidence in working with VBHC and found it meaningless trying to make smaller changes in the process when the great problem was lack of capacity"</i> (24)
Patient contact (improved and challenging)	VBHC resource	(50, 61, 73)	<i>"CPW [clinical pathways] not only improve communication among team members but facilitate conversations with patients and families regarding plans of care"</i> (73)
	VBHC demand	(49–51, 55, 57, 69, 73–75)	<i>"Nearly 40% reported that clinicians are uncomfortable discussing the costs of tests or treatments with patients and reported that clinicians do not feel that physicians should discuss costs with patients"</i> (57)
Teamwork and communication	VBHC resource	(24, 44, 53, 61, 66, 73)	<i>"Planning the production also included improvements in the communication between in- and outpatient wards"</i> (32)
	VBHC demand	(24)	<i>"People get confused when we have to start working between silos according to the principle of value for the patients"</i> (24)
	Environment demand	(33, 47, 49, 51, 73)	<i>"This pressure to comply results in providers describing feelings of guilt when non-adherent, which can prevent high-quality care and create conflict within a team"</i> (73)
Comfort and confidence	VBHC resource	(73)	<i>"CPW [clinical pathways] offer the additional benefit of providing practice validation, fostering confidence, and affirming clinical decision-making skills"</i> (73)
	VBHC demand	(48, 51, 55, 60, 69, 75)	<i>[Certified Medical Assistants mention] "a lack of comfort with the complexity of the new tasks"</i> (60)
	Environment demand	(33)	<i>"The participants were also uncertain as to whether or not this manual work could negatively influence the validity of the data"</i> (33)

(Continued)

TABLE 1 | Continued

Job demands and resources	Specification	Studies	Exemplifying quote
Feedback and opportunities for personal development	VBHC resource	(9, 56, 57, 73)	"Measuring outcomes and discussing them at an OCN [obstetric collaborative networks] level was considered to have the potential to stimulate learning" (56)
	VBHC demand	(57, 73)	"In the absence of such tools, participants perceived a lack of insight into their own care delivery, which was considered a real hindrance to critical reflection on HV3C delivery and their ability to train residents in such behavior" (57)
Pace of change and time availability	Environment demand	(14, 24, 33, 49, 50, 55, 60, 74)	"[They] expressed the view that they were burdened by the pressure of time. Participants did not have time to anchor changes in work outside the pilot project team. It was more important to uphold the consultants' time plan than actually to allow enough time for related health personnel" (24)
Data and IT	VBHC resource	(32, 50)	"Experienced facilitators focus on the availability of individual, $N = 1$ , PROMs scores, that could prepare both patients and professionals for discussion of patient values" (50)
	Environment resource	(50, 61)	"Advanced visualization of the bars and graphs of the PROMs scores ( $N = 1$ ) [as facilitator]" (50)
	VBHC demand	(50)	"Lack of overview of all existing options for the specific patient groups, for example, regarding transmurial care, rehabilitation, and primary care" (50)
	Environment demand	(14, 24, 31–33, 35, 48–50, 62, 66, 69, 72, 76)	"They also reported poor access to both quality data and cost data" (48)
Authority and say	Environment demand	(14, 24, 33, 55, 76)	"The lack of power within the implementation team to drive change" (76)
Autonomy	VBHC demand	(73)	"Physicians reported pressure to abide by CPW [clinical pathways] [...] Participants expressed concern that CPW encourage providers to adhere to an algorithm or an outlined plan, which can stifle one's education by limiting critical-thinking skills and autonomy. CPW lead to 'prescriptive medicine' where care may be simplified too much" (73)
	Environment demand	(24)	"The high tempo during the first three months deprived the participants of their own autonomy" (24)
Organizational support and legitimacy	VBHC resource	(24)	"Even if it was impossible to make use of all the patient representatives' opinions and experiences, participants were proud of their cooperation with the representatives as this contributed to the legitimacy of their implementation work" (24)
	Environment resource	(24, 33, 48, 50, 69)	"Over time, participants came to understand the importance of the hospital director's unequivocal standpoint that VBHC was to be used as a management tool. This standpoint gave legitimacy to decisions within the teams" (33)
	Environment demand	(24, 32, 33, 35, 55, 72, 76)	"Participants felt they had been thrown into the deep end when it came to implementation work" (33)
Pride	VBHC resource	(24)	"[...] participants were proud of their cooperation with the representatives as this contributed to the legitimacy of their implementation work" (24)

complexity with new tasks in VBHC as a result of task expansion (60). The second study suggested information overload due to working with care pathways (73).

### Work Method

Professionals appreciated VBHC's contribution to easier, more effective and better structured ways of working (24, 31, 32, 49, 50). VBHC was mentioned to make patient follow-up easier, to bring more focus, specific tasks, and better insight in care processes. Moreover, VBHC was considered a tool for well-founded decisions and documentation (31, 32). However, professionals mentioned to lack an approach to quality improvement and felt hindered by pathways and guidelines that were inexplicit and difficult to access and interpret (14, 49, 73). Organizational structure and division of financial responsibilities

were environmental factors experienced to obstruct care processes (24).

### Meaning in Work

Participants experienced successes from their value-based efforts and increased sense of purpose and mission (24, 31, 32, 35, 56, 60, 61, 66, 73). Examples of successes were better care transitions, achievement of the Triple aim, reduction of low-value care, elimination of care variation, and overall improved care in favor of the patient. Visible effects were mentioned to be motivating, and when invisible this had negative impact on engagement (24, 31). Remarkably, one study reported that only half of the participants saw success from their efforts to promote quality care at lower cost (69). Furthermore, one study described that implementation work was seen as an "obligation" and considered meaningless in light of persisting root-cause problems in the organization (24). This experience was characterized



as a job demand that stemmed from characteristics of the environment.

### ***Patient Contact***

Both beneficial and adverse outcomes of VBHC on patient contact were reported. On the one hand, VBHC was experienced to improve patient contact. In particular, PROMs prepared patients and professionals for discussing patient values (50), care pathways facilitated conversations with patients and families regarding plans of care (73), and patients perceived their professionals to be better informed as result from strengthened team-based care (61). On the other hand, professionals seemingly faced more challenges in value-based patient contact (49–51, 55, 57, 69, 73–75). Professionals reported difficulties, reluctance and discomfort when discussing VBHC with patients, specifically costs (48, 55, 57, 69), and the choice of non-treatment (50). Professionals also mentioned to face demanding patients and patients with wrong expectations, which hindered or even prevented them to provide VBHC (49, 51, 55, 75). Last, concern was expressed about pathways limiting patient discussions by creating “tunnel vision” (73).

### ***Teamwork and Communication***

VBHC created organizational imperative for professionals to cooperate and was considered to facilitate cooperation by providing a shared language. This resulted in the perception of more and better teamwork (24, 32, 44, 53, 61, 66, 73). However, collaboration between silos was mentioned to cause confusion (24). Prompted by the environment, participants felt it was difficult to maintain staff engagement, faced adverse behavior of colleagues, and reported on being tangled up in discussions about (im)possibilities regarding data collection (33, 47, 49, 51, 73).

### ***Comfort and Confidence***

While pathways enhanced confidence by affirming clinical decision-making (73), professionals also experienced lack of comfort and uncertainty in VBHC (48, 51, 55, 60, 69, 73, 75). Among others, professionals felt lack of comfort with the complexity of new tasks (60) and comfort with cost conversations varied (48, 51). Diagnostic uncertainty and concerns about inadequate patient follow-up were identified as reasons why professionals overuse resources (75). Professionals also felt insecure when they had to capture data manually due to IT limitations (33), being an environment-specific factor.

### ***Feedback and Opportunities for Personal Development***

VBHC education and training, as environmental factors, have not been included in this study. However, it is of interest to note that professionals reported on learning potential being stimulated by outcome information (9, 56), feedback tools (57), and pathways (73). However, professionals also recognized that pathways possibly limit learnings (73). Feedback tools were considered useful and when absent professionals experienced this as hindering (57).

### ***Pace of Change and Time Availability***

Participants felt pressured by time, especially due to the absence of dedicated time for VBHC activities and rapid pace of

implementation (14, 24, 33, 49, 50, 55, 60, 74). Due to this pressure, participants felt deprived of their autonomy (24) and reported losing focus (55). They regretted not working up to their best (33) and fell back into care of lower value (74).

### ***Data and IT***

Professionals valued that VBHC provided access to PROMs scores of individual patients and patient codes (32, 50). Professionals appreciated work environments that provided advanced PROMs score visualizations and adequate access to the electronic health record (50, 61). Hindrance was experienced as a result of not having access to aggregated PROMs data and lacking overview of treatments options (50). Furthermore, various deficiencies related to data, IT, data collection routines, and infrastructure hindered professionals in pursuing VBHC (14, 24, 31–33, 35, 48–50, 62, 66, 69, 72, 76). These demanding situations were triggered by inadequate organizational structures and resources in the professional's work environment.

### ***Authority and Say***

Some professionals felt obstructed to participate in VBHC and drive VBHC as a team leader (14, 24, 33, 55, 76). This was caused by a lack of authority and say within their work environment. This lack was considered problematic as it hindered decision-making.

### ***Autonomy***

As a characteristic of VBHC, professionals experienced reduced autonomy due to the felt pressure to abide by pathways (73). As an environmental demand, professionals described being deprived of their autonomy due to rapid implementation of VBHC (24). Additionally, two studies reported on autonomy of professionals being purposefully adjusted in VBHC. One study increased professionals' autonomy to advance VBHC. In this study professionals were authorized to select their own performance metrics (23). In another study, autonomy of junior residents was reduced as they were seen as potential providers of lower value care and hence in need of guidance and limits (57).

### ***Organizational Support and Legitimacy***

Professionals experienced legitimacy in value-based work as a result of involving patient representatives (24), which was consequently considered a resource stemming from VBHC. There was variation to what extent professionals felt supported in their work environment. On the positive side, professionals described, among others, support from managers, leadership, and champions as role model (24, 33, 48, 50, 69). On the negative side, professionals described, among others, disinterest of managers, skepticism in IT departments and lack of, and unclear, policy (24, 32, 33, 35, 55, 72, 76). VBHC consultants and guidelines were mentioned to potentially be helpful but also risked to cause drawbacks when utilized inappropriately (24, 55).

### ***Pride***

A single study reported that the involvement of patient representatives made professionals experience pride (24).

## Employee Well-Being and Job Strain

Positive and negative outcomes of VBHC for professionals were reported. These, as discussed below, related to employee well-being and job strain. **Table 2** provides an overview.

### Employee Well-Being

Related to employee well-being in VBHC, positive outcomes included professionals who were engaged (24, 35, 44, 60, 61), felt energized (24, 66), experienced joy in practice (66), and experienced improved job satisfaction (24, 32, 44, 60, 66). These outcomes were suggested to positively impact subsequent VBHC behaviors (24, 35, 61).

Job resources associated with aforementioned positive outcomes were “role fit,” “work method,” and “meaning in work.” Professionals valued being able to focus on what matters to patients, working on specific tasks, seeing effects of their efforts, having outcomes to demonstrate, and meeting the Triple aim (24, 66). Positive outcomes also resulted from working in line with standard care plans (32), team-based care (66), redesigned workflows (60), multidisciplinary rounds with an experienced physician as coach (61), and practice transformation (44, 66).

Of interest, two studies reported that engagement and joy in practice were moderated or reduced by job demands. Job demands that decreased engagement were “role strain,” i.e., professionals who felt divided between different obligations, and “lack of meaning,” i.e., professional who did not see visible results from their VBHC efforts (24). The job demand that decreased joy in practice was increased “workload” (66).

### Job Strain

Concerning job strain in VBHC, professionals experienced four negative outcomes, namely: exhaustion and energy drain (24, 32, 33), negative emotions (24, 33, 47, 55, 73), losing focus and getting stuck (24, 33), and several concerns (24, 31, 32, 48, 50, 51, 53, 55, 56, 69, 73–76). Negative emotions comprised frustration, fear, and feelings of guilt. Concerns related to care quality, VBHC continuity, pathways use, legal repercussions in combination with use of outcomes, hierarchy, and sustainability of the care system. A single study investigated burn-out as an input variable, showing that residents who felt burned out after their education scored lower on the “high-value care culture” scale (38).

Exhaustion and energy drain was associated with the job demand inadequate “data and IT.” Negative emotions were triggered by the job demands lack of “available time,” “teamwork” challenges, “role strain,” and inadequate “data and IT” including professionals’ inability to change the IT system. Negative emotions also resulted from staffing constraints, hindering organizational structures and were associated with possible adverse consequences of pathways. Participants lost their focus and mentioned to risk not being able to uphold VBHC due the job demands “role strain,” insufficient “organizational support,” inadequate “pace of change and time availability,” challenging

“patient contact,” meso-level obstacles and because of various concerns professionals had concerning VBHC.

## DISCUSSION

The founders of VBHC state that professionals play a crucial role in VBHC and hence argue that employee well-being should be part of organizations’ imperatives in addition to improving health value (1). However, to date, knowledge about what VBHC means for healthcare professionals is scattered. This review synthesizes insights from 45 included studies about how VBHC relates to the healthcare professional, and vice versa.

This review shows that the term VBHC is used for a variety of value-enhancing activities. Consequently, behaviors of professionals in VBHC may be specific to the type of activity performed. Thematic analysis reveals 10 specific behaviors that healthcare professionals pursue in VBHC, next to acting upon their professional standards. These interconnected and mutually reinforcing behaviors, as visualized in **Figure 4**, are to (1) focus on what matters to patients & adopt other VBHC mindsets, (2) measure outcomes, (3) learn and improve care, (4) organize care around the full cycle of disease, (5) participate in population health and prevention, (6) discuss value in the clinical encounter, (7) involve patient representatives, (8) take accountability for patients and resources, (9) practice bottom-up engagement, and above all (10) work in teams and collaborate.

### Job Demands-Resources in VBHC

This review confirms that VBHC “brings change to the current landscape by introducing new or different roles for people, different workflows or processes, and new tools or existing ones that have been used in other settings or all the above” (65). These changes impact the job demands and resources professionals experience in VBHC and, in turn, their well-being and job strain. More specifically, this review reveals that healthcare professionals in VBHC may experience 16 job resources and/or job demands, four constructs related to their well-being, and five constructs related to job strain. **Figure 3** visualizes these outcomes in a modified Job Demands-Resources (JD-R) model.

Among others, the identified job resources suggest that VBHC connects professionals with their role and interest, making them appreciate VBHC as an approach to caring. Professionals report on increased meaning in their work and improved patient contact, teamwork, and communication. However, implementation of VBHC also takes energy from professionals. Although some studies report on reduced administrative workload in VBHC, other studies suggest that VBHC increases workload. This difference, as well as how other work factors are evaluated, may be partly explained by variety in professionals’ work environments such as the level of organizational support, as elaborated below. Other job demands professionals may experience are role strain, teething problems with the transformation to VBHC and overall challenges evoked by change. Furthermore, within their organization, professionals seem to experience paucity of adequate IT resources, authority to implement VBHC and time to become acquainted with VBHC. Professionals also report on difficulties in discussing

costs with patients. The latter is striking as we do not find literature that advises professionals to discuss costs with patients as part of VBHC besides themselves taking accountability for adequate use of resources. Hence, this disparity may suggest that the job demand that relates to discussing costs with patients is redundant.

This review reveals that increased job resources resulting from the adoption of VBHC may increase professionals' engagement, energy, joy in practice, and job satisfaction, which corresponds to findings from research on clinician engagement during organizational change (80). Respectively, job demands professionals experience in VBHC can make them feel exhausted and evoke negative emotions, loss of focus and concerns. This review reveals that job demands may moderate employee engagement and joy in practice, as has also been suggested in JD-R literature (81). The positive effect of job resources on job strain that this literature describes is not explicitly mentioned in the included studies of this review. Remarkably, the included studies only qualitatively investigate employee well-being and exhaustion while quantitative measurement instruments exist, for example as part of the JD-R questionnaire (82).

Altogether, the aforementioned job demands, job resources and outcomes related to employee well-being and job strain show similarities with earlier research on job demands and resources in healthcare setting (41, 80) albeit sometimes in slightly different wording. This may imply that VBHC involves various established psychosocial factors at work and not so much radically introduces new factors that seek our attention. However, the results from this

review may be too rosy as VBHC projects to date possibly focused on low-hanging fruits. Moreover, the identified factors may apply to specific VBHC components and be partly environment specific. This implies that the results from this review are not expected to apply to all professionals and hence should be interpreted with care.

## Organizational Support as Enabler

The strength of this review is that it distinguishes between job resources and job demands that stem from (1) VBHC in terms of content and (2) the environment in which VBHC takes place. For example, professionals who experience that VBHC takes more effort is considered a demand that stems from VBHC. Professionals who feel pressure from the pace of implementation is considered a demand that stems from the work environment, as it depends on how organizations shape and facilitate VBHC. This distinction is in line with the concept of psychosocial factors at work, which explicitly distinguishes between job content, work environment, and organizational conditions as factors that impact employee well-being (13).

Strikingly, this review finds that several job demands stem from organizations' inadequate management of VBHC, i.e., speeded VBHC implementation, suboptimal workforce composition connected to care pathways and insufficient organizational resources and capacity. This observation underlines the need for organizations to better support their employees by providing the necessary resources and designing appropriate organizational structures and interventions to

**TABLE 2 |** Overview and illustrative quotes on employee well-being and job strain in VBHC.

Employee well-being	Studies	Exemplifying quote
Engagement	(24, 35, 44, 60, 61)	"The focus on value for the patient, emphasized by the hospital management team, contributed to their feelings of 'enthusiasm for the concept and strong engagement in implementation work'" (24)
Engagement being moderated by demands	(24)	"These hindrances contributed to decreasing engagement in carrying the process forward. [...] Engagement for VBHC also decreased when participants did not see any actual activity or result of their implementation work" (24)
Being energized	(24, 66)	"I think even greater sense of meaning that we're all working towards the greater good of patient health and well-being, and I think that genuinely energized people" (66)
Having joy in practice	(66)	"All but one of the practices indicated that their transformation efforts led to increased joy of practice" (66)
Joy in practice being moderated by demands	(66)	"The one outlier practice indicated increased sense of purpose and mission and did not indicate decrease in joy or well-being, but did acknowledge that increased work necessary for practice transformation moderated increased joy of practice" (66)
Increased Job Satisfaction	(24, 32, 44, 60, 66)	"All participants in the structured interviews noted improved job satisfaction after the transition period, given the new sense of employee engagement and accountability" (44)
Job strain	Studies	Exemplifying quote
Exhaustion and energy drain	(24, 32, 33)	"This was experienced as a long and energy-draining process" (32)
Negative emotions	(24, 33, 47, 55, 73)	"Participants expressed both their colleagues and their nonadherence to CPW [clinical pathways] can result in a range of emotions from fear to frustration" (73)
Losing focus and getting stuck	(24, 33)	"In all, these residents sometimes let time pressure, demanding patients, concerns over supervisors potentially overruling them, their wish to develop or maintain a patient-resident relationship, and fears of claims make them lose their focus on HV3C delivery" (55)
Concerns	(24, 31, 32, 48, 50, 51, 53, 55, 56, 69, 73–76)	"Nearly 50% reported that the clinicians' fear of legal repercussions affects their frequency of ordering unneeded tests or procedures, and 30% reported that individual clinicians are blamed for complications" (69)
Burnout	(38)	"Those who felt burned out at the completion of training ( $\beta = -0.52$ , 95% CI $-1.00$ – $0.04$ , $p=0.03$ ) were more likely to score lower on the [Residency High Value Care] scale" (38)

mitigate or avoid job demands and enhance job resources. Subsequently, this may sustainably improve professionals' contributions to VBHC via improved employee well-being. This is especially relevant in the light of research relating employee experience and well-being to organizational performance measures (83, 84) such as workforce engagement in healthcare development (85). In other words, just personal engagement of professionals is insufficient as is illustrated by the following quote: "[They] recognize that HV3C [high-value, cost-conscious care] practices depend in part on the patient population, available resources, and organizational structure [...] Although they initially aimed to provide HV3C, under external pressure their pro-HV3C aspirations waned" (55).

The view that VBHC is a shared responsibility and requires multi-level support is supported by the adapted JOINT model (42). This model defines five layers, being the (1) individual layer, (2) interpersonal layer, (3) job level layer, (4) organizational layer, and (5) national layer. Each of these layers has been suggested to impact nurse absenteeism and turnover (42). Not only can multi-layered support help us reduce negative psychosocial work factors in VBHC and hence prevent disease and dysfunction in the workforce, but also can this layered support contribute positive psychosocial work factors in VBHC and hence support professionals to flourish. On the organizational level, support may be best shown to advantage as part of a "top-guided bottom-up" approach. In a top-guided bottom-up approach efforts of professionals, primarily teams, are orchestrated centrally (86). Within this approach organizations provide their employees supportive infrastructure, tools and resources including protected time, relevant data, staff training, and administrative and analytic support.

## Limitations

This study has five biases. First, the identified outcomes of VBHC on professionals' experiences and their well-being may not be generalizable to all professionals working in a VBHC context for three reasons. Namely, scholars may use different criteria for judging whether their intervention is part of VBHC, studies report on different combinations of VBHC activities and – as this review concludes – experiences may be partly work environment specific. A second bias is that studies reporting on high-value care and high-value, cost-conscious care are generalized while there may be subtle differences between these care models. Hence, we may expect professionals to pursue slightly different behaviors in each of these care models, which, in turn, may evoke slightly different experiences and outcomes. Third, this review does not distinguish between the type of healthcare professional and her educational status. Clinicians, nurses, and residents, who form the main populations in the included studies, may fulfill different roles in VBHC and hence can be expected to have different experiences and encounter different personal outcomes. Consequently, based on this review, it is not possible to target focused interventions to specific populations. Fourth, the temporality of the findings is uncertain as some experiences and outcomes may be connected to implementation efforts more than being a lasting characteristic of VBHC. However, judging whether VBHC has become part of the normal work

is complicated as this perception is suggested to vary from professional to professional (24). Last, assessing whether a job demand or resource is a characteristic of VBHC or a characteristic of the environment is a delicate task and requires certain interpretability as all care activities take place in an environment. This implies that different takes on the resulting overview of job demands and resources are possible.

## Practical Implications

Prompted by the insight that healthcare professionals may experience paucity of competence to optimally pursue value in care, we identify the need for more guidance for professionals. Providing adequate guidance is especially relevant as professionals play a prominent role in VBHC (1), which aligns with our findings. Moreover, value-enhancing behaviors of professionals, such as shared decision making, increasingly become legal requirements (87, 88). The 10 behaviors this review describes (see **Figure 4**) may serve as a base for this guidance. While some of these behaviors correspond to Porter's value agenda (89), this review also proposes new behaviors. In line with an earlier proposed extension to Porter's value agenda (7), this review suggests to incorporate behaviors to "learn and improve care" and to "discuss value in the clinical encounter" as additional elements. Furthermore, this review focusses attention to the need for professionals to "adopt appropriate mindsets for VBHC," in particular by truly focusing on what matters to patients. Other behaviors this review contributes are to "work in teams and collaborate," "involve patient representatives," "take accountability for patients and resources," "practice bottom-up engagement," and "participate in population health and prevention."

Besides guidance for professionals, this review also supports organizations to better care for their employees and strive for a sustainable VBHC model. This review shows how organizations can use a psychosocial model such as JD-R to manage and improve employee well-being, as has been previously suggested to Human Resource Management as well (HRM) (83, 90). Caring for employees is besides being morally integer and beneficial for organizational performance also a legal obligation in Europe (91). In addition to mitigating and avoiding adverse effects of VBHC on the professional, organizations may seek to exploit VBHC to contribute to positive psychosocial factors at work. For example, organizations may amplify job resources such as "meaning in work" by enhancing the visibility of VBHC outcomes.

As previously mentioned, organizations can consider a top-guided bottom-up approach (86) to optimally support their employees in VBHC. Within this approach, attention should be given to the pre-implementation and delivery phase of VBHC to prevent professionals from having avoidable adverse experiences. The International Labour Organisation (13) studied frequent omissions and mistakes when implementing changes at the workplace. From this research we derive that technical and psychological preparation is needed prior to implementation. For VBHC this implies that, among others, PROM technologies and care pathways should be adequately established and professionals need to be sufficiently informed and trained. Second, during VBHC delivery, professionals should



be offered support depending on their personal needs. Next to the use of PROMs and PREMs, we see opportunity to periodically evaluate psychosocial factors at work and use these results for improvements. Third, organizational should give explicit attention to implementing VBHC at a satisfying pace in the eyes of professionals since professionals reported to feel pressured. Furthermore, organizations need to ensure that professionals have necessary authority to implement and deliver VBHC as professional mentioned lack of authority as impediment to VBHC. Last, by preventing staff shortages, providing professionals dedicated time for VBHC and optimizing team composition, organizations can mitigate or avoid increases in professionals' workload and even exploit VBHC to reduce administrative workload and optimize job resources such as meaning in work, comfort and collaboration.

## Future Work

Contributions of this study to literature are two-fold. First this work contributes to JD-R literature by considering that job demands and resources may both result from the nature of the job and the way actors in the environment facilitate and shape the job. Future work using the JD-R model may want to explicitly research the antecedents of job demands and resources as this allows for focusing interventions at the source. Antecedents identified in prior research on psychosocial factors at work may provide inspiration (13). Second, this work contributes to VBHC literature by shifting attention toward the professional. This review reveals several behaviors professionals pursue to achieve value in care, job demands and resources professionals experience in VBHC and, in turn, outcomes related to employee well-being and job strain.

Further research to estimate the effects of VBHC on healthcare professionals is warranted. First, application of existing theories and frameworks is recommended as only one of the studies included in this review did so. Second, this review provides an overview of factors that impact the professional and her delivery of VBHC both positively and negatively. Future work may investigate sufficient and necessary conditions to make VBHC work such as strong leadership, a culture of continuous improvement and strengthened team-based care. Third, future work may focus on personal resources in VBHC as these seem understudied. Personal resources, such as optimism and self-efficacy, may affect a person's functioning and are hence integrated in the JD-R model (92). Another opportunity for future work focuses on pre-existing care practices that gained a new life in VBHC, such as efforts to improve care and working with PROMs. This review builds on the assumption that these care practices are experienced differently now they are applied as mechanisms to optimize value in care as opposed to satisfying different purposes or being an end-goal in themselves. However, future research is necessary to validate this

assumption. Finally, due to the multifaceted nature of VBHC, scholars may attempt to study how, and to what degree, each component of VBHC, as well as possible interactions between components, impacts job experience and employee well-being. Impact evaluations of VBHC implementation programs across different hospitals would allow to generate such insights among healthcare professionals. The ongoing transformation from traditional healthcare delivery to VBHC provides momentum for evaluation of the effectiveness of VBHC in relation to job experience and employee well-being by comparing traditional care practices to value-based care practices.

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

## AUTHOR CONTRIBUTIONS

VE led the development of the search strategy, screened all papers (first screener), led the analyses, and wrote the first draft of the manuscript. IB was involved in conceptualization of the study, development of the search strategy, screening of the papers (second screener), analyses, and reviewed the manuscript. KA was involved in conceptualization of the study, development of the search strategy, analyses, and reviewed the manuscript. MB-S led the conceptualization of the study, was involved in development of the search strategy, screening of a subset of papers (third screener), analyses, and reviewed the manuscript. All authors approved the final version of the manuscript.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2021.800702/full#supplementary-material>

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# Value-Based Healthcare Project Implementation in a Hierarchical Tertiary Hospital: Lessons Learned

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An important innovation in healthcare is the value-based healthcare (VBHC) framework, a way to solve health services' sustainability problems and ensure continuous improvement of healthcare quality. The Quality and Safety Unit at the Hospital Universitario 12 de Octubre has been since May 2018 coordinating the implementation of several healthcare innovation projects within the paradigm of VBHC. Implementing innovations in a complex institution, such as a tertiary hospital, is a challenge; we present here the lessons learned in the last 4 years of work. We detail exclusively the aspects related to continuous improvement and value addition to the process. In summary, for any VBHC project implementation, we found that there are five main issues: (1) adequate data quality; (2) development of data recording and visualization tools; (3) minimizing healthcare professional's effort to record data; (4) centralize governance, coordination, and transparency policies; (5) managerial's implication and follow-up. We described six steps key to ensure a successful implementation which are the following: testing the feasibility and complexities of the entry process; establishing leadership and coordination of the project; developing patient-reported outcomes and experience measurements; developing and adapting the data recording and data analysis tools; piloting in one or more medical conditions and evaluating the results and project management. The implementation duration can vary depending on the complexity of the Medical Condition Clinical Process and Patient Pathways. However, we estimate that the implementing phase will last a minimum of 18 and a maximum of 24 months. During this period, the institution should be capable of designing and implementing the proposed innovations. The implementation costs vary as well depending on the complexity, ranging from 90,000 euros to 250,000 euros. Implementation problems included the resistance to change of institutions and professionals. To date, there are few successful, published implementations of value-based healthcare. Our quality of care and patient safety methodological approach to the implementation has provided a particular advantage.

**Keywords:** value-based healthcare, operative implementation, quality of care, resources estimation, patient-reported outcomes (PRO), patient-reported experience (PRE), clinician-reported outcomes (CRO)

## INTRODUCTION

Offering value-based healthcare is a tempting opportunity for any healthcare institution (1–6), and, to do so, a systematic measurement of health outcomes is the necessary first step for any healthcare process evaluation and improvement (2, 7, 8). Moreover, any real innovation of the healthcare process must favor sustainability and equity, be very adaptive to a dynamic environment and ensure the best possible care in any circumstance (including crises such as pandemics) (9–11).

Value-based healthcare (VBHC) is an international trend that implies significant changes at several levels of the healthcare institutions from managerial viewpoints to the doctor-patient relationship (1, 12). Therefore, implementing and evaluating these innovations needs some structure and considerable effort (1, 13). As an institutional strategy for continuous improvement of healthcare quality, implementing systems to measure value for patients, populations, and professionals was essential, along with organizing the healthcare practice around clinical processes (medical conditions) instead of specialties, services, or units (**Figure 1**). Moreover, to calculate the value, it is necessary to measure the costs *per patient* through the entire process (12, 14). Since May 2018, the Quality of Care and Patient Safety Unit at the Hospital Universitario 12 de Octubre (HU12O) has been coordinating the implementation of five healthcare innovation projects (**Supplementary Table S1**), including the following clinical conditions: lung cancer (LC), age-related macular degeneration (ARMD), inflammatory Bowel Disease (IBD), breast cancer (BC), and coronavirus disease (COVID). Those projects are currently at different stages of implementation and imply different complexity and resource allocation.

The hospital is also part of a European Consortium of Hospitals called VOICE for breast and lung cancer outcomes research coordinated by the Institute for Health Services Research Kronikgune. We are part of the Spanish Consortium of Hospitals EIIMPROVE for IBD, and in a Spanish Community of Hospitals in ARMD sponsored by Novartis.

As in any complex and learning organization, any medical act is as much a source of data and information as it uses data and information from past medical acts transformed in knowledge through a shared reflection. Therefore, the data quality of the variables is key to allowing proper healthcare and avoiding errors and biases. Recording from the primary source, either the clinician (clinician-reported outcomes measures; CROM) or the patient (patient-reported outcomes measures; PROM) variables, reduces the variability of data quality. The effort of translating data to clinical decision aids benefits from an appropriate data visualization and a methodologically robust analysis (**Figure 1C**).

Contexts are quite different among different institutions and countries. Our experience is limited, but a lot of the work already done could be adapted to other cases to help avoid mistakes. We present in this work the strategies and approaches that assist us in the implementation and the barriers identified.

## MATERIALS AND METHODS

### Organizational Setting and Context

The population attended by the Hospital Universitario 12 de Octubre, and the inclusion criteria for each Cohort were the ones defined by the Communities adapted to the characteristics of the hospital. The inclusion criteria are detailed in the **Supplementary Material**. Several study designs were used during the implementation of the VBHC innovation. From qualitative studies to prospective cohort studies. The protocols are available in Spanish if needed, and all were approved by the Ethics Committee when required. The approval documents are available as well in Spanish. The consensus studies were either focal and discussion groups with key stakeholders or modified Delphi studies with experts. During the implementation process, the piloting study was a descriptive observational cohort study.

### Process Definition and Limits

Our projects focus on the in-hospital part of the complete medical condition process. However, the process was analyzed from the initial diagnosis (suspected diagnosis) in primary care or screening program to the last follow-up consultation in either primary care or hospital care.

The process analysis included the following:

- Workflow
- Archetype patient journey covering at least 80% of the causes of each medical condition
- Identification of the variables of interest within the process workflow
- Information flow from the data generation to the warehousing of the data
- Identification data life cycle within the process: primary sources of the data; databases, communication within the databases, and the person or machine responsible for the data generation and recording

### Variables

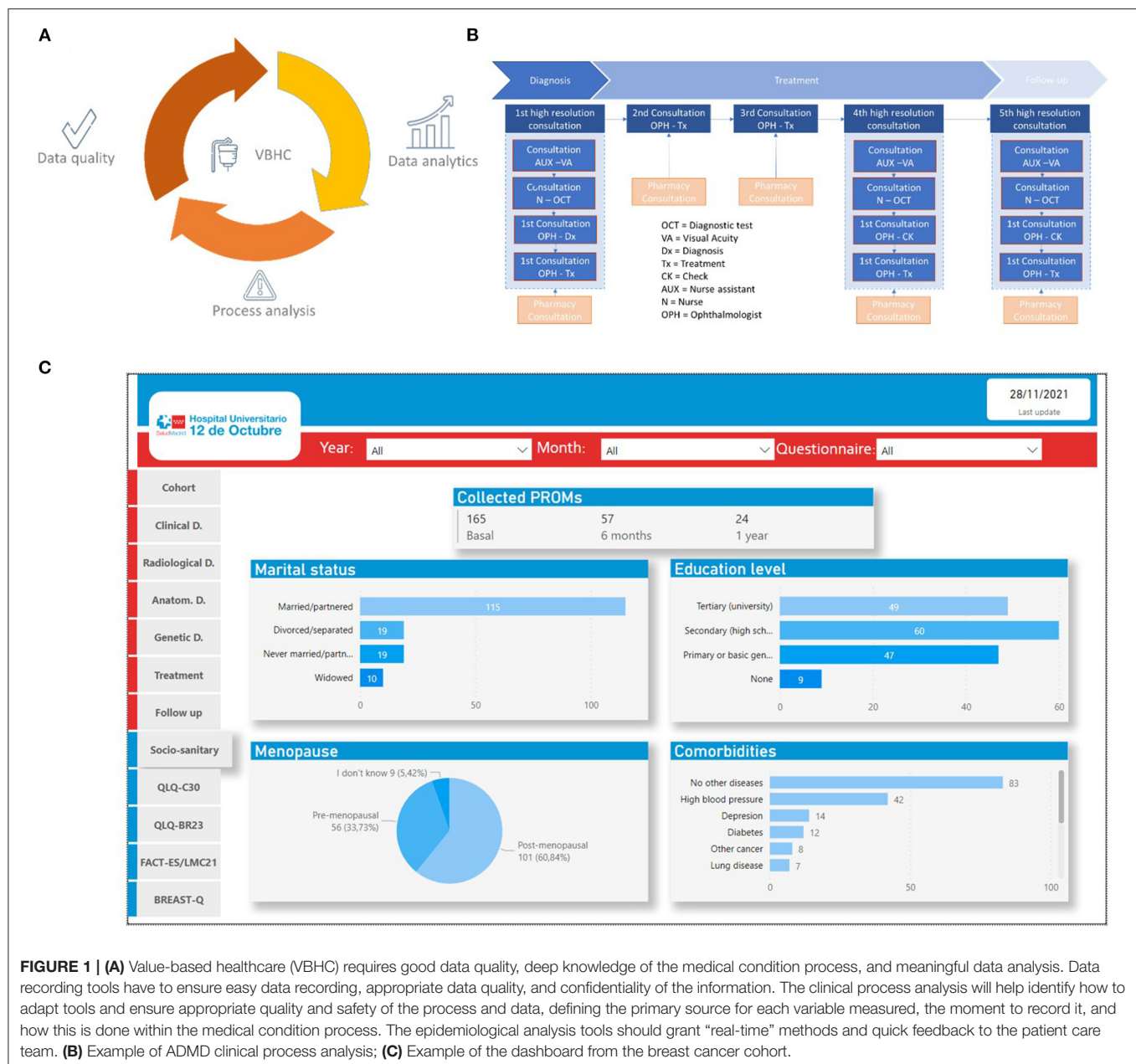
The clinical variables included in the standard dataset (ICHOM data set for breast cancer, lung cancer, ARMD, and IBD) and some variables chosen by the physicians and nurses *ad hoc* in every project, patient-reported variables from the PROM and patient-reported experience measure (PREM) questionnaires, variables of process indicators, (e.g., times and delays, a numerical account of activity and outputs, costs information).

### Hardware

The server must have at least RAM with 4 GB, four cores in the central processing unit (CPU), a 64 bits operative system, and a minimum storage space of 15 GB. The computers must have RAM with 9 GB, 64 bits operative system, and four cores in the CPU. Patients should have access to the Internet by computer, smartphone, or tablet for PROM and PREM recording.

### Software

- Tools for data recording that warrants confidentiality and data quality: Redcap (Vanderbilt, USA) or similar solutions. Institution Electronic Health Record system (HCIS) (Madrid,



**FIGURE 1 | (A)** Value-based healthcare (VBHC) requires good data quality, deep knowledge of the medical condition process, and meaningful data analysis. Data recording tools have to ensure easy data recording, appropriate data quality, and confidentiality of the information. The clinical process analysis will help identify how to adapt tools and ensure appropriate quality and safety of the process and data, defining the primary source for each variable measured, the moment to record it, and how this is done within the medical condition process. The epidemiological analysis tools should grant “real-time” methods and quick feedback to the patient care team. **(B)** Example of ADMD clinical process analysis; **(C)** Example of the dashboard from the breast cancer cohort.

Spain) as CROM source and recording and PROM/PREM recording platforms.

- Statistical analysis software, the amount of data to be managed is going to grow exponentially and therefore is necessary to have professional statistical software to analyze the data. We have used the R package, an open-source software.
- Visualization software to construct dashboards for patients and cohort follow-ups, such as Power BI (Albuquerque, Nuevo México, USA) software or *ad hoc* tools as HOPES (Valencia, Spain) adapted and developed by IDIEIKON (Valencia, Spain) for CROM and PROM or PanelHealth (Madrid, Spain) for PREM.
- ICT Software for project management, coordination, and team communication: Microsoft TEAMS (Albuquerque, Nuevo México, USA) and Google Drive (Perth, Australia), Dropbox

(San Francisco, California, USA), Miro, Trello (New York, New York, USA), and Slack (Vancouver, Canada).

- Internal and external communication: Microsoft Office (Albuquerque, Nuevo México, USA), Slidesgo (Malaga, Spain), Powtoon (Londres, United Kingdom), Piktochart, Canva (Perth, Australia), and Pixabay (Berlin, Germany).

## RESULTS

### Patient Recruitment

At the cut-off time for the Cohort in August 2021 for the breast cancer project, 148 patients were included in the Cohort with an average age of 56 years. One thirty-six (91.9%) of the patients agreed and filled up the baseline PROM, and all the 57 participants with 6 months follow-up filled in the

**TABLE 1** | Budget impact of each professional role key for implementation.

Human resources	E	A	Person per year (Average estimated)	% Total HR (**)	% Adjusted HR (**)	% Total budget (**)	% Adjusted budget (**)
Medical condition leaders	X		1	29.07%	38.76%	20.10%	24.31%
Managerial leader		X	0.1	3.20%	0.00%	2.21%	0.00%
Communication manager	X		0.1	2.03%	2.71%	1.41%	1.70%
Project manager	X		0.5	10.17%	13.57%	7.04%	8.51%
Quality and Safety coordinator (15)	X		0.25	6.54%	8.72%	4.52%	5.47%
Process engineer or analyst		X	0.25	6.54%	8.72%	4.52%	5.47%
Data manager		X	0.75	10.90%	0.00%	7.54%	0.00%
Epidemiologist/data scientist	X		0.5	10.17%	13.57%	7.04%	8.51%
Case manager		X	0.75	10.90%	0.00%	7.54%	0.00%
ICT engineer	X		0.2	5.23%	6.98%	3.62%	4.38%
EHR referral	X		0.2	5.23%	6.98%	3.62%	4.38%

E, Essential (a must-have for the project); A, Advisable (needed for an optimal implementation). (\*) Salaries calculated within the Spanish socioeconomic context. (\*\*) Estimation for medium complexity projects. The complexity classification was developed with a Delphi study.

6-month questionnaire. The first 24 patients within the Cohort were followed for 1 year and filled in the 1-year follow-up questionnaire. For the lung cancer project, 110 patients were included in the Cohort and had an average age of 69 years. In this study, 98 (89.1%) of the patients agreed to fill out the baseline PROM. No patient has yet been followed for 6 months. In ARMD, patients are currently being recruited, and in IBD, the tools are still being adapted. During the 3 years, four projects were conducted with more than 200 patients included in the cohorts. Two of our physicians have collaborated in the expert panel for the COVID-19 ICHOM dataset and partially implemented it in the last year. The five projects before the piloting had engaged more than 70 professionals and around 30 patients for tools design and adaptation.

## Working Teams and Responsibilities

The workload was arranged in five teams with specific objectives for the implementation and skills of the team member, the managerial team (MT) focused on project advocacy and coordination; the technological team (TT) focused on technological integration and coordination with external technological partners; the cost-analysis team (CAT) focused on cost analysis and economic evaluation; the clinical team (CT) focused on process analysis, database and dataset agreement, and clinical interpretation of results. Finally, the data analytics and research team (DART) focused on quality of life and experience analysis. The average composition of the teams was 5–8 professionals.

## Improvement Cycle

More than 20 improvement actions have been identified. Three have been prioritized regarding the waiting time for chemotherapy, the image, and the patient information, clinical and organizational.

## Resources and Budget

From our experience, we have successfully applied for private funding for the projects, and we estimated the implementation costs. We assumed two main cost groups, one derived from

technological needs (hardware and software) and the second being human resources. As explained, human resources are classified as essential if their roles are compulsory for the project or advisable if they help improve the quality of the implementation, methods robustness, or quicken the process. Thus, we considered a total budget with costs derived from essential and advisable profiles participation the total budget; and an adjusted budget excluding the advisable profiles and including the essential ones exclusively. Using an *ad hoc* complexity assessment, we classified projects in low, medium, and high complexity since they implied different costs, due mainly to more or less human resources required.

From the total budget, hardware and software entailed 30.3% and human resources the 69.7%; in the adjusted budget, the technological resources consumed 35.6% of the total and human resources a 65.4%. The detailed weight was as follows. Eighty-six percentage (around 75,000 euros) of the technology investment was dedicated to software development (recording storage and data visualization platforms, database integration, dashboard design, and coding), and 14% (around 12,000 euros) was used to buy hardware and data analytics software.

**Table 1** shows the internal implementation costs; therefore, the horizon time for this budget is 18 to 24 months; the time estimated for implementing the innovation according to the complexity of the different medical conditions considered.

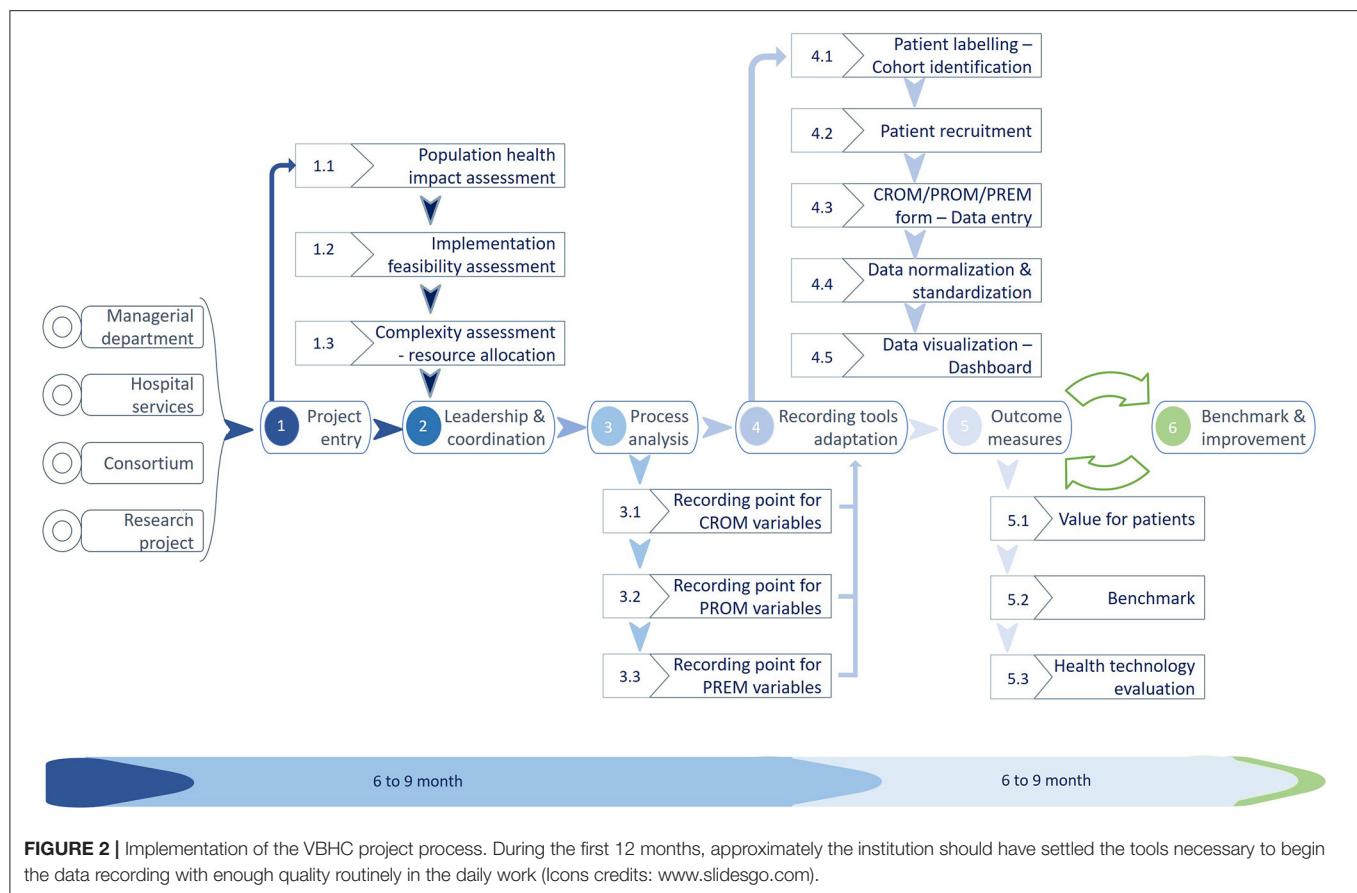
## RECOMMENDATIONS

### Implementation Process per Medical Condition

The implementation process had a duration that varied depending on the complexity of the Medical Condition. However, we estimate that the implementation phase will last a minimum of 18 and 24 months, depending on the medical condition's clinical process complexity.

For the sake of clarity, we have divided the timeline into semesters, from one to four. The first semester is the moment for inclusion of the medical condition in the implementation





procedure, analysis of the situation, resources estimation, and advocacy of the project within the CT, complexity, and feasibility evaluated. The tools for proper data recording and teams' coordination should be implemented during these months.

The following two semesters are the piloting phase that will help test the tools and evaluate the appropriateness of the innovation applied in this particular medical condition. During the four-semester, the institution has to introduce the innovations within the daily tasks of the clinical process (with minimum intervention of the project and data managers), to analyze the first-year data, and give feedback to the clinicians and patients with the evaluation of the health technology innovation proposed (DART and CAT). After that, the innovations should work out in the daily care process without incrementing the professionals' workload. However, there are at least 6 months for adaptation to the daily work.

**Figure 2** represents the proposed implementation process from the initial idea for a given medical condition until the end of the implementation. From there on, the implemented innovation should become part of daily healthcare.

### Instructions for Use: Process Steps

1. **PROJECT ENTRY:** The proposal to include a new medical condition usually came from the hospital services or the managerial department, a consortium such as ICHOM, or

a research project. Once proposed, the coordination team evaluates the population (9, 16, 17) and patient health impact (appropriateness of the innovation), and the feasibility of this particular project (feasibility of the project) in this particular moment of the institution. Once considered appropriate and feasible, the institution needs to estimate the resource allocation to make it available (complexity assessment). To do so, we developed two tools for complexity and feasibility assessment.

2. **LEADERSHIP AND COORDINATION:** The project coordinator usually manages more than one project and depends on the MT. It is advisable and normally done either by the Quality-of-Care Units or Innovation Units since the professionals have the necessary skills. Identifying the clinical leaders within the medical condition will be the next step. Both the MT and the project manager will be in charge of the task.
3. **PROCESS ANALYSIS:** Then the implementation team (including CT, CAT, and DART) has to focus on the variables and indicators validation, given healthcare coherence and utility, and once the specialist agrees, it is important to decide on adequate tools for data recording. The clinical process underlying any medical condition helps understand where the health information system data should be recorded and how and who is responsible (primary source) for the key data recording.

4. **RECORDING TOOL ADAPTATION:** Once consensus is obtained in what, by whom, and when each variable is recorded, the existing tools must be appropriately adapted for the task by the TT. Suppose there is no infrastructure for data recording within the institution. In that case, some external tools can be used and have to be integrated into the Health Information System (HIS) (e.g., PROM or PREM recording platforms). To the best of our experience, that is the trickiest part of the implementation. To collect clinical data, we developed specific forms within the electronic health record system to facilitate data recording by healthcare professionals. For the collection of PROM, the company HOPES has developed the technological infrastructure, and the company Whykers has developed the PREM and the recording tool PanelHealth.
5. **OUTCOME MEASUREMENT (PILOT):** No innovation is good or bad by design. It has to be evaluated and adapted for each case of use; therefore, after the adaptation and putting in place of tools and the Cohort's follow-up, a piloting phase offers the information to evaluate the innovation benefits, pitfalls, and issues.
6. **BENCHMARK AND IMPROVEMENT:** If the evaluation proves positive in terms of added benefits to the system and value to the patient, population, and professionals, it must be transferred from innovation to daily work and enter the cycle of continuous improvement.
2. Usable tools for both clinical practice and research without the need for double data recording.
3. Patients, provided with a forum to talk regularly and systematically with professionals and researchers
4. No information from the EHR is missing. It is advisable to enrich results with the exploitation of unstructured data.
5. Clear data-management governance.
6. Assured the real portability of the data.
7. Reduce unnecessary variability with the continuous improvement cycle based on real-world quality data.
8. Ensures comparability using common recording and analysis methods.
9. Systematic analysis of the data quality
10. Systematic generation of clinical dashboards (**Figure 1C**) and other decision aids for clinicians.

### Health Information System: Requisites, Adaptations, and Evolution

Data comes from several primary sources, clinicians, patients, and analytic software (such as laboratory information systems and cost information systems). All data were included in a central repository and shared with the DART and CT to fulfill their primary (health care of individual patients) and secondary (observational studies) objectives.

Once CT has agreed upon the dataset (CROM, PROM, and PREM), these variables are converted in a structured form for data recording and integrated with a system that allows data extraction and sharing. The next step is to enable cohort identification, labeling each patient individually in the Electronic Health Record (EHR). Thus, we can access the individual patient data to export and construct the indicators. Underneath the form, the data (and information) normalization system according to international standards (SNOMED, LOINC, ICD-10...) is autonomous from the professional intervention. This standardization would be the basis for comparison with other organizations.

The expected result is to have a new approach to data recording and availability for primary and secondary use of the information to improve the system and the health results (**Figure 3**).

### Anticipated Results

The anticipated results for the HIS and the process improvement are as follow:

1. Versatile and diverse data exploitation (outputs).

### New Interdisciplinary Professional Roles

Enrichment of the teams with interdisciplinary and science diversity is provided by hiring new professional specialties (bioengineers, epidemiologists, data analysts and data scientists, data managers, communication and negotiation experts, etc.) and by searching for mixed profiles capable of peer communication among disciplines, e.g., health professionals with a deep knowledge of artificial intelligence and engineers with a high understanding of the clinical process. **Table 2** resumes the professional profiles necessary for VBHC implementation. The common vocabulary and concepts make these mixed roles the perfect medium for peer communication and reducing the information gap or asymmetry between team members.

### Implementation Maturity Set of Indicators

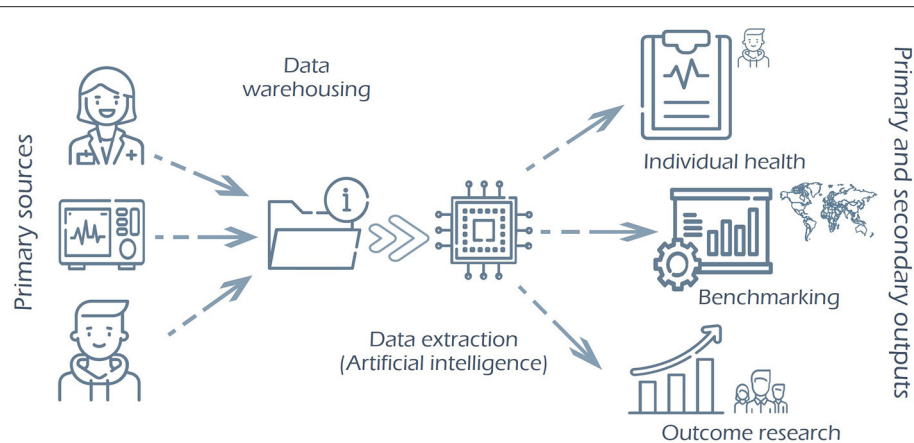
A set of indicators of implementation maturity have been developed; however, they have not yet been tested. The proposed set of indicators is as follow (**Supplementary Table S3–Supplementary Material**):

#### Implementation Process Quality

- Team diversity: Number of different knowledge areas included
- Professional engagement: Number of persons participating in the meeting x 100/persons invited to participate
- Patient engagement: Number of patients that fill up at least one PREM. The number of patients that fulfill at least one PREM x 100/Total patient on the Cohort.
- Performance of the continuous improvement cycle: Number of agreed compromises agreed in teams meetings x 100/total of improvements developed

#### Data Recording Quality

- Recruitment success: Number of patients included in the cohort x 100/total patients with inclusion criteria.
- First intention data fulfillment: Number of data recorded without data manager intervention x 100/all the data that should have been recorded.
- Data recording automation: Number of variables fulfill automatically per patient HER x 100/Total variables from the dataset (CROM).



**FIGURE 3 |** Expected evolution of the Health Information System (HIS). From the primary sources (clinician, diagnose or treatment machines, patients), data is warehoused in a central repository of information, normalized and standardized within an international standard. Thus, the data inside is shareable for multiple purposes, such as patient follow-up, benchmarking, or outcome research.

- Availability of the cost information: Costs available per patient/total costs considered in the cost dataset.

### Data Quality and Patient Follow-Up

- PROM Recurrence ratio: Number of patients that answer the previous PROM x 100/patients that answer the following PROM
- Follow-up calls: Number of follow-up calls made by the data manager both to patients and professionals

### Feedback and Improvement

- PROM utilization: Number of professionals access to the PROM x 100/total of professionals caring for the patients.
- Areas of improvement detection: Number of alerts identified
- Alerts response: Number of responses to an alert (e.g., schedule a new appointment with mental health once depression or anxiety levels rise in PROM) x 100/Total number of alerts
- Continuous improvement opportunities: Number of improvements derived from PREM and PROM analysis

### Managerial Implication

- Professional substitution: Days without a professional role (e.g., case manager) x 100/total of the professional leave days

## DISCUSSION: THE 10 LESSONS LEARNED

**ONE:** The main lesson is that implementing VBHC is not free of implementation costs, which means an investment of resources. In agreement with the results from Ackerman et al. (18), we found that a minimum amount of 90.000 euros was required to implement VBHC in medium to high complex medical conditions processes. The institution has to provide the human resources to coordinate, manage and communicate the project. It is important to implement and develop agile tools to understand the healthcare clinical management processes and the outcomes of each medical condition to patients and caretakers. It should facilitate the means to understand the experience of

the patients and their families along the healthcare process. It is important to have the human resources to develop and adapt the current Information and Communication Technologies (ICT) tools for the best quality data recording and exploitation in real-time to influence the cycle of the decision-making process with the patients.

**Two:** In the process of data appropriateness and data-recording tools adaptation for outcome measures within the local system, 6 months were spent for the first medical condition to be considered. During the second semester, a key milestone happened when the data of the first 100 patients were collected with the data manager's help. This information will first evaluate the innovation impact and appropriateness (project pilot), and the main technical problems will be identified and solved.

**Three:** The clinical process is the main structure of the healthcare assistance and the appropriated outcome measurement. Skills and knowledge in process managing and analysis are paramount.

**Four:** Clinical-reported outcomes measures (CROM) have to be normalized and standardized by international standards. Thus, the information of the clinical condition and the individual patient characteristics would be available for processing in real-time for both primary use (individual patient clinical management, economic evaluation, healthcare, quality, and safety management and studies) and secondary use (observational studies, clinical trials recruitment platforms, pragmatic clinical trials).

**Five:** The patient perspective is the core of the VBHC. Therefore, the role of the HIS for VBHC is paramount. Therefore, it is important to develop the PROM tools to evaluate the patients' and carers' quality of life and perceived quality. The main challenge for systematic data recording on health outcomes is to assure the baseline and follow-up of PROM and PREM since they cannot be recovered retrospectively by data managing or mining as the CROM can (if they have been appropriately recorded).

**TABLE 2 |** Professional profiles and competencies, skills and responsibilities; E, essential; A, advisable.

	E	A	Skills and competencies	Tasks and responsibilities	Timing
Leaders in the medical condition management	X		Highly specialized clinical knowledge in medical conditions. Interpersonal relationships and negotiation skills Communication	Project advocacy and internal communication within the team. Project results presentation in science forums	Whole implementation project
Managerial leader		X	Healthcare management Project management Negotiation and conflict solving skills Empathy and compromise	Project advocacy internally and externally, especially in managerial forums. Professional incentive program Projects performance follow up	The whole first year
Communication manager	X		Internal and external communication skills Persuasion	Diffusion and communication of the project and its milestones to the main stakeholders	The whole duration of the implementation
Project manager (implementation coordinator)	X		Project management Healthcare management Negotiation and conflict solving skills Empathy and compromise Data analytics understanding Process analysis skills	Coordinate the different teams to the same objectives Management and meeting optimization. Project milestones, deliverables, and schedule follow-up Document the project	The whole duration of the implementation
Quality and safety coordinator	X		Process analysis skills Coordination and negotiation skills Communication skills	Process analysis Patient archetype definition and identification Internal coordination	The whole duration of the implementation
Process engineer or analyst		X	Process analysis skills	Analyze the process Redesign the process (continuous improvement)	First semester
Data manager		X	Data Quality knowledge Data's Life cycle understanding	Patient cohort follow-up Request for the proper fulfillment of the variables	Second and third semester
Epidemiologist/data scientist	X		Analysis and data visualization	Design of the analysis and visualization tools. Analysis plan and interpretation of the results	Third and four-semester
Case manager		X	Clinical and care knowledge	Follow-up patients and attend to their care needs	Whole duration
ICT engineer	X		Data life cycle understanding Data interoperability and integration of databases ICT tools design and integration	Database integration Data models and archetypes definition Dataset codification and translation to different standardized models	First and second semester
EHR referral	X		Knowledge of the EHR management EHR modification of the software	Local adaptation of the need into the tools in the EHR	The whole first year

**Six:** The continuous improvement of the clinical conditions care process is the main objective of the VBHC framework. The PREM tools to evaluate the patient's subjective experience along the lifespan of care provided a fast and appropriate identification of critical improvement areas. Thus, we always accompany the VBHC implementation with PREM development. In parallel develop a professional-reported experience tool to evaluate the experience along their professional life should strengthen the project.

**Seven:** VBHC focus on real shared clinical and healthcare decision-making with a particular focus on the burden of treatment and the patient care plans. Developing the tools to analyze and visualize real-world data in real-time inpatient care is the leading resource for informed decision-making.

**Eight:** Another main objective of the VBHC is to establish a community of hospitals for best practices sharing and benchmarking, bearing in mind that it is not possible to adopt without an adaptation to the particular context of each institution.

**Nine:** We have also learned that data is, basically, imperfect and introduces bias in medical information. Thus, for data quality sake, the primary source should be the origin of the data in the system. Clinical information should be introduced by the clinician responsible for the data generation. If the information comes from analytical equipment, it should be imported directly, avoiding human interaction with the data recording. When data has to come from patients (or patient family), such as subjective data as symptoms or experience, it



should be introduced by patients to the system. That helps to reduce interpretation bias and improves data quality. It is the main advance introduced by PROM vs. traditional quality of life questionnaires.

**Ten:** In this process, especially during the first 6 to 12 months, someone has to be responsible for the cohort follow-up to increase the data collection, project coordination, and advocacy (19). These professionals need skills in the data life cycle, quality and safety, process analysis, and interpersonal communication. The professionals in the quality units, services or directions, usually have a high level of these skills.

It has been a bumpy road, but we have learned valuable lessons to implement similar projects along the way. To date, all our projects used the ICHOM datasets (20–23), including CROM and PROM. We have developed our own set of PREM. In conclusion, there is a need to reduce missing and unclear data in real life, ensure the relevant information recording systematically outcomes, and record data from the primary source (clinician, patient). Implementing innovations such as VBHC is not “free of charge.” On the contrary, essential implementation costs must be considered (24).

## DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Comité de Ética en investigación (CEIm)-Hospital Universitario 12 de Octubre. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

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CV-R has contributed to the conceptualization, main methodology, data extraction, check spelling data curation, writing and editing the original draft preparation, investigation, and supervision. AG-C has contributed to the conceptualization, check spelling, data curation, writing, and editing the original draft preparation. PR-L has contributed to the conceptualization and methodology of the article. BB-P has contributed to the data curation and critical review of the article. All authors have contributed to reviewing. All authors contributed to the article and approved the submitted version.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2021.755166/full#supplementary-material>

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# Disability Weights Estimates From India in 2018: Measurements From Community Members From Two Distinct States of India

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**Background:** India is undergoing a rapid demographic and epidemiologic transition. Thus demanding prioritization of diseases based on burden estimation is befitting our cultural diversity. Disability weights (DWs) by Global burden of disease (GBD) studies may not be representative. Hence, a study was conducted to estimate state-specific disability weights to capture the community health perceptions that included urban–rural settings as well as different socio-economic and literacy levels.

**Methods:** A total of 2,055 community members (participants) from two distinct states of India, Odisha and Telangana, were interviewed to assign disability weights to the selected 14 health states based on the state burden and relevance. Each health state was described to the participants using pictorial representations of the health states and valued using visual analog scale and card sort methods.

**Results:** We noted that DWs in Odisha ranged from 0.32 (0.30–0.34) for upper limb fracture due to road traffic accident (least severe) to 0.90 (0.88–0.93) for breast cancer (most severe) among the 14 health states. While, in Telangana, diarrhea was considered least severe [DW = 0.22 (0.19–0.24)] and breast cancer remained most severe [DW = 0.85 (0.83–0.88)] as in Odisha. Marked difference in the DWs for other health states was also seen. Further, on comparison of community weights with GBD weights using Spearman correlation, we observed a low correlation ( $\rho = 0.104$ ).

**Conclusion:** Our study provides community-based findings that show how participants valued noncommunicable diseases higher than short-term ailments or infectious diseases. Additionally, the low correlation between GBD also suggests the need for local disability weights rather than universal acceptance. We therefore recommend that decisions in policy-making, especially for resource allocation and priority setting, need to be based not only on expert opinion but also include community in accordance with high scientific standards.

**Keywords:** disability weights, global burden of diseases, health state valuation, community, India

## INTRODUCTION

In the last three decades, India has been experiencing a rapid epidemiological shift owing to the increase in aging population and structural changes in disease patterns (1). Such changes imply that it is essential to prioritize the health states based on their relative burden across the country to foster efficient policy planning and thereby an effective allocation of resources. The Global burden of disease (GBD) initiative by Murray et al. in the 1990s (2) was a major stride in this regard. The study introduced disability-adjusted life years (DALYs) as a single metric measuring the disabling power of any disease (in terms of mortality and morbidity) and enabled comparison across different health conditions to support evidence-based decision making (3). Disability weights (DWs), an essential component of DALYs, reflect the relative severity of health states as a scaled measurement. Computation of these DWs is broadly a two-step procedure. Firstly, it requires the quantification of different health states through a rigorous valuation or scoring by the valuers or respondents based on their perspective and understanding of a disease condition. This is usually done using different methods for health state valuation. Secondly, the scores obtained after health state valuation are used to arrive at the DWs through multiple computational approaches.

However, even over the years, the weights derived from the various GBD studies lack representativeness of the socially and educationally vulnerable populations. Though the GBD 2010 study addressed the criticism by reestimating the DWs after a valuation that tried to incorporate the opinions of socially and culturally diverse populations, a majority of respondents included in the survey had tertiary level education at least. Subsequently, various health state valuation studies have been conducted across the globe over the past decade to establish DWs using different health state valuation methods as person trade-off (PTO), time trade-off (TTO), paired comparison (PC), standard gamble (SG), and visual analog scale (VAS). Some of these studies have been described briefly in the **Table 1**.

Most of the studies listed in **Table 1** were conducted on the educated population using rather challenging methods of valuation, and the perception of the lesser educated or rural or urban poor was unaccounted for. Additionally, an important gap in the literature and survey design is helping respondents and policy-makers distinguish among several factors likely affecting the disability weight assigned to a condition, such as: its severity, duration, and availability of treatment. If the description of the disease state does not include these items, respondents in different contexts will likely have contrasting impressions and generate disparate disability weights. Further, studies also suggest that health is greatly influenced by socio-cultural differences as well as geographical variations and thus guided by the perception of the people. For a country as geographico-culturally diverse as India with a large population of lesser educated and rural inhabitants, it is bound to have manifold health perceptions. However, there is a paucity of community-derived disability weights, especially in India. A relevant study was done by Mahapatra et al. (11), in a single village of ~1,000 rural participants from Andhra Pradesh in India almost two

decades ago (in the year 2000) to establish community-derived disability weights. The tools and methods used require an urgent revision, refinement, and contextualization to the current societal changes and health states accounting for epidemiological and demographical transitions.

Hence, there is a vital requirement to focus on health state valuation of the general population for obtaining disability weights for health states that would be country- and state-specific that captured the community perception. Although Art and Science are entirely different from one another, they have been known to influence each other. One helps the other in creating knowledge that is distinct. However, when both are used together, the results enhance the value of the knowledge and the product. Through the use of visual analog scale method in our study, we used the opportunity to use visual graphics. Knowingly, we made use of art and science to add value to our study such that the information of the selected health states would aid the participants in better visualization and understanding. There is an urgent need to provide experts and laypersons alike tools that allow easy comprehension of health states and the means to help obtain disability weights. Thus, we conducted a study to estimate disability weights assigned by communities for various health conditions in two distinct states of India across different settings as urban and rural, as well as different socio-economic and literacy levels.

## METHODS

### Health States and Description

An array of health states was selected that represented the region- and country-specific diseases and injuries. A total of 14 health states were selected based on the state burden and relevance. Three individual exercises were undertaken to shortlist health states: (i) review of literature from PubMed, Institute of Health Metrics and Evaluation (IHME) databases; (ii) consultation with medical experts (primary care and specialist providers); (iii) community exploration in urban slums and rural pockets. The selection procedure attempted to encompass various health conditions that represented the broad spectrum of diseases and injuries afflicting human population, which were also assessed by the GBD studies. Hence the health states included: communicable, nutritional diseases, such as diarrhea, tuberculosis, malaria, anemia; noncommunicable diseases including mental health, such as diabetes, quadriplegia due to stroke, oral and breast cancer, osteoarthritis, asthma, schizophrenia, depression, alcohol use disorder; and injuries, such as upper limb fracture due to road traffic accident. Detailed explanation of the process has been published earlier (12).

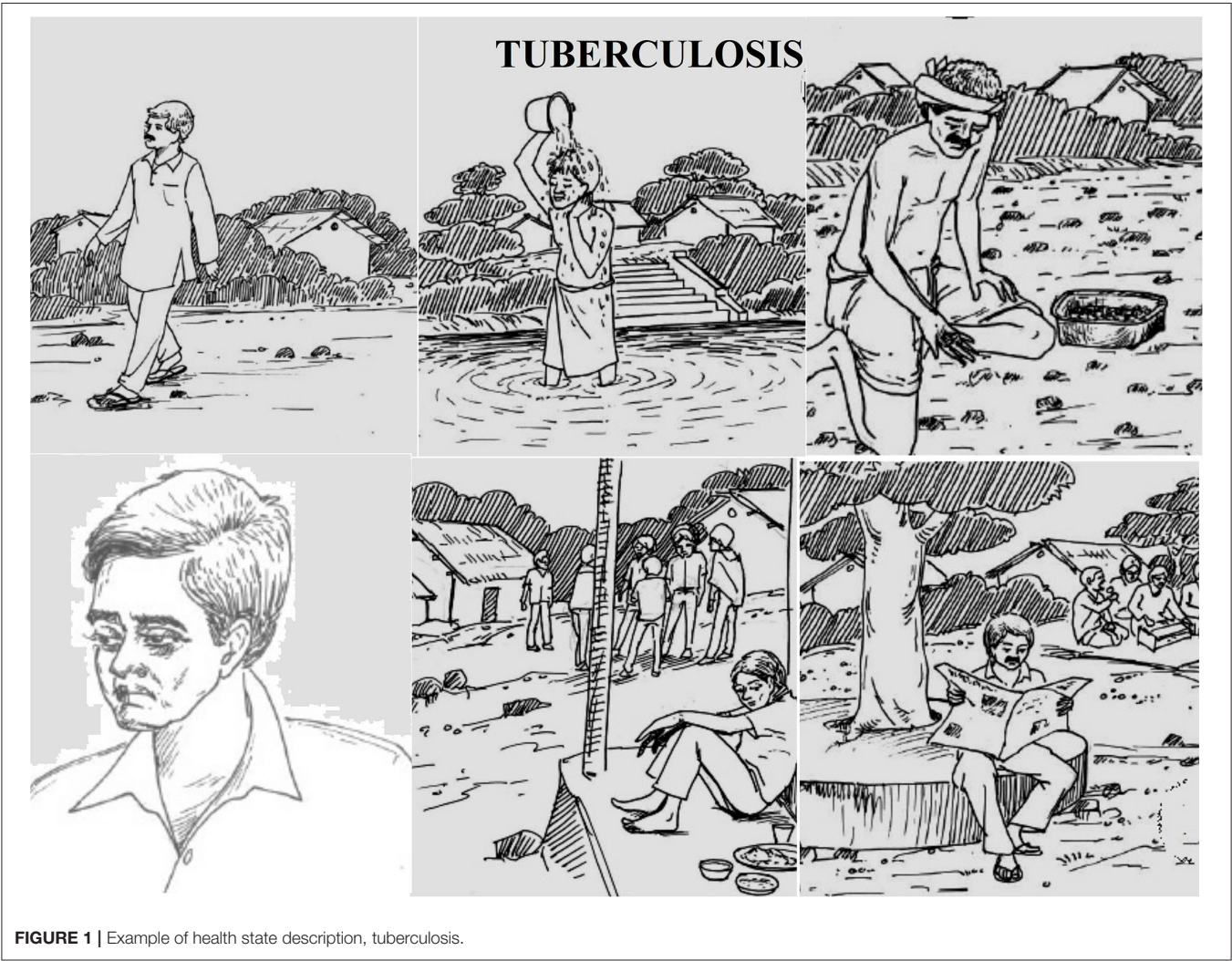
Each health state's descriptions were developed by means of thorough discussions with medical experts and team consensus. These descriptions included salient clinical symptoms characteristic of the given health state, along with the modified EuroQol EQ-5D+ (13, 14) instrument to further describe the health state's functional status. Six dimensions of EuroQol ("mobility," "self-care," "usual activities," "pain/discomfort," and "anxiety/depression" along with "cognition") were used



**TABLE 1 |** List of various health state valuation studies conducted across the globe and the valuation methods used.

S.no	Reference	Year	Health state description	Valuation method	Study population
1	Murray et al. (4)	1996	DS	PTO, VAS	Medical professionals
2	Stouthard et al. (5)	1997	DS+ EQ-5D	PTO, VAS	Medical professionals
3	Jelsma et al. (6)	2000	-	VAS	General population and medical professionals
4	Baltussen et al. (7)	2002	DS	VAS	Rural population and medical professionals
5	Schwarzinger et al. (8)	2003	DS+ EQ-5D	VAS, TTO, PTO	Medical and non-medical (educated) professionals
6	Haagsma et al. (9)	2008	DS+ EQ-5D	VAS, PTO	Educated population
7	Salomon et al. (10)	2012	DS(without labels)	PC	General population (mostly educated)

\*DS, disease specific; EQ-5D, Euro QOL 5 dimensions (functional status description); PTO, Person trade-off; TTO, Time trade-off; VAS, Visual analog scale; PC, Paired comparison.



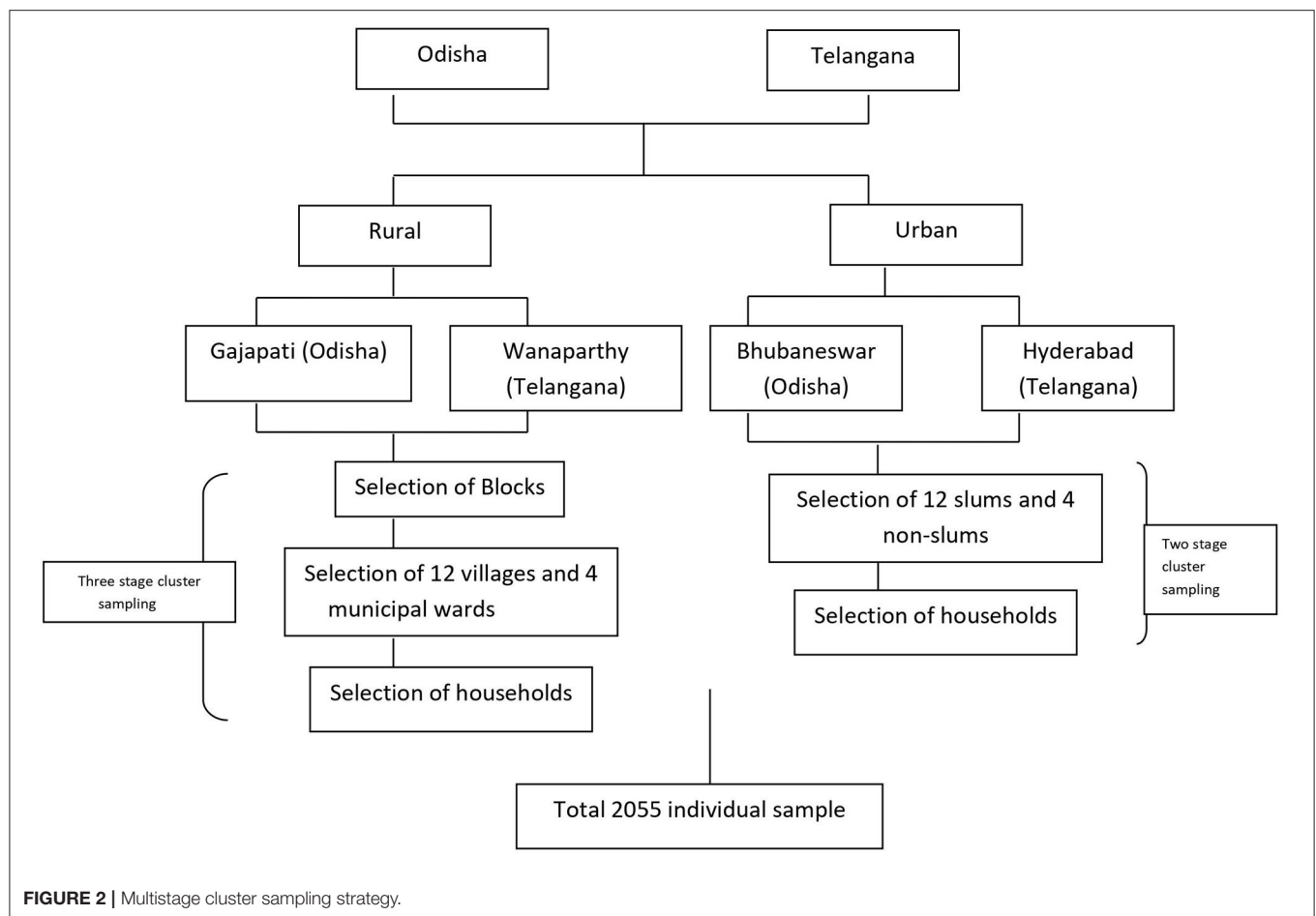
**FIGURE 1 |** Example of health state description, tuberculosis.

in the present study with three levels of severity in each dimension with 1 = no problem, 2 = some problem, and 3 = severe problem.

For instance, the health state “tuberculosis” was described according to cardinal symptoms, prognosis, treatment along with an image of functional status describing varying levels of each dimensions (**Figure 1**).

**Tuberculosis**  
**Clinical Description**

- Patient with:
- cough for more than 2 to 3 weeks (average 15 days)
  - hemoptysis
  - weakness



- fever
- under anti-TB treatment.

### Functional Status Description

- No problems in walking
- No problem in washing or dressing self
- Some problem with performing usual activities (work, study, housework, or leisure)
- Some pain or discomfort
- Moderately anxious or depressed
- No cognitive impairment (concentration, memory, orientation).

### Study Setting, Design, and Sampling

The study was conducted with community members (participants) from two distinct states of India, Odisha and Telangana. The neighboring states were purposefully selected due to their cultural differences with a focus on urban–rural dissimilarities. Hence Gajapati and Wanaparthy districts for rural, and state capitals Bhubaneswar and Hyderabad, from Odisha and Telangana were chosen, respectively. To ensure representation of community members, 2,055 individuals were sampled using a multistage-stratified cluster design to ensure the probability of selection proportional to population size. Hence,

a three-stage sampling technique for rural (12 villages and four wards including municipal corporations) and a two-stage for urban setting (12 slums and four non-slums) were adopted (Figure 2).

### Data Collection: Participants and Valuation Procedure

Previous studies suggest that cognitively less demanding methods as visual analog scale (VAS) (15, 16) are adept for generating scores used to calculate disability weights from individuals of varied backgrounds. Hence, we valued the proposed health states through the visual analog scale method after a warm-up exercise using card sort or ranking of diseases. The VAS method uses a continuous graduated line segment, one end labeled as “death” and the other labeled as “perfect health” ranging from 0 to 100. It allows the user to rate a particular health state between the mentioned anchor points. The card sorting exercise further helped to strengthen the process of arriving at the final VAS scores through various iterative rounds.

The community survey was done through face-to-face interviews with consenting participants from February to May 2018 by trained public health researchers in the preferred local language of the participants (Odia and Telugu). Community

members residing in the selected location, aged 18 years, and above with an acceptable level of cognitive functioning who provided their written consent were included in the study.

To reduce cognitive burden during the valuation process, every participant valued 11 health states including location- and gender-specific diseases.

The valuation process was divided into two parts:

1. After the participant valued their “own health”, individual health states were read aloud and they were asked to rank the health states in their preferred order of severity, starting with the less severe between 1 and 5, and more severe between 6 and 11.
2. The participants were then asked to rate proposed health states on a scale ranging from 0 to 100, where 0 indicates “undesirable health state” and 100 “most desirable health state”.
3. Iterations were conducted by the participant until harmonization between card sort ranking and VAS scores were acquired. “Final” scores were noted in the data sheets.

## Data Analysis

Quantitative data analysis was done using R version 3.2.2. Descriptive statistics of the socio-demographic participant profile are presented with frequency and percentage. Further, considering the complex nature of the study design, survey means of disability weights with 95% confidence intervals (CI) were computed using the VAS scores.

Computation of disability weights (DWs) was done using the formula:

$$DW = 1 - VAS/100$$

Significance tests for comparisons across states, locations (rural and urban), age groups, gender, literacy level, and socio-economic status was done using the analytical statistics. *P*-values below 0.05 were considered statistically significant. Additionally, disability weights derived from this study were compared to those obtained from the global burden of diseases using the Spearman rank correlation.

## Ethics Consideration

The study was approved by the Institutional Ethics Committee of the Indian Institute of Public Health, Bhubaneswar vide IEC no. IIPH/IEC/2017/20. Informed consent was obtained from all participants.

## RESULTS

Socio-demographic profile of the participants interviewed in the study has been presented in **Table 2**. A total of 2,055 participants were recruited for the study from the two states among which a higher proportion of men from Telangana and a higher proportion of women from Odisha were interviewed. The majority of participants belonged to the age group of 18–34 years, were Hindus, and belonged to the advantaged caste in Odisha as compared to almost half of the participants (47.5%) in Telangana that belonged to the lesser advantaged castes. More than 70%

**TABLE 2 |** Socio-demographic profile of the participants.

Categories	Odisha (N = 1,013)	Telangana (N = 1,042)
<b>Age (in years) n (%)</b>		
18–34	461 (45.5%)	478 (45.9%)
35–54	400 (39.5%)	469 (45.0%)
55 and above	152 (15.0%)	95 (9.1%)
Mean age (Range)	37.9 (18–80)	36.8 (18–75)
<b>Sex n (%)</b>		
Male	479 (47.3%)	518 (49.7%)
Female	534 (52.7%)	524 (50.3%)
<b>Literacy n (%)</b>		
Literate	802 (79.2%)	733 (70.3%)
Illiterate*	211 (20.8%)	309 (29.7%)
<b>Income contribution n (%)</b>		
Contributing	540 (53.3%)	639 (61.3%)
Non-contributing	136 (13.4%)	87 (8.4%)
Homemakers	337 (33.3%)	316 (30.3%)
<b>Religion n (%)</b>		
Hindu	766 (75.6%)	941 (90.3%)
Muslim	47 (4.7%)	74 (7.1%)
Christian	199 (19.6%)	23 (2.2%)
Others#	1 (0.1%)	4 (0.4%)
<b>Caste** n (%)</b>		
General	453 (44.7%)	171 (16.4%)
Scheduled caste	78 (7.7%)	318 (30.5%)
Scheduled tribe	302 (29.8%)	58 (5.6%)
Other backward class	180 (17.8%)	495 (47.5%)

\*, \*\*Definition according to Census and NFHS (National family health survey); # includes Jains, Buddhists, Sikhs.

participants were literate, and one-third were homemakers in both the states.

Further as seen in **Table 3A**, the survey mean disability weights in Odisha and Telangana with urban and rural locations have been shown. We noted that DWs in Odisha ranged from 0.32 (0.30–0.34) for the upper limb fracture due to road traffic accident (least severe) to 0.90 (0.88–0.93) for breast cancer (most severe) among the 14 health states, while, in Telangana, diarrhea was considered least severe [DW = 0.22 (0.19–0.24)] and breast cancer as most severe [DW = 0.85 (0.83–0.88)], similar to Odisha. We also noted that a marked difference in the DWs for alcohol use disorder was perceived as more severe by the communities in Odisha [DW = 0.73 (0.71–0.76)] as compared to Telangana [DW = 0.52 (0.50–0.55)]. Communicable diseases, such as tuberculosis, were considered moderately severe across both the states with almost negligible differences [Odisha: DW = 0.59 (0.57–0.62), Telangana: DW = 0.57 (0.55–0.60)]. Further, two mental disorders, depression and schizophrenia, were included in the list of health states. Depression was valued by the rural participants and was considered more severe in Odisha [DW = 0.63 (0.60–0.63)] and comparatively less severe in Telangana [DW = 0.57 (0.66–0.58)]. However, DWs for

**TABLE 3A |** State-wise survey mean disability weights across urban and rural locations.

Health states	Odisha (N = 1,013)			Telangana (N = 1,042)		
	Urban survey mean (95% CI)	Rural survey mean (95% CI)	Pooled mean (95% CI)	Urban survey mean (95% CI)	Rural survey mean (95% CI)	Pooled mean (95% CI)
Tuberculosis	0.55 (0.54–0.57)	0.63 (0.60–0.67)	0.59 (0.57–0.62)	0.57 (0.54–0.61)	0.56 (0.55–0.59)	0.57 (0.55–0.60)
Diabetes	0.52 (0.49–0.55)	0.56 (0.54–0.58)	0.54 (0.52–0.56)	0.54 (0.52–0.56)	0.56 (0.55–0.57)	0.55 (0.52–0.57)
Diarrhea*	0.34 (0.32–0.35)	0.48 (0.43–0.52)	0.40 (0.38–0.43)	0.21 (0.19–0.23)	0.22 (0.20–0.24)	0.22 (0.19–0.24)
Anemia*	0.44 (0.42–0.46)	0.63 (0.58–0.68)	0.53 (0.51–0.56)	0.48 (0.45–0.51)	0.44 (0.42–0.47)	0.46 (0.44–0.48)
Breast cancer*	0.90 (0.88–0.92)	0.91 (0.89–0.93)	0.90 (0.88–0.93)	0.83 (0.81–0.86)	0.87 (0.86–0.88)	0.85 (0.83–0.88)
Malaria*	0.36 (0.34–0.38)	0.45 (0.38–0.54)	0.41 (0.38–0.43)	0.30 (0.28–0.33)	0.30 (0.29–0.31)	0.30 (0.28–0.33)
Asthma*	0.57 (0.53–0.61)	0.59 (0.57–0.62)	0.58 (0.56–0.60)	0.50 (0.48–0.51)	0.51 (0.49–0.52)	0.50 (0.48–0.52)
Alcohol use disorder*	0.69 (0.66–0.72)	0.78 (0.76–0.80)	0.73 (0.71–0.76)	0.50 (0.48–0.51)	0.55 (0.51–0.59)	0.52 (0.50–0.55)
Fracture*	0.33 (0.30–0.372)	0.31 (0.26–0.36)	0.32 (0.30–0.34)	0.50 (0.47–0.54)	0.54 (0.51–0.57)	0.52 (0.50–0.55)
Stroke	0.80 (0.78–0.81)	0.84 (0.83–0.85)	0.82 (0.79–0.84)	0.80 (0.78–0.83)	0.81 (0.80–0.82)	0.81 (0.79–0.83)
Oral cancer*	0.88 (0.86–0.90)	0.88 (0.87–0.89)	0.88 (0.86–0.90)	0.80 (0.77–0.81)	0.83 (0.80–0.86)	0.81 (0.79–0.84)
Depression	NA**	0.63 (0.60–0.67)	0.63 (0.60–0.65)	NA	0.57 (0.55–0.59)	0.57 (0.55–0.58)
Schizophrenia	0.64 (0.60–0.67)	NA	0.64 (0.62–0.66)	0.66 (0.62–0.71)	NA	0.66 (0.64–0.69)
Osteoarthritis*	0.32 (0.28–0.36)	0.43 (0.37–0.50)	0.38 (0.35–0.40)	0.48 (0.46–0.50)	0.49 (0.46–0.53)	0.49 (0.46–0.51)

\*The pooled mean disability weights for Odisha and Telangana were found to be statistically significant ( $p < 0.05$ ) in these health states.

\*\*Depression was valued only by rural inhabitants whereas Schizophrenia was valued only by urban inhabitants; 95% CI; 95% confidence interval.

schizophrenia did not show any marked difference across the two states.

Further as seen in **Table 3B**, all the health states were perceived to be less severe in urban areas than the rural areas. For instance, DW for anemia was 0.46(0.45–0.53) in urban locations whereas 0.53(0.45–0.53) in rural locations because city people may be taking into account better access to healthcare services.

A Spearman-rank order correlation test was done to compare the DWs obtained from our study and the GBD 2015 study, as seen in **Table 4**. We observed that when the community weights were compared to GBD 2015 weights, the correlation was found to be low ( $\rho = 0.104$ ). However, the Spearman-rank order correlations between the two states were high as well as statistically significant ( $\rho = 0.82$ ,  $p = 0.0002$ ), indicating a similar rank ordering.

## DISCUSSION

Results from our pioneering community-based Health State Valuation (HSV) method could establish that through the use

of simple and easy-to-use valuation methods DWs for health states can be estimated with high levels of overall concordance across diverse communities, representing to a large extent the heterogeneity of the Indian population. Therefore, DWs can be used to estimate national and subnational disease burden(s) in the Indian context. By using art and science through the use of visual analog scale method and the individual images of functional status describing varying levels of each dimension of a health state, we believe our study has added value in assessing disability weights among populations with mostly lower levels of education.

To prioritize health research and interventions, donors and countries need to have concrete and reliable data in terms of the burden of diseases. The 1990 GBD study was an important step toward DW calculation and burden estimation (17). However, in later GBD studies, until almost a decade ago, the perspective of professional healthcare providers was assumed to be representative of the society's preferences with regard to resource allocations in health care. Gradually, it was realized that health as well as healthcare are greatly influenced by an individual's perception, education, culture, environment, and life



**TABLE 3B |** Mean disability weights for different health states across Location (urban/rural).

Health states	Urban survey mean- (95% CI)	Rural survey mean- (95% CI)	p-value
Tuberculosis*	0.56 (0.56–0.59)	0.59 (0.56–0.59)	0.0000
Diabetes*	0.52 (0.53–0.55)	0.56 (0.53–0.55)	0.0000
Diarrhea*	0.27 (0.25–0.35)	0.34 (0.25–0.35)	0.0000
Anemia*	0.46 (0.45–0.53)	0.53 (0.45–0.53)	0.0000
Breast cancer*	0.86 (0.86–0.89)	0.88 (0.86–0.89)	0.0038
Malaria*	0.33 (0.31–0.39)	0.35 (0.31–0.39)	0.0000
Asthma*	0.52 (0.51–0.56)	0.54 (0.51–0.56)	0.0853
Alcohol use disorder*	0.59 (0.57–0.67)	0.65 (0.57–0.67)	0.0002
Fracture	0.42 (0.37–0.47)	0.42 (0.37–0.47)	0.3460
Stroke*	0.80 (0.80–0.82)	0.82 (0.80–0.82)	0.0001
Oral cancer*	0.84 (0.82–0.86)	0.85 (0.82–0.86)	0.2100
Depression	NA	0.65 (0.62–0.68)	-
Schizophrenia	0.65 (0.62–0.67)	NA	-
Osteoarthritis*	0.40 (0.40–0.45)	0.46 (0.40–0.45)	0.0000

\*The pooled mean disability weights were found to be statistically significant ( $p < 0.05$ ) in these health states.

Depression was valued only by rural inhabitants whereas Schizophrenia was valued only by urban inhabitants; 95% CI; 95% confidence interval.

**TABLE 4 |** Comparison of the community disability weights with GBD 2015 weights.

Group 1	Group 2	Spearman correlation ( $\rho$ )	p-value
Community	GBD	0.104	0.721
Odisha	Telangana	0.823	0.0002*

\* $p < 0.005$ .

experiences, across communities, states, countries, and regions (18). Hence, the weights obtained from GBD studies were not regarded universally representative and garnered criticism across the world (19). Moreover, for allocation of resources or designing interventions intended for the marginalized population, DWs needed to be accurate and representative of the community. Therefore, to address this gap in developing countries, a study by Mahapatra et al. in 1999 was conducted in a village in Andhra Pradesh to obtain India-specific disability weights (11). Though the study was able to capture location-specific DWs, the cultural diversity of our country, with the changing disease patterns and the rising burden of NCDs, urgently required an update on the local DWs. People belonging to different social status, education level, and health state have different perceptions regarding health (18). Hence, our study is pilot in nature and thus an initial attempt to assess community disability weights for selected health states that varied in terms of severity across different locations and covered a varied population from different sections of the society, including the urban slums and rural areas.

Through the use of simple and easy-to-use valuation methods, we were able to successfully achieve high levels of overall concordance across diverse communities that represented a

heterogeneous mix of the population. Similar to the GBD 2010 disability weights measurement study, our study aspired to quantify health loss as opposed to welfare loss (19). The extra-welfarist approach was used in our study, which considers health as the descriptive entity of the people (11). This approach allowed for the use of rating scales as the visual analog scale for the measurement of disease severity and establishing DWs. Previous studies have shown clear cultural differences in the ways people perceive health problems and how such problems affect their lives. This was endorsed by Üstün et al., who found significant differences in the ranking of health states between 14 countries (20). Furthermore, the findings from Jelsma et al. and Baltussen et al. suggest that the effect of cultural differences on health perceptions should be reflected in the DWs as well, and hence there is a need to develop socio-culturally contextualized weights (7).

In our study, disability weights obtained for different health states were more or less universal, in the sense of being uniform or similar across locations, states, and cultures. Card sort and visual analog scale methods were thus chosen rather than the cognitively demanding methods (15, 16) that usually include specialists. The health state with most the variability in terms of DWs was alcohol use disorder (AUD) with a DW of 0.73 in Odisha as compared to a lower disability weight of 0.52 in Telangana, suggesting that AUD was perceived as less severe in Telangana. Similarly, upper limb fracture due to a road traffic accident was considered as more severe in Telangana (DW = 0.52) than in Odisha (DW = 0.32). Probable reasons that affected the perception could be awareness and availability of treatment in both the states that vary greatly. This divergence reflects how the local context and culture shape disability perception of communities. Further, for health states affecting physical conditions such as quadriplegia due to an episode of stroke or osteoarthritis, the DWs were more uniform than the mental health states across states and locations (18). We also note that although there were significant differences between health states, the factor regarding the duration (acute vs. chronic) should also be noted, as health states with shorter duration were most often than not scored with a higher disability weight. Additionally, due to the small sample size of non-slum participants (130 out of 2,055), our study has presented a limitation for exploring differences between slum and non-slum populations. We also highlight that a disadvantage of using a less cognitively challenging tool such as VAS gives higher values than that from choice-based valuation methods.

Our study provided the evidence based on disability weights derived from community settings for comparison with the GBD disability weights since the valuation of health states was highly correlated across the two states in the study. Furthermore, our pilot disability weight study covered relevant health states that are required for updating the burden of disease study in the country and can be used for the next GBD as well. However, the present methodological pilot attempted to capture DWs of two neighboring Indian states. Additional research, especially of qualitative nature, is needed to gain greater insight into the effects of cultural differences on disability weights,

particularly across the country in varied settings. Further, studies should intend to include the entire spectrum from noninfectious, non-contagious conditions to highly infectious, noncommunicable, and nationally relevant health states that would be a great value addition to the national disease burden estimates and health policies.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The study was approved by the Institutional Ethics Committee of the Indian Institute of Public Health, Bhubaneswar vide IEC no. IIPH/IEC/2017/20. Informed consent was obtained from all participants. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

EL, SA, CS, and RR were involved in the conception and design. EL and SA were involved in drafting of paper. EL and AD

were involved in the revision of the manuscript. LN and GM were involved in critical analysis of the paper. All authors have approved the final version of the article submitted.

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## SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2022.752311/full#supplementary-material>

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# Strengthening Community Participation by People With Disabilities in Community-Based Group Homes Through Innovative Action Research

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In the US and beyond, a paradigm shift is underway toward community-based care, motivated by changes in policies, payment models and social norms. A significant aspect of this shift for disability activists and policy makers is ensuring participation in community life for individuals with disabilities living in residential homes. Despite a U.S. government ruling that encourages community participation and provides federal and state funding to realize it, little progress has been made. This study builds on and integrates the expanded model of value creation with relational coordination theory by investigating how the resources and relationships between care providers, adults with disabilities, family members, and community members can be leveraged to create value for residents through meaningful community participation. The purpose of our community case study was to assess and improve the quality of relationships between stakeholder groups, including direct care staff and managers, residents, family members, and the community through an action research intervention. This study took place in a residential group home in a Northeastern US community serving adults with disabilities from acquired brain injury. A pre-test post-test design was used and quantitative assessments of relational coordination were collected through electronic surveys, administered at baseline, and post-intervention. Direct care staff, supervisors, the house manager, and nursing staff completed the survey. Qualitative data were collected through focus groups, change team meetings, and key informant interviews. Direct care staff formed a change team to reflect on their baseline relational coordination data and identified the weak ties between direct care staff, family members, and the community as an area of concern. Staff chose to hold a community-wide open house to provide an opportunity to foster greater understanding among staff, residents, family, and community members. The change team and other staff members coordinated with local schools, business owners, town officials, churches, and neighbors. The event was attended by 50 people, about two-thirds from the community. Following the intervention, there was an increase in staff relational coordination with the community. While statistical significance could not



be assessed, the change in staff RC with the community was considered qualitatively significant in that real connections were made with members of the community both directly and afterwards. Despite a small sample size, a residential setting where management was favorable to initiating staff-led interventions, and no comparison or control group, our small pilot study provides tentative evidence that engaging direct care staff in efforts to improve relational coordination with community members may succeed in building relationships that are essential to realizing the goal of greater participation in community life.

**Keywords:** community participation, residential facilities, long term care, relational coordination, action research, Olmstead decision, direct care staff, people with disabilities

## INTRODUCTION

In the US and beyond, a paradigm shift is underway toward community-based care, motivated by changes in policies, payment models, and social norms. People with disabilities are being cared for in residential group homes rather than large institutional settings with the goal of enhancing their participation in community life (1). This shift to community living is allied with general principles of The Convention on the Rights of Persons with Disabilities (CRPD) that call for the full and effective participation and inclusion in society of all people.

In the US, the 1999 Olmstead decision, as part of the Americans with Disabilities Act (ADA), required that services for people with disabilities be provided in the most integrated settings possible (2). This was a landmark decision for disability rights, and states were required to develop Olmstead Plans to indicate how they would meet these requirements. An analysis of these plans, however, found that the main focus was on medical services and activities of daily maintenance, rather than on plans to involve residents in community planning and social activities that could facilitate their participation in community life (2, 3).

To more fully meet the Olmstead mandates, a broader paradigm shift from person-centered to relationship-centered care is required (4) through an expanded model of value co-creation across all those who care for the individual (i.e., care providers, family, etc.) and across different contexts (i.e., within the home and within the community where the home is located) (5, 6). Person-centered care means learning and supporting the values, preferences, and goals of care recipients and placing the care recipient at the center of dynamic relationships among his or her caregivers (7). Centering the care recipient enables their expertise and experiences to be a part of the process of providing high quality care (8). To fully achieve the Olmstead vision requires an expanded focus on the quality of relationships among all involved in the care process, including the caregivers, the care recipient, the family and members of the broader community (9). It is not sufficient to focus only on the micro-level (i.e., the environment within the home); a focus on community-level and societal-level factors that play a role in facilitating or limiting participation is also needed (10).

First-person accounts of what full community participation means to individuals with disabilities have informed policy discussions (10, 11). In addition to the physical aspects of

community integration, individuals with disabilities care about the social and psychological aspects of community integration (12). A participant in the Angell et al. (11) study emphasized the importance of social connections: “It just feels better when you’re being with people and being a part of something” (p. 5). Other first-person accounts note the importance of acceptance and casual connections to others in the neighborhood (13). Study participants have emphasized opportunities for social activities as a way of forming and maintaining social relationships (14). In our specific study context, three prior research projects found that residents consistently valued opportunities for social interaction both inside and outside their group home (15–17). One study used the visual action research method known as photovoice to increase awareness of environmental factors impacting the community integration of older adults with acquired brain injury (17). Residents have identified independence, relationships, and meaningful things to do as the key aspects of community integration and acknowledged that they require support from others to realize their community participation goals (17).

## CONTEXT AND AIM

### Relational Coordination as an Approach to Strengthen Community Participation

Addressing these social and psychological aspects of community integration can be particularly challenging (10). Relational coordination theory deepens our understanding of relationship-centered care, its outcomes, and how it is achieved (18). Relational coordination is communicating and relating for the purpose of task integration and has been associated with a wide range of positive outcomes including quality and safety outcomes [e.g., (19, 20)], efficiency and financial outcomes [e.g., (21, 22)], staff well-being [e.g., (23, 24)], family well-being [e.g., (25)], and learning and innovation [e.g., (26)].

Research shows that many of these positive outcomes cannot be achieved by formal care providers alone (27). Relational coordination theory has thus expanded to include coordinating care with clients and their families, especially when care is delivered across multiple settings (28). Relational coordination between care providers and family members positively predicts care recipients’ psychological well-being and clinical outcomes (28) and family members’ quality of life (25). Relational

coordination between care providers and care recipients has also been shown to predict the well-being of people with a range of care needs [e.g., (29)].

To integrate care recipients into the community, as mandated by the Olmstead Act, we expect that relational coordination may also need to be strengthened with the community. We know that direct care providers impact residents' quality of life (15) and their community participation (30). But there is little evidence regarding the strength of relational coordination between direct care providers and the community, and how to design interventions to strengthen coordination when needed. We expected that relational coordination might be relatively weak in the context of community-based residential care for people with disabilities due to some community members' discomfort with people who have disabilities (11). Differences in the ethnocultural background and language between staff of color and the communities in which they work may pose a further obstacle to relational coordination (31). Finally, when direct care staff are recent immigrants, ingrained cultural behaviors such as appropriate ways to interact with strangers may pose yet another obstacle to relational coordination (32).

In this paper, we describe a pilot study designed to assess and strengthen relational coordination between direct care staff and residents, families, and local communities. The work was guided by the Relational Model of Organizational Change which proposes that interventions can be designed to strengthen relational coordination among diverse stakeholders in order to achieve desired outcomes (33).

## METHODS

### Setting and Population

The context for this study is residential care for people with disabilities associated with acquired brain injury (ABI). The benefits of community participation for people with chronic ABI include reduced mortality, slower rates of decline in cognition and physical function, lower drug use, reduced use of health services, and improved well-being (34). Since 2002 when the World Health Organization established a conceptual framework for functioning, disability and health (ICF) (35), the goal of community participation by people with disabilities has become a near-universal norm. Although the ICF conceptual framework encompasses both personal and environmental factors related to community participation, the impact of environmental factors on participation of people with disabilities in community-based group homes has received little attention.

### Study Design

The purpose of our community case study was to assess and improve relational coordination between stakeholder groups, including direct care staff and managers, residents, family members, and the community through an action research intervention. We utilized aspects of case study methodology tailored to program evaluation (36) and action research in health care settings (37). True to the action research approach, the project sought to investigate and improve practice through

working collaboratively with staff to plan and evaluate new ideas and introduce innovations.

This pilot study used a pre-test post-test design in a community-based residential care site. Quantitative assessments of relational coordination were collected through electronic surveys, administered at baseline and post-intervention. Direct care staff, supervisors, the house manager, and nursing staff completed the survey. Qualitative data were collected through focus groups, change team meetings and key informant interviews to inform the change process and interpret quantitative findings. Direct care staff at the selected site were invited to form a change team to reflect on their baseline relational coordination data, identify areas of concern, and develop and implement an intervention to address them. The study protocol was approved by the Brandeis University Human Research Protection Program. In addition, the study protocol was also approved by the Research Review Committee at the Massachusetts Department of Developmental Services.

### Site Selection

Two of the four group homes for people with disabilities from acquired brain injury operated by a non-profit organization were considered for participation. To be eligible, a site had to meet four criteria: at least 2 years of operation, high quality of care as suggested by a lower staff turnover rate than the industry norm, full occupancy, and management willingness to support the study. Only two sites within the non-profit organization met all four criteria during the recruitment period. The paper will describe the study experience and community intervention developed in one of them. Although consideration was given to including the site that was not selected as a control or comparison site, the research team decided against this approach. Having a traditional control site would have required random assignment to two different sites which thwarts the participatory approach taken. In addition, looking at the second site as a comparison site would be comparing very different interventions making it hard to assess what additional insights would be gained. The second site identified a different problem to solve based on data gathered by the Relational Coordination (RC) survey. Staff discussion of those results yielded a different intervention.

The site selected was in a middle to upper-middle class suburban setting. Sixteen residents live in the home, which is located next to the community's downtown, including stores, coffee shops, the public library and near a small nature reserve with disability access. The residence was grandfathered from the current Medicaid requirement limiting group homes for individuals with ABI to four residents. Each resident has a private room and bathroom, shared dining and activity areas, and an adaptive exercise area on site.

### Recruitment

Following site selection, the research team conducted informational meetings with staff (i.e., direct care staff, supervisors, nursing staff, and managers) to introduce relational coordination concepts and extend an invitation to participate in the study. All staff received an email invitation to complete the baseline survey, as well as an invitation to participate on

the change team. Surveys were administered online and de-identified by a third party to ensure anonymity. Staff members each received a \$25 gift card upon survey completion. The rate of staff participation was 79% (15/19) at pre-test and 74% (14/19) at post-test.

The importance of ensuring that participation was voluntary informed the recruitment processes. Several approaches were taken to be clear that staff could participate or not (or participate occasionally) and that their decision regarding participation would not influence their job or future opportunities. All messaging about the project emphasized this. In addition, the fact that recruitment was continuous supported this message. Staff who did not participate in the early stages were invited again to participate as the project moved forward. There was an open invitation to participate throughout the life of the project.

A focus group was held to share baseline survey results with staff and gain their perspectives on those results. Facilitators described response rates and findings about relational coordination. The RC results indicated that timely communication and shared knowledge had the lowest scores, especially with the community. The focus group questions then asked: (1) What does community mean to you? (2) How does it feel to be in the community with residents? and (3) what can be done to change these experiences?

All members who attended the focus group were invited to join the change team. The change team's role was to discuss baseline results in-depth, define problems, and develop possible remedies to correct them. Change team meetings were held during the afternoon shift change to allow for greater participation and were facilitated by a research team member. Staff received a \$15 gift card for each focus group or change team meeting attended.

## Sample

The sample was drawn from staff at the site. Two staff were in leadership positions, the house manager and a manager who oversaw several other residences for people with disabilities from acquired brain injury (ABI). Three-quarters of staff were fulltime, the rest were part-time and no one was employed casually. A total of 19 staff were employed when the project began and when it ended; 15 (79%) completed the baseline survey and 14 (74%) completed the post-intervention survey. **Table 1** shows the response rate at baseline and post intervention by participant role. The direct care staff at the residence had worked there for 4 years on average and in residential care or human services for more than 6 years on average.

Socio-demographics of survey respondents at baseline (direct care staff, nursing staff, supervisors, and managers) are summarized in **Table 2**. Forty percent of respondents were female. Most of respondents had completed a bachelor's degree or higher and had worked in other professions in their countries of origin (e.g., accounting, education, social work, and music). Respondents had a median of 5 years of experience in direct care. About half of respondents were native English speakers from English-speaking countries in Africa. Three quarters of respondents worked full time.

**TABLE 1 |** Response rate by participant role.

Participant role	Baseline ( <i>n</i> = 15) <sup>†</sup>	Post-intervention ( <i>n</i> = 14)
Direct care staff	11 (73.3%)	11 (73.3%)
Program director	1 (100%)	1 (100%)
Program nurse	2 (100%)	2 (100%)
Residential supervisor	1 (100%)	0 (0%)

<sup>†</sup>Response rate percentage were calculated using the total number of staff members eligible/invited (*N* = 19).

**TABLE 2 |** Staff demographics.

Characteristics	Participants ( <i>n</i> = 15)	(%)
<b>Age</b>		
18–44 years old	9	(60.0%)
45–64 years old	6	(40.0%)
<b>Gender</b>		
Female	6	(40%)
Male	9	(60%)
<b>Education</b>		
Associate degree or less	8	(53.3%)
Bachelor's degree or higher	7	(46.7%)
<b>Management<sup>a</sup></b>		
Yes	4	(26.7%)
No	11	(73.3%)
Experience in years: Median [range]	5.0	[1–21]
<b>English as first language</b>		
Yes	7	(46.67%)
No	8	(53.3%)
<b>Working full-time</b>		
Yes	11	(73.33%)
No	4	(26.67%)

Demographics are based on staff responses to the baseline surveys.

<sup>a</sup>Management includes: program director, program manager, residential supervisor, and senior direct care workers workgroups.

For the intervention (change team) meetings described in detail below, seven direct care staff and the House Manager participated in all of the meetings. One direct care staff member and the House Manager participated in every change team meeting. Three direct care staff members participated in almost all the meetings; each missed one meeting. Three direct care staff participated 1–2 times each closer to the end of the project when planning for the event was being finalized.

## Intervention

The intervention comprised two main components. The first component was a rigorous discussion of baseline relational coordination survey results among members of the change team. The second component was the development and implementation of a participatory event to strengthen the weakest ties identified by the relational coordination survey—with family members and community members.

**TABLE 3 |** Themes, definitions, subthemes, excerpts, and sources: sample qualitative data findings.

No.	Themes and sub-themes	Definitions	Quote or excerpt from qualitative data source	Source
<b>Knowledge</b>				
1	Brain injury	Impact of injury on cognition, behavior, and lives	The community needs to have greater awareness of brain injury, that it could happen to anyone, that it should not be stigmatized.	FGD 1-19-17
2	DCS role and work	Role and care work of DCS	The community does not know who we are. How can we get to know each other? How can we get them to accept us?	CTM 1-26-17
<b>Community</b>				
3	Stigma	Stigma toward residents and care staff	The community does not understand that brain injured individuals are not harmful, despite some potential behavioral issues.	CTM 3-16-17
4	Respect	Respectful treatment and perceptions (or lack of)	Our work with residents who have brain injury is not valued.	CTM 1-26-17
5	Sustainability	Sustainability of efforts to engage community	Building relationships between the community and residents and staff is a cycle. This will be an ongoing process.	CTM 3-16-17
<b>Family</b>				
6	Respect	Respectful interactions (or lack of same)	Negative behaviors by family hurt staff morale and make staff feel their care work is not appreciated.	CTM 2-23-17
7			Some family members are surprised to learn that “staff really care.” This new information makes them want to know staff better.	CTM 3-2-17
8	DCS role and work	Role and care work of DCS	Yelling at staff by family members shows lack of respect for staff role	CTM 2-23-17
<b>Communication</b>				
9	Sustainability	Build new communication skills	Staff can be supported by management to learn ways to curb rude behavior from family. For example, the rudeness of others can be limited with polite talk, e.g., “How are you today?”	CTM 3-16-17
10			We are concerned about how our comments might be received by the community and family. We need advice on communication and language.	CTM 3-31-17
11	Respect	Respectful interactions (or lack of same)	We need to thank the community and make sure they know how much we appreciate their presence and what they already do.	CTM 3-31-17
12			I felt people were listening.	SM 4-21-17
<b>Intervention</b>				
13	Goal	Goal for intervention	Improve relationships between residents and community, staff and family, staff, and community.	CTM 1-26-17
14	Activity	Activity at intervention	A fishbowl exercise is better than a panel presentation because it is informal, and more people can participate.	CTM 3-9-17
15			We want to share the fact that the US and English-speaking African countries were colonized by England, and each has resistance heroes (like the Minutemen).	CTM 3-9-17
16	Outcome	Self-report, during FGD or KII	An expectation has been set: staff are going into the community, and the community has said to us “Come to us, we will be welcoming.”	KII June 2017 (DCS)
17			The level of effort involved in a project like this is a barrier. Keeping staff involved is difficult.	KII June 2017 (HM)

CTM, change team meeting; DCS, direct care staff; FGD, focus group discussion; HM, house manager; KII, key informant interviews; SM, staff meeting.

The development of the participatory event was an extension of earlier research at the site and therapeutic practices utilized there. In an earlier qualitative study, residents expressed interest in involvement in the community (15), which is also an expressed goal of residents’ family members and guardians. For this and all studies conducted at the site, family members and guardians are required to provide informed consent for participation of their loved one, and residents provided informed assent. In the Northeastern US where this study took place, it is common practice for people living with ABI to “tell their stories” during support group meetings and brain injury prevention activities in schools, in the community, and at policy advocacy events. In the study setting, activities creating art and songs about their lives,

and research using photographs and captions sharing residents’ perspectives about their community integration (17) provide valued opportunities to be “seen and heard.”

A major activity planned for the participatory event was a “fishbowl” exercise. Change team members thought this would be an effective way to engage event participants. Change team members developed the questions to be answered in the fishbowl. Residents were asked the questions verbally. For other groups questions were provided on index cards. Questions for residents included: How did you get your brain injury? How did it change your life? How do staff help you? How do they help you reach your goals? For staff, questions included: What was your work before you moved to America? What is your experience working



in brain injury? How has it changed over time? How do you feel about working at this residence? What supports and challenges do residents and staff find in the community? Do you have anything else you would like to say? For family and community members, questions included: What is your view of brain injury? How does this residence contribute to the community? How can you contribute to life at the residence? How can you help to increase participation in the community by residents and care staff? What have you learned today?

## Data and Measures

The validated relational coordination survey (38–40) was completed by staff pre- and post-intervention. The survey includes seven dimensions—frequency, timeliness, accuracy, and problem-solving nature of communication, and the extent to which relationships are characterized by shared goals, shared knowledge, and mutual respect—which together form a construct called relational coordination or RC, with scores ranging from 1 to 5, where higher scores indicate stronger relational coordination.

Relational coordination is typically measured from the perspective of each key role in the work process—in this case staff, residents, family members, and community members—allowing the creation of a complete network measure (41). As recommended in the case of data limitations, we measured only the staff's experience of relational coordination with each of the other key roles—residents, family members, and community members. Averaging together the seven dimensions of relational coordination for each of the roles, we constructed three separate measures: staff RC with residents, staff RC with family members, and staff RC with community members. Higher scores represent stronger relational coordination with residents, family members and community members, from the perspective of staff. The reliability coefficient (Cronbach's alpha) for RC with residents was 0.72 at baseline and 0.67 post-intervention, RC with family members was 0.77 at baseline and 0.73 post-intervention, and RC with community members was 0.90 at baseline and 0.80 post-intervention.

Data were also qualitative and included participant observation notes, notes recorded on flip charts during focus group discussions and change team meetings, and transcripts from key informant interviews. Change team meetings were not audio-recorded due to the potential to re-traumatize or cause discomfort for direct care staff who had migrated from their home countries in Africa due to civil unrest or authoritarian regimes. A research assistant (RA) took extensive notes during the meetings and wrote significant statements verbatim. A co-Principal Investigator (co-PI), the second author, reviewed, and added to the RA's notes after each meeting.

## Data Analysis

Descriptive statistics were generated to characterize survey results. RC data were plotted at baseline and post-intervention. The quantitative data analysis plan was centered on examining pre and post intervention differences based on the data from the validated RC survey.

Qualitative data included: (1) focus group discussions on the baseline RC survey results and the post-intervention RC survey results, (2) change team meeting notes, and (3) post-intervention interviews with the House Manager, a Senior direct care staff member, and a change team member. These data were used to reflect back to participants and inform the change process and were analyzed to identify themes and quotes (42) that enhanced the description of the residential home and understanding of the direct care staff experience. Direct quotes were captured to illustrate the emerging themes. The initial thematic analysis was done by the RA. The co-PI separately reviewed a sample of the notes. The RA and co-PI discussed their findings and adjusted the thematic analysis as needed to reach consensus.

The mixed methods data analysis—integrating the quantitative and qualitative data—was based on the approach of blending variables and themes as described by Creamer (43) to develop a fuller understanding of the phenomenon being examined.

## RESULTS

### Baseline Data

The residential home had been designed to limit solitude and isolation and to provide a community-integrated residential alternative for people with disabilities from acquired brain injury. Yet at baseline, staff reported their weakest relational coordination ties with the community (3.10 on a 5-point scale), followed by somewhat stronger ties with families (3.55 on a 5-point scale). Poor relational coordination between staff and community members is reflected in selected quotes in **Table 3** (excerpts #1, 3, 4). Reflecting on the data, staff attributed their weak ties with the community to racial and disability stigma, as reflected in these quotes:

*People are not friendly. They have faces of "stone." This is hurtful for staff and for residents (FGD 1-19-17).*

*There is always the anxiety of drop in houses prices with a disability residence facility in the neighborhood. They won't encourage our presence by bonding with us or the residents (FGD 1-19-17).*

*Being black [in America] is often associated with crime. People feel afraid to come say hi, when we are pushing [or] assisting the residents in the neighborhood (CTM 3-16-17).*

### Intervention Developed

Direct care staff and members of the research team formed a change team to address these issues. The action research principals of working collaboratively, evaluating new ideas, and trying something innovative (37) were utilized throughout the change team's work. The change team met 10 times over a 6-month period, with 3–4 workers participating consistently and one who became a champion, sharing information among all staff, and encouraging participation in the intervention. Change team members were slow at first to take on assignments that required attention during non-work hours. Finding an entry point was a key to engagement. Identifying a commonality in

the U.S.-African history of colonization and resistance helped to motivate participation as did highlighting staff efforts to improve residents' quality of life (see **Table 3**, excerpt #15).

To address weak ties with the community, staff chose to hold a community-wide open house to provide an opportunity to foster greater understanding among staff, residents, family, and community members. The change team and other staff members coordinated with local schools, business owners, town selectmen, churches, and neighbors. The communication that occurred in preparation for the Open House was the first communication to occur between the home's staff and some family members and members of the community (see **Table 3**, excerpts #2, 7). The agenda for the Open House evolved to address (1) the causes and effects of brain injury among residents, their prior and current lives, and their perceptions of direct care staff, (2) the motivations, backgrounds, and culture of origin of the direct care staff, and (3) ways that community members could better support residents' community participation (see **Table 3**, excerpts #1, 2, 3, 4, 10). The agenda included fishbowl presentations by residents (their stories), direct care staff (their work and personal stories), and family and community members (their hopes for their loved ones, their perceptions of care provided, and their efforts to encourage community participation). The event was attended by 50 people, about two-thirds from the community, including elected officials, business owners, members of a local church, high school students, volunteers, and neighboring homeowners (see **Table 3**, excerpt #12).

The event started an exchange of perspectives and opened discussion on issues such as lack of access to local businesses due in part to uneven sidewalks. Family members who attended expressed appreciation for staff's dedication to providing care for their loved ones, a "new" viewpoint for some family members. The intervention was the entire process of engagement between staff, residents, family members, and community members described in this section, and not just the event itself. The process of engagement was expected to strengthen relational coordination between staff members and key community stakeholders, and also family members. It was seen as a beginning of ongoing efforts (see **Table 3**, excerpts #5, 7, 12, 13).

## Outcomes

Changes in RC as experienced by direct care staff are shown in **Figure 1**, which plots the mean scores for each RC index using data gathered at baseline and post intervention. The mean change between each data point is represented by the line connecting the points for each measure.

Following the intervention, staff RC with the community increased by 0.38 of a point, while RC with families (+0.07) and residents (−0.01) remained relatively constant. While statistical significance could not be assessed, the change in staff RC with the community was considered qualitatively significant in that real connections were made with members of the community as a result of the intervention both directly and afterwards (see **Table 3**, excerpts #12, 16).

To assess what has happened since the community event took place, the house manager was interviewed by two of the research

team members. The focus of the interview was to identify events and experiences enjoyed by residents and staff that provide evidence of greater community participation after the open house event. Activities such as a staff appreciation event at a local church and a weekly "Let's Eat Together" program orchestrated by the town on Wednesday evenings are examples of the value co-created by the action research intervention. Unfortunately, these have since been disrupted due to COVID-19. The interviews highlighted the challenge of sustaining this type of participatory action effort by direct care staff and their managers (see **Table 3**, excerpts #5, 17).

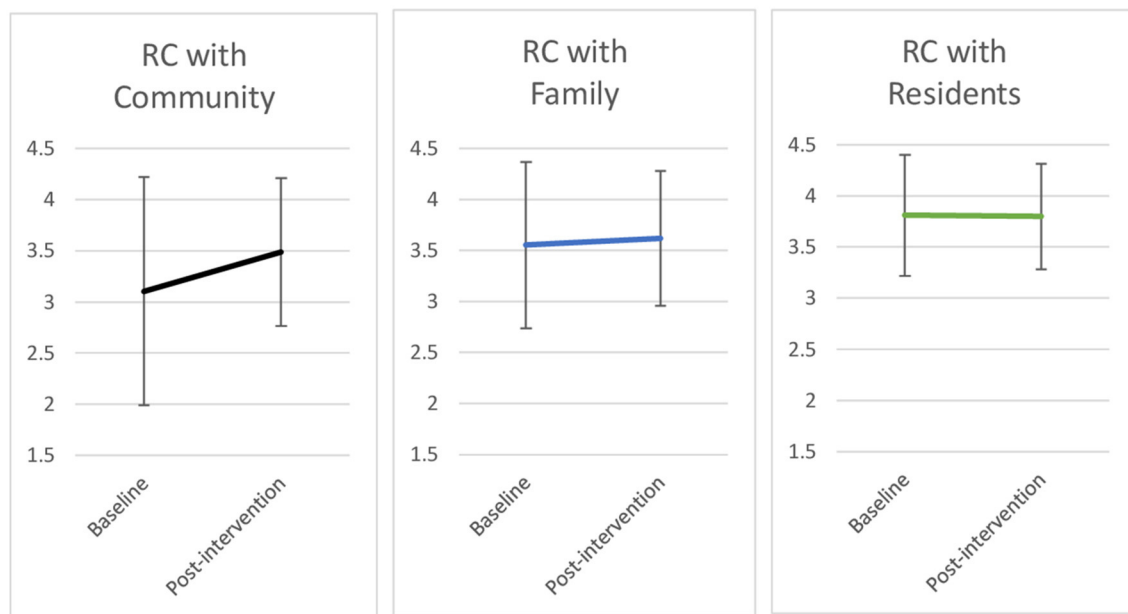
## DISCUSSION

Even though state and federal funders have sought to increase participation in community life by people with disabilities, a focus on safety and assistance with Activities of Daily Living has dominated the residential care work environment (44). Realizing the goal of greater participation in community life may require a greater focus on building relationships with community members.

Our study identified weaknesses in relational coordination especially between direct care staff and the local community. These findings may have been due to cultural differences between immigrant staff and the families they serve and the communities in which they were embedded, and by negative family and community stereotypes toward both staff of color and people with disabilities (45) (see **Table 3**, excerpts #4, 6, 8). Results suggest that interventions may have the potential to support the development of positive relationships between people with disabilities in community group homes and the broader communities in which these homes are located. For this to happen, however, cultural barriers toward people with disabilities and foreign-born direct care staff, including ableism and racism, may need to be addressed through relational interventions as they were in this pilot study (see **Table 3**, excerpt #9).

## Feasibility of Participatory Intervention Processes

Our study suggests that it is feasible to engage direct care staff in designing and implementing interventions to strengthen relational coordination with key stakeholders. Our participatory intervention process—the use of change teams, surveys, and a co-created intervention based on the Relational Model of Organizational Change—provided direct care staff with opportunities to share their experiences of their work, their work environment and the meaning of their work. These opportunities resulted in workers feeling heard. The participatory intervention methods used in this study may thus promote relational coordination where there is organizational support to address the problems identified (46). Long-term sustainability of these types of efforts can be challenging (see **Table 3**, excerpt #5, 17).



**FIGURE 1 |** Changes in relational coordination with the community, family, and residents<sup>†, ‡</sup>. Line graph shows changes in RC scores at baseline and post-intervention and their standard deviation. Sample sizes: baseline ( $n = 15$ ); post-intervention ( $n = 14$ ).

## Involving Family and Community Stakeholders in Interventions

Study findings suggest that improving relational coordination in residential care means expanding our understanding of the caregiving role to include family members and community members, and taking concrete steps to support direct care staff in playing a bridging role between residents, their families and their communities. We suggest calling this conceptual expansion “relationship-centered care” to recognize the broader set of relationships that can contribute to quality of care and quality of life for people with disabilities living in the community. Adopting a relationship-centered care approach could help direct care staff, family members, and community members appreciate the interconnectedness of the care process for people with disabilities in community settings and achieve better quality of life and outcomes for them (47).

## Supporting Relationship-Centered Care Through Human Resource Management

The one-time event implemented during the study was not expected to alter the status quo permanently, but rather to initiate ongoing efforts to build high quality relationships among direct care staff, families and the community (see Table 3, excerpt #5). Such efforts will require ongoing leadership support, including changes in human resource practices as suggested by relational coordination theory [e.g., (38)]. An essential next step is therefore to support the bridging role of direct care staff through job design and other supporting human resource practices (48). Revising human resource practices to hire and support individuals who are willing to interact with family

members and community members may be essential (32). Revised job descriptions, training and performance evaluations for direct care staff could all support engagement with family and community. When staff come from cultures that are different from that of residents, their families and the local community, additional support could include training in ways of communicating with people in the community when accompanying residents to activities. This training could focus on how the staff can use polite language as well as how they can handle conversations when family or community members are rude (see Table 3, excerpts #9, 11). Residential managers could also use a relational coordination framework when orienting family members of new residents to help families understand the important role that direct care staff play in helping residents to achieve the community integration they desire, with coaching for how they as family members can help. Providing a foundation of stronger relational coordination inside and outside the residence requires consistent messaging internally and externally that community-based residential care is best provided by a coordinated network of individuals and roles, including direct care staff, family members, and community members.

Our study recommendations are consistent with relational coordination theory and a growing number of studies in multiple sectors showing that human resource practices are a significant driver of relational coordination and associated performance outcomes, for better or worse depending on their design [e.g., (22, 38, 49–51)]. Our recommendations also build on our findings that it may be possible to intentionally improve relationships between direct care staff and the community through low cost, replicable interventions.

## Limitations and Challenges

Although the findings from this pilot test of innovative interventions by direct care staff are consistent with an emerging evidence base regarding relationship-centered approaches to care, our sample was small with insufficient observations to assess statistical significance of changes in relational coordination. No power analysis was conducted a priori to calculate a desired sample size. Maximizing the sample size was limited by the number of staff members working at the residence.

Second, we selected a site that already had management support for the change process and low staff turnover. Our selection protocol facilitated the success of our pilot study but also introduced the challenge of generalizing findings beyond high-functioning sites. The ability to generalize the findings is also influenced by the fact that staff were remunerated for their participation in data collection and the change team. Third, our pilot measured relational coordination with multiple stakeholders from the perspective of staff only, as in a prior influential study of residential care (22). Follow up studies would benefit from assessing relational coordination from the perspective of residents, family members, and community members.

Fourth, the research assistant (RA) and co-PI who participated in the change team meetings reflected together on their researcher lenses. The RA was a graduate student from Africa (Arabic-speaking North Africa). The co-PI had lived and worked for 4 years in two different sub-Saharan African countries and had traveled for shorter assignments to another six African countries. The researchers reflected that their life and work experience likely generated in them a greater level of empathy and understanding with regard to the project's change team members as compared to the average US researcher who had not experienced life and work in Africa. In particular, they could appreciate that direct care staff were educated professionals with a certain status in their home countries, and that they had changed their status when they emigrated to the US and started working in direct care for people with brain injury. Their researchers' lenses could be considered a strength of this pilot project.

The endeavor was designed to be a small pilot case study, with a minimal budget and a short- timeline. Thus, we focused on engaging staff with the hope of learning from them and building relationships with them as starting points for including the perspective of residents, family members, and community members in the future.

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## CONCLUSION

Our small pilot study provides initial, tentative evidence that engaging direct care staff in efforts to improve relational coordination with residents, family members, and community members may succeed in building relationships that are essential to realizing relationship-centered care. Community-based residential care will continue to grow as a policy-mandated alternative to institutional care for people with disabilities. In this context, finding ways to improve relationships among staff, residents, family members, and community members becomes increasingly urgent. Engaging direct care staff in data-driven efforts to improve relationship-centered care for people with disabilities living in the community is one potential solution.

## DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

## ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Brandeis University Human Research Protection Program and the Research Review Committee, Department of Developmental Services, Massachusetts. The patients/participants provided their written informed consent to participate in this study.

## AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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