# WARM SOLUTIONS:
# MEDICAL MAKING & COLLABORATIVE INFRASTRUCTURE FOR CARE

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# WARM SOLUTIONS:
# MEDICAL MAKING & COLLABORATIVE INFRASTRUCTURE FOR CARE

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For Amma, Paati, and Thaathi,

my mother and grandmothers.

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I flip to the acknowledgements in books to glimpse at the names of people holding up the author. This document too has benefited from many glorious alliances.

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| | |
|---|---|
| AT | Assistive Technology |
| CAD | Computer Aided Design (Software) |
| CDC | Centers for Disease Control and Prevention |
| CIHR | Canadian Institutes of Health Research |
| CSCW | Computer-Supported Cooperative Work |
| DIY | Do-It-Yourself |
| FDA | Food and Drug Administration |
| HHS | The U.S. Department of Health and Human Services |
| HCI | Human Computer Interaction |
| IFU | Information for Use packet |
| NIC | Nursing Interventions Classification |
| NIH | National Institute of Health |
| NIOSH | National Institute for Occupational Safety and Health |
| OSHA | Occupational Safety and Health Administration |
| PPE | Personal Protective Equipment |
| RSNA | Radiological Society of North America |
| STEM | Science, Technology, Engineering, and Mathematics |
| STS | Science and Technology Studies |
| SOP | Standard Operating Procedures |
| VHA | Veterans' Health Administration |
| WHO | World Health Organization |

**SUMMARY**

Making, as an activity and culture, shares a commitment with HCI to uphold values of democratized participation, user empowerment, and technological production. Makers in healthcare communities, much like makers at large, collaborate in non-traditional sites in design activities. However, little is known about making in healthcare settings. Whenever clinicians act to improve care delivery at the point of care – a radiologist at the Veteran Health Affairs in the United States, an ER physician at the Gaza border, or a registered nurse in the pediatric ward during a pandemic – they reveal gaps in care infrastructure. The inclusion of stakeholders in medical making, both onsite and off-site, further requires adequate infrastructure to uphold the universal healthcare values of safety, reduced risk, and optimal care. While healthcare institutions invest in traditional infrastructure (e.g., fabrication labs), this work describes the adaptive role of medical makers in creating caring and careful solutions through collaborations.

This dissertation contributes a critical view of medical making to re-position power within traditional healthcare practice. Medical making reveals competing norms that communities must resolve as tensions emerge during activities. Embedded in practice, infrastructure becomes visible when technological systems are observed in use [174]. I develop an understanding of how stakeholders in healthcare settings and extended networks could innovate care infrastructure with maker technologies. I do this by foregrounding the norms, values, and expertise related to stakeholder participation across three sections. First, I re-locate the site where physician-led making begins from labs to the bedside as safe, reliable, small-scale prototypes. Second, I re-frame the importance of medical making, with lessons from the COVID-19 pandemic, when grassroot and

institutional makers' efforts repaired temporary manufacturing breakdowns with reliable medical supplies. Third, I re-center the role of nurses in medical making and contrast their historically undocumented contributions in routine care. My research work culminates in a discussion of the human infrastructure required to design environments for innovation based on care settings to larger social innovation.

Within the scope of my work, I argue that making creates more than artifacts; it creates a dynamic environment with new hierarchies. An environment, where social infrastructure, not technologies, afford opportunities for ongoing innovation. This has practical, methodological, and ethical implications for interdisciplinary research. Centered on collaboration, this work makes three key contributions to Human Computer Interaction (HCI). At the outset, it characterizes the situated activity (i.e., medical making) of an emerging community of makers in healthcare practice. Second, it identifies two kinds of infrastructure – human and information systems – shaped by the norms in medical making communities. Lastly, this dissertation offers HCI researchers an understanding of how our professed value of widening participation requires fresh approaches to examine technology's role based on people's contexts in innovation related research.

Implications for HCI research and design extend beyond healthcare to question how values of novelty interact with healthcare values of safety, reliability, and verifiability. Medical making offers broader lessons to build fair, equitable, and sustainable infrastructure for collaboration between experts and non-experts.

# CHAPTER 1 – INTRODUCTION

Making for health is a visceral and material response to care for others. In responding to communal needs, makers participate in democratized means of production that may lead to innovation. Maker technologies are known to shift power from top-down systems to diversify responses through social innovation. As a movement [18], the shift in process to prototype solutions indicates a shift in culture towards more equitable outcomes for communities directly capable of producing artifacts for their needs.

## 1.1 Motivation

I became interested in making for health after an opportunistic conversation. Around March 2017, I learned about a physician-led innovation in a Wired magazine article featuring The Glia Project, a Canadian non-profit organization [39]. Their open-source distribution of low-cost 3D printed stethoscopes developed in Gaza, a perpetual warzone with few medical devices, was intended for hospital use in other low-resource settings. Over an email exchange with the makers, a more nuanced discussion of opportunistic design and sociotechnical collaboration emerged to allow my understanding of the infrastructure their required to safely test, then release fully verified designs through Health Canada. The complexity of their activities led me to ask how such makers at points of care use maker technologies. More so, to ask who else may or may not use maker technologies to understand its adoption in healthcare settings.

Makers worldwide, such as Dr. Loubani at The Glia Project, seem to harness digital fabrication among other maker technologies to produce and create prototypes. Their outcomes are studied in healthcare, disability, and caregiving (e.g., [32, 88, 141]).

Unsurprisingly, making in healthcare is studied as an alternative movement outside professional healthcare [140] often excluding clinical stakeholders. Yet clinician-led artifact design or development in healthcare settings precedes the advent of maker technologies. Today, clinicians continue to innovate at points of care especially in the U.S. [3, 16, 55, 65, 183] where fabrication labs exist onsite.

Around 2012 in the U.S., the maker movement received public attention with the Obama administration's efforts to foster maker interest [211]. This trend mirrored a rise in clinician-makers – physicians in private practice [120] or public hospitals (e.g., VHA) and access to medical makerspaces in private hospitals (e.g., Mayo Clinic, John Sealy). I became interested in how does power shift within healthcare systems when making is shaped by larger systems? I undertake a systematic investigation to understand how maker technologies interact with larger healthcare infrastructure. My work is grounded in stakeholder experiences alongside public notions around making as a movement outside traditional healthcare. It helped re-contextualize making at the onset of the COVID-19 pandemic in 2020 when a medical supply crisis was offset by maker-led responses.

Utopian narratives of making in HCI need a critical lens. Studies of making situated in clinical practice [82, 166] build on such critical agendas [15, 119] to distinguish knowledge sharing, material practices, and inclusion in maker communities [5, 32, 87]. Unlike making for expression, making for healthcare is charged with medical community values: safe and reliable device use. These norms are embedded in healthcare infrastructure to regulate risk primarily through litigation. Strict rules for medical manufacturing and distribution define institutional procedures for compliance with safety and reliability. Understanding maker efforts despite gaps in regulatory guidance offers an opportunity to

identify critical infrastructure for bottom-up innovation through making along a reflectionist-interventionist stance [119].

### 1.2 Definitions

- **Device** – Unless specified, the term device in this document refers to the dictionary definition of "*a thing made or adapted for a particular purpose, especially a piece of mechanical or electronic equipment."* However, considering the medical context of my research in the U.S., an expansive classification of medical devices subject to FDA regulation can be found in the Section 201(h) of the Food, Drug, and Cosmetic Act [85]. The definition covers a wide range of artifacts and products intended for use in healthcare delivery that may affect patients' body though it explicitly excludes software.
- **Distributed Manufacturing** – Based on *"manufacturing networks as sets of loosely coupled interacting smart factory objects loosely coupled interacting smart factory objects"* [98]. It relies on cloud-based repositories for design, quality control, and shared infrastructure. These processes have peer-produced repositories often leveraged in making at a smaller, personal scale.
- **Infrastructure** – *"Infrastructure appears only as a relational property, not as a thing stripped of use*." — [174]

  The study of infrastructure requires observing how people interact and manage activities by *using* it. Susan Leigh Star explores the political aspects of the designed experience of infrastructure by describing its relationship to the context of use. Star and Strauss's later work further shifts attention to global—local relationships between stakeholders, structures, operations, resources, and norms

[175]. I take this relational view instead of the traditional view of infrastructure as an underlying, fixed property. It orients my work in different contexts of use, where infrastructural relations arise *when* embedded systems breakdown. For example, a security system is invisible till it breaks down.

- **Innovation** – Clayton Christensen, a Harvard business professor, popularly describes it as novel product- or process- driven technological products [38]. However, I refer to an earlier definition introduced by Thorstein Veblen, an economist and sociologist, as collective and social contributions to meet essential community needs [188]. The latter view allows the recognition of innovation separated from technology.
- **Making –** (related to Maker Movement, Makerspace, Maker technologies)
  I refer to activity adjacent to Hartman et al.'s description of "*opportunistic design*" with "*site-specific tools*" [72].
- **Makers** – Roedl et al. describe an enthusiastic approach to craft [155] that includes the subculture of expert amateurs described by others as the drive to innovate [148]. Though makers are motivated by a creative approach to solve a problem, their use of technology for technology's sake [180] tends to define each maker community by its focus on tools to organize shared expertise in design, technical, and other skill areas (e.g., 3D printing on Thingiverse).
- **Medical Making** – Defined in Study 1, medical making is activity that modifies processes and practices for medical settings or healthcare purposes. Unlike hobbyist making, these modifications result in prototypes for use in healthcare institutions. Their actions are subject to medical liability and these makers are

committed to upholding patient safety. Stakeholders take a solution-centered approach to use maker technologies (e.g., 3D printing, laser cutting), low-tech materials, and expertise. Stakeholders who create, prototype, or participate in related processes are *medical makers*. They need not be medically licensed to undertake medical making or operate in any capacity within traditional healthcare systems. However, they primarily support medical practice through artifact creation, facilitation, or other roles.

- **Point of Care –** Limited to places of practice where interactions occur between individuals or families seeking healthcare services from medical and related professionals. Points of care can be intensive care units, emergency rooms, patient wards, clinics, hospitals, camps, private or public practices, and non-profit organizations supporting healthcare needs. Membership in these communities involve but are not limited to traditional roles in which medical providers' presence is required for healthcare delivery. Artifacts made at the point of care are typically used to meet direct or indirect patient needs as discussed in Study 1.

## 1.3 Thesis Statement

Stakeholders in healthcare settings innovate care infrastructure with maker technologies. My thesis draws upon the rising incidence of making for healthcare settings in response to onsite needs through artifacts or devices. I investigate multiple efforts in a wide ecosystem of medical makers across private and public healthcare practice, STEM institutions, academic research labs, and non-profit groups. A critical view of medical making is an investigation into the emerging opportunity to re-position power within

traditional healthcare practice. Instead of technology- or artifact-centered approaches, my research draws relational themes from stakeholders' on-ground experiences.

I take Bijker's approach to include users and non-users of maker technologies [23] to understand the stabilization of these technologies through *"technical frames"* and the negotiations in social relationships formed around technological adoption. My questions focus on the infrastructure underlying medical making informed by the long tradition of other interdisciplinary scholars [10, 51, 174] to show how different types of labor are hidden in hierarchies. I hope to understand technology users based on those who are engaged as well as those who are excluded by studying activities involved in on-ground technology innovation, in response to pre-existing and emerging problems, for healthcare.

In the first three chapters, I organize findings from stakeholder experiences against changing environmental contexts to understand socio technical factors in collaborative work. First, I establish how multiple stakeholders support physician-led makers to prioritize safe, reliable, small-scale prototypes in routine practice at institutional makerspaces. Second, set during a public health crisis, I explore how grassroot and institutional makers repair temporary manufacturing breakdowns to produce safe and reliable devices. Finally, having studied users of maker technologies in healthcare, I turn to potential non-users based on under-representation in my previous studies. I re-examine the undocumented contributions of nurses in routine care from a historical lens to foreground present-day nurse positionality to craft material solutions. The next section outlines my research questions underlying each study.

## 1.4 Research Questions

My goal is to widen an understanding of factors influencing stakeholder participation in shaping the future of work at points of care. My studies are organized to answer three research questions:

**RQ1.** How is maker technology *used* in clinical practice at the point of care?

**RQ2.** How do different maker communities adapt infrastructure to collectively act for medical supply needs in a public health crisis?

a. How do grassroot makers *uphold* medical community norms?
b. How do organizers in institutions *pivot* existing infrastructure for production?

**RQ3.** What factors *impact* nurse inclusion in medical making at the point of care?

a. How do historical influences *shape* nurse roles in problem solving and innovation?
b. How do current institutional structures *affect* nurse participation in innovation?
c. What are the opportunities to *engage* nurses in future medical making?

Participants described in Table 1 contribute multiple perspectives on maker-led innovation at points of care primarily in the U.S. These participants include facilitators, engineers, researchers, and clinicians – nurses and physicians among others – associated mainly with institutional making efforts. I use mixed methods: individual interviews, public media articles, ethnographic work, literature reviews, and social media exchanges in emerging online maker communities. I apply qualitative research methods to analyze data collected in my studies [42, 63, 113]. My approach is grounded in theories that I describe in each chapter.

**Table 1 Summary of Research Questions**

| Study | Research Question | Objectives | Methods | Participants |
|---|---|---|---|---|
| 1 | **RQ1: How is maker technology used in clinical practice at the point of care?** | Understanding an alternate maker mindset and healthcare infrastructure as toolset for "point of care manufacturing." | Media articles<br>Semi-structured interviews | N = 18 (10 clinicians, 4 facilitators, 2 researchers, 2 engineers) |
| | **RQ2: How do different maker communities adapt infrastructure to collectively act for medical supply needs in a public health crisis?** | Adaptation of infrastructure in reaction and response to a public health crisis by manufacturing medical equipment or COVID-19. | | |
| 2* | RQ2a: How do grassroot makers uphold medical community norms? | Examining trade-offs in grassroot communities between norms of safety, expertise, and action. | In-person & Online Ethnography | N = 14 communities (12 Facebook; 2 in person) |
| 3* | RQ2b: How do organizers in institutions pivot efforts to scale up production? | Mediation efforts to prototype or produce, distribute devices in institutions for temporary point of care needs. | Semi-structured Interviews<br>Media articles | N = 13 organizers in 8 institutions |
| 4 | **RQ3: What factors impact nurse inclusion in medical making at the point of care?** | Shaping of maker technology use and non-use in present day hospital makerspaces for innovation. | | |
| | RQ3a: How do historical influences shape nurse roles in problem solving and innovation? | Historical barriers to inclusion of nurses in innovation. | Literature Review and nurse blogs | N = 16 organizers in 6 institutions<br>2 non-users |
| | RQ3b: How do current institutional structures affect nurse participation in innovation?<br>RQ3c: What are the opportunities to engage nurses in future medical making? | Present day structures as resources and challenges for nurse participation in innovation, problem-solving, and making for care purposes. | Semi-structured Interviews | |

**Parallel studies*

## 1.5 Contributions

Making offers potential expansion of design participation by defining non-expert roles to facilitate, collect information, and participate in informal design for niche problem-solving activity. Previous HCI studies outline the critical need to reflect alternative perspectives to counter techno-optimistic views of design practices, stakeholder empowerment, and material practices [10, 15, 116, 119, 157]. In healthcare design, such alternative perspectives further extend technology designers' and researchers' attention to a larger ecology of stakeholders [53, 94]. My findings inform value-centered design in HCI in two areas: first, diversifying design values of novelty to include healthcare values of safety, reliability, and verifiability creates implications for collaboration systems, and second, extrapolating how medical making offers lessons to build fair, equitable, and sustainable infrastructure for collaboration between experts and non-experts.

### *1.5.1 Implications for Wider Collaboration*

Making provides a rich source of insight into collaborative work. Healthcare providers bring specialized expertise with unparalleled visibility into patient- and practice-centered insights. Their medical expertise sets them apart from the *"expert amateurs"* typically associated with hobbyist maker culture. The constraints in practice in fact contribute to more precise problem identification in accordance with the medical community's values. In each study, I center value-driven perspectives of medical makers instead of an outcome-driven analysis of their process. I develop a critical view of medical making from multiple stakeholders' relationships [173] in an emerging ecosystem. This view diversifies HCI's understanding of maker roles, processes, expertise, and norms.

Stakeholder perspectives are integrated within networks between institutions, online communities, and makerspaces. These integrated perspectives, especially about regulation, situate how systems formally support stakeholder values yet fall short of social innovation needs. I further contrast public perceptions from media articles, social media, and historical accounts to provide broader temporal contexts for their social collaboration. From these observations, I contribute design implications and speculations for communication, knowledge exchange, and social infrastructure for collaborative work.

### *1.5.2 Implications for Infrastructure Design*

Relational factors in care infrastructure have consequences on future technology-driven work [89]. Opportunities to reconcile a deepening digital divide in the U.S. [34] can be explored with making as a means of technology-driven production. In 2012, 3D printers were installed in public libraries under the Obama administration's efforts to foster maker activities for STEM education and entrepreneurship [211]. Yet the appropriation of these community resources as infrastructure is unknown. While healthcare institutions invest in innovation primarily through fabrication labs in hospitals, norms of care [186] suggest that design through collective action [44] relies on more than physical infrastructure. My studies show how some clinicians are required to write protocols because of missing regulations to ensure safe distribution through other pathways. Within healthcare institutions, contextually motivated by professional values, different stakeholders may be guided to do no harm (physicians) or ensure material reliability (engineers) or prioritize the person (nurses) to create solutions. The articulation of the different types of labor involved in their generative approach to routine care can help us speculate how to activate, mediate, and amplify stakeholder participation for collaborative, social innovation.

## 1.6 Overview of Dissertation

A layered perspective to making in healthcare settings sets up the foundational themes in my research around values, expertise, and material collaboration. I argue that making creates environments, with new hierarchies, where social infrastructure not technologies afford opportunities for innovation. I do this from a study of making in healthcare based on my research organized across five chapters. In Chapter 2, I first outline the background for making in healthcare with related work from HCI, medical journals, organizational science, and public media sources. Chapter 3 includes results from my first study from prototyping experiences to *locate* a dispersed multi-stakeholder ecosystem around artifacts for medical use. Chapter 4 combines findings from two studies during the COVID-19 public health crisis to examine *when* makers manufacture medical supplies within institutions and grassroot communities. I contrast both communities' efforts to create or subvert infrastructure required to scale artifact production. Chapter 5 delves into nurse experiences with problem-solving to ask *who* uses maker technologies in healthcare settings. Within the context of routine care at the bedside, I uncover a parallel ecosystem of nurse educators, leaders, and facilitators.

Over the course of my dissertation, I explore making for health as an ongoing sociotechnical negotiation to innovate, repair, and maintain care infrastructure. In the final chapter, I discuss the implications from these four studies to support my argument how key stakeholder roles in medical making offer implications for innovation in care. I extrapolate these implications for system designers, researchers, and related fields.

# CHAPTER 2 – BACKGROUND & APPROACH

The maker health movement in the U.S. intersects with a broader movement to democratize means of innovation. Participation in the movement is however contingent on norms, processes, and infrastructure access. The first section contrasts how norms and processes in maker communities at large [5, 155, 190] differ from making in healthcare communities. The second section describes the stakeholder roles and activities involved in innovation and repair at the point of care. In the third section, I outline key theories on infrastructure that inform my discussion of medical makers and their invisible work to encourage collaboration.

## 2.1 Widening Participation: Making for Health

In the last decade, studies on making for health uncovered how collaborative design occurs outside traditional settings [32, 142]. The ingenuity of such maker communities has attracted Human-Computer Interaction (HCI) researchers to center stakeholders engaged in customization [140], innovation [87, 116], and repair [157, 160]. As Lindtner et al. explored in their Shenzhen based case study [115], it is an opportunity to understand how sociotechnical infrastructures shape activities at emerging sites. Along these lines, Bardzell et al. and others outline research agendas to understand making directly centered on social justice, mindful rhetoric, and alternate making ecologies evolving at sites of making [15, 119, 166].

Making in healthcare communities, much like making at large, orients itself around artifacts to meet their collective needs. Instead, my work pursues a critical and reflexive research agenda to ensure the participation of stakeholders. To understand the scope of

work, I looked to the values and expertise defining maker roles in medical making leading to characterizing the ecosystem of stakeholders.

### *2.1.1 Who are Stakeholders Making for Health*

Roedl et al. differentiate two approaches to making. One is a nearly universal practice of everyday design and the other, an enthusiastic approach to craft community-wide solutions that represents a subculture [155] of expert amateurs [105]. Makers engaged in everyday design are motivated by a creative approach to solve a problem, often facilitated by the "*hedonistic*" use of specific technologies [180], involving both clinical [82] and non-clinical makers [32]. The other solution-centred approach is preferred by communities with a Do-It-Yourself (DIY) orientation often seen in Assistive Technologies (AT) [20, 147] and patient communities [112].

Ultimately, medical making incorporates both approaches to making from the DIY advances in wider communities [140] and a culture of innovation inside healthcare institutions [65]. Medical making is identifiable as empowerment for both groups of makers for opportunistic design with materials [178] in healthcare environments and risk mitigation of prototypes for end-users as well as makers (not only physicians). In the next two sections, I describe the ecological context for both movements with a focus on stakeholder roles in evolving community norms (i.e., values and expertise).

#### 2.1.1.1 <u>DIY Advances in Health and End-User Empowerment</u>

The DIY movement empowers patient-caregiver communities to play an active role in the design, creation, and application of healthcare technologies [88, 140, 141, 212]. It

coincides with advances in personal informatics, which tend to blur the boundaries between disability, health, and clinical practice [140]. As end-users, patients and caregivers' values of empowerment are adjacent to medical making concerns with actual device use. For example, DIY assistive devices often consider device safety [79] though few studies include healthcare professionals (e.g., [82, 126, 167]), preferring to foreground device recipients (e.g., people with disabilities).

The empowerment of end-users is focused on customization within maker communities integrating craft and digital fabrication supported by information systems. They rarely innovate at a larger scale unless to modify and repair the collective needs of the community. DIY patient-caregiver makers at the Nightscout project have successfully designed a community information system called Open APS for remote glucose monitoring of people with Type 1 Diabetes [212]. Supported by volunteer groups, these efforts tend to be organized by people who represent and/or are directly engaged in the communities (i.e., parents as caregivers) that require specific medical devices. However, membership in these communities defines the extent of participation and by extension the users empowered to make for health.

Previous studies [32, 80, 141] indicate most DIY communities are organized around stakeholders outside healthcare institutions – patients, caregivers, and other experts. The most prominent criticism of DIY movement, in the AT community in particular, is that its exclusion of medical professionals leads to unverified medical technology with consequences on patient safety [82]. The tension between clinicians and DIY communities [81] in this context arises from risk of actual usage falling on the patient [46, 146]. Few studies have focused on the specialized application of

technologies in some medical fields (e.g. Radiology [125], Occupational Therapy [167]). However, other studies in healthcare [53, 94] point to the value of understanding larger ecologies of care with multiple stakeholders supporting end-users.

#### 2.1.1.2 Culture of Innovation & Maker Empowerment

Innovation in healthcare is uniquely situated in maker culture. Makers are often viewed as non-technical hobbyists who create physical artifacts for themselves either in pursuit of pleasure or utility; maker spaces are sites for innovation and entrepreneurship [87, 116]. However, making devices and other artifacts in healthcare settings dates back at least to the early 20th century in literature [55] when clinical staff created solutions as they encountered problems at points of care. Some specialized physicians and nurses create artifacts at a greater frequency in the course of their routine work [3, 16, 55, 67]. Nurses for instance engage in "*stealth innovation*" [67], building on a tradition of ad hoc improvisations of processes and workflows in collaboration with medical professionals. More importantly, clinicians enlist other hospital staff to create solutions when equipped with adequate support, in the form of tools, skills, and other material design resources [65, 124, 153, 178]. The few studies in HCI describing medical professionals' roles [82, 167], enmeshed in healthcare practice, do not contrast their expertise with other stakeholders across contexts.

Clinical staff are healthcare experts with highly specialized skills in medical or related technical fields. Unlike makers at large, medical makers are rarely novices; often participating as or with access to medical experts responsible for meeting patients' point of care needs. If a physician interacts with 3D printing technologies, it is usually at a

smaller scale as studied in diverse medical fields [111]. While their activity is similar in scale to other makers, it carries greater consequences. A study of maker motivations, especially within healthcare institutions, can reveal emerging tensions in values and expertise described in the next section.

### *2.1.2 How Making Differs at the Point of Care*

Whereas previous research has focused on the DIY community, a focus on medical makers engaged in activities or processes in institutional settings can highlight necessary tensions and trade-offs to support in the medical making process. Awori and Lee offer a perspective from their dual standpoint as medical practitioners and makers in *A Maker Movement for Health* [11]. They identify four fundamental challenges: unpredictable cost of innovation, safety and quality of technologies, cultural tensions in a traditional healthcare system, and scalable cross-dissemination of innovation. However, they offer a top-down view and neglect the ground prototyping experiences explored in my research. From on-ground experiences of stakeholders, I highlight two areas first to uphold patient safety while mitigating risk of medical liability, then to balance openness and reliability of digital design distribution for wider collaboration.

#### 2.1.2.1 Risk of Medical Liability & Patient Safety

The defining feature of medical making is safety. Making for the medical context exposes the maker and end-user to real and significant risks; it is not an exaggeration in some cases to say that lives are on the line. In patient-caregiver communities, makers rely on their peers to innovate for technology based solutions with an intent to *do good* for patients and caregivers [108, 147, 190]. Yet patients, typically the end-users of the

devices, ultimately accept the burden of risk for device failures and the related safety consequences [46]. In healthcare use, medical community members prototype medical devices or improvise processes at points of care (e.g., hospitals) with ethical and legal intent to *do no harm* [82]. Hofmann et al. highlighted prosthetists' concerns that the potentially unsafe practices of grassroots communities (e.g., e-NABLE) likely keeps clinicians away from collaborations because they are placed in a default position of responsibility [79]. However, studies of medical making outside institutional settings have rarely found comparable risk mitigation attempts by non-medical professional makers. For example, Parry-Hill et al.'s study of the e-NABLE community showed that clinicians' attempts to inform other makers about safety-driven practices were rarely adopted by the wider community [147].

Based on how the legal systems in the U.S. define medical liability, physicians with a medical license become liable as individual manufacturers unless they make within institutional settings. The liability then is passed on to the healthcare organization for safe making and distribution by various medical manufacturing authorities (i.e., the NIH, NIOSH, FDA). Following the medical-malpractice model [213], the healthcare provider is further liable for injury as the seller of the device. Prior work shows that clinical staff who make at the point-of-care (e.g., hospitals), are likely to apply risk mitigation techniques regardless of regulatory clarity [79, 108]. Further research can describe the mechanisms of risk mitigation in device deployment, standard compliance when ultimately the risk to patients remains unknown.

#### 2.1.2.2 Openness for Remixing & Product Reliability

Past studies show that maker interactions extend from care [97, 186, 190]. Kuznetsov and Paulos's survey of makers in a range of these communities demonstrated a core value of information exchange where makers are expected to share intermediate artifacts to contribute to collective sense making [105]. Alternatively, Khanapour et al. report a lower incidence of such behaviour within more fluid and unregulated communities focused on the empowerment of stakeholders' unique projects [97]. The collective re-purposing of a digital artifact is referred to as "*remixing*" in Cheliotis et al.'s work with a music community where remixing is seen as a key part of ongoing progress [36, 57]. Others report how makers associate their practice with care-work beyond efforts to innovate and learn from others, some makers are intrinsically motivated to help [190] and extrinsically motivated by communal recognition for *doing good* [60]. Vyas's interviews of women makers showed a relationship between maker communities that emphasize care and the values of the makers themselves [190]. Fox et al. extended this understanding by evaluating the way in which makers in a feminist hacker space use making as a tool to work out their place in that community and their relationships supporting others [60].

When medical making has been studied in the wild [67, 108, 124], clinicians tend to limit usage of artifacts at the point of care rather than openly sharing the process like other hobbyist makers [32]. It is possible that the open-source model of making creates friction in the medical field because the open exchange of intermediate artifacts would expose incomplete and possibly dangerous designs to the public. However, it remains unclear how values of openness, and altruism are managed in medical domains where the

risks associated with innovation and openness may conflict with medical priorities. In their role as providers, they are bound to protect patients who are vulnerable to the most risk [146]. As a distributor in the U.S., the seller or hospital is regulated by the FDA or a similar agency limiting distribution of design, device, or even skill [46]. In the collaborative process of medical making, stakeholder roles are unclear. For example, when digital fabrication happens in a hospital, it is not clear who should be accountable. Should it be the clinician that printed and prescribed the device, the 3D printer company (e.g., Prusa, Form Labs) who sold the manufacturing device equipment, or the designer who invented the virtual design? Even if designers are liable [114], once openly distributed, the designer cannot be held accountable for unknown instances of device deployment.

Outside the U.S., open-source distribution is subject to the regulations set by the makers' country of origin. For example, the Glia Project founded by a Canadian ER physician distributes 3D printed designs for low cost medical supplies in areas of need [149]. The Glia project's designs are regulated by Health Canada's global license transferring medical liability onto individual makers. However, when e-NABLE in U.S. publishes open-source designs for assistive devices, it does so in a regulatory void. This returns the risks of safe, reliable use to the end-user [147].

Overall, the scope of medical making reveals competing values that communities must manage as they emerge during activities. Makers must make safely by appealing to the expertise of clinicians and researchers, however doing so could limit the open participation of innovative outsiders. Open distribution can widen participation, but it also distances makers from the design's intended recipients (e.g., clinicians, patients, people with disabilities) acting as a deterrent to makers. It limits the sense of

empowerment felt from creating a material artifact for a community [88] while also delinking control over the reliability of the final form that the product may take elsewhere. Understanding the need to embed safety-orientation at varied sites of origin for medical making designs can guide insights into infrastructures designed to uphold other value-driven activities towards different ends.

## 2.2 Medical Maker Process: Innovation, Repair, & Collective Action

Making set within traditional healthcare systems intersects with work performed in care roles. Previous HCI research describes how some healthcare stakeholders (e.g., caregivers of chronic patients [128], occupational therapists [167], nurses [144] take on activities to improvise devices or processes when care situations present such opportunities subject to their professional capacities. For most clinicians, the capacity to make devices at different scales extends from intimate and prolonged care relationships. For example, nurses express a moral responsibility to create custom workarounds in standardized procedures even when it is unethical [21] to care for patients' unanticipated and critical demands. Physicians, as Hofmann et al.'s study of making in occupational therapy clinics suggests, appropriate digital fabrication technologies for their practices (e.g., point-of-care manufacturing) to produce, not iteratively design, every time they customize a device for a patient [82]. Overall, the activities of medical makers are understudied across different stages of medical making across contexts.

To understand medical making, I use different theoretical lens to frame activities. In doing so, I learn about the interplay of context within institutions and outside organizational boundaries that influence the emerging use of maker technologies for care.

First, innovation related theories support broader claims of openness to participate in market or scientific outcomes [76, 78]. Second, theories of repair offer insights into responses in moments of breakdown [91]. Third, theories of collective action foreground labor relationships and extending communities for social innovation [44, 122]. Finally, I highlight the organizational context where medical making occurs to account for hierarchies that are known to exist in medical innovation [132].

### *2.2.1 Open & Closed Innovation*

Most maker innovation studies in HCI are framed from Hippel et al.'s lens of open-source software communities [78] with features of "*private-collective model of innovation."* A private-collective model uncovers how individuals personally benefit from recognition of contributions to the community and the collective benefits from the product. Yet this model does not extend beyond makers who act as inventors to create personal gain or their recognition in the final product-focused outcomes [116]. Clear market-oriented pathways for entrepreneurs in the U.S. encourage clinicians who are medical makers to become lead innovators [77].

Some clinician-makers develop open source prototypes within social enterprises to *do social good* in shared, open infrastructure for collective action [44, 78]. Nevertheless, innovation is secondary to care delivery for most medical makers. For instance, the clinicians studied by HCI researchers [82, 126, 167] in AT communities all opposed any significant changes to the device designs they delivered; they only wanted to modify how those devices were made. Focus on novelty and scale are intertwined with notions of technology-led innovation [10] in ways that hide the intentions of makers. Moreover, a

desire to innovate can conflict with the value of safety when innovation happens at the point of care. Opportunities to innovate come with risk that may be acceptable when modifying labor practices (e.g., maker nurses printing test tube holders) or appear acceptable when the maker rarely interacts with the recipient effected by those risks. But when delivering a device directly to a patient at the point of care, most medical makers will forgo opportunities to innovate to reduce the risk of doing harm. When faced without other alternatives, they may create temporary or one-off solutions in their local practice.

### *2.2.2 Repair during Breakdowns*

In Susan Leigh Star's work on infrastructure, embedded structures or systems become visible when interactions or activities are disrupted by breakdowns [172]. Similarly, Jackson et al. [91] call for a repair orientation to observe such moments of breakdown, instead of progress, to recognize acts of maintenance, reuse, and re-purposing of materials in design processes. Dye et al. and Jackson et al. undertake these repair-oriented explorations in low-resource communities situated in Havana and Bangladesh [50, 90]. In my work, I examine small scale manufacturing in healthcare practice in response to every day and exceptional breakdowns in ongoing practice as the collective maintenance of care infrastructures.

Tasks aligned to repair work, instead of innovation, reveal a relationship between activities and a larger context of fluctuating tensions and breakdowns [196]. Repair work is not empowering by default, as Rosner and Ames observe in the influence of context at two sites in acts of endurance affected by community values, ability, and willingness to engage in acts of repair [161]. Effectively, a repair-oriented framing centres activities in a

temporal context (urgency) and stakeholder motivations (improvement) instead of the end-outcome. It is particularly useful to inverse notions of scale and novelty inherent in techno-optimistic visions of technologies [10]. At sites of making, repair orientations can help identify infrastructure as ongoing and emerging relationships with larger sociotechnical environments. In study 2 and 3, I apply this analytical approach to widen a perspective of crisis response beyond acts of resilience [123] to recognize the work of medical makers, particularly facilitators, in organizing collective action.

### *2.2.3 Collective Action for Social Needs*

I aim to understand how medical making can lead to design through collective action [44]. Healthcare stakeholders affected by system failures or challenges have designed alternative solutions with maker technologies [80, 149, 212]. When making moves beyond personal to collective endeavours, as in Fox et al.'s study [60], non-expert labor to create artifacts within maker communities can become invisible. Manzini argues that for social design, or collective action, to become feasible by communities of diverse non-experts, such invisible labor must be made visible and tangible [122]. Lindtner et al. discuss one known form of intangible labor in the varying notions of expertise and "*expert-ness*" recognized by the community during innovation [116]. However, collective action through design overlooks other efforts of making (e.g., organizing, ideating, advocacy) required to sustain maker activities.

A medical maker is rarely a lone tinkerer who prototypes artifacts for limited, personal use. The public perception of making, for instance, highlights a lone inventor using a 3D printer [12] than a collective community [103] even during a public health

crisis. In fact, recent studies identify making is communal [5, 185, 190] with social infrastructures for collaboration [187] and cultural practices emerging around material production [18]. Yet most information systems model interactions between lone makers with isolated information systems organized around specific technologies. In medical making, the process may not be centred on technologies as it is among hobbyists [180]. Instead, understanding the relational structures that support such social design can streamline attention to invisible organizational labor and demystify maker communities' approaches to sustain collective action.

### *2.2.4 Organizational Hierarchies in Medical Innovation*

Critical making researchers in HCI and elsewhere [116, 166, 169] scrutinize artifacts in sites of innovation from a multitude of social, economic, and cultural perspectives to describe hierarchies. The language of innovation is apparent as a shift in political power (e.g., profit, scale, ownership) with an impact on multiple stakeholders. Innovation requires negotiating asymmetries in power, access, and participation within organizational practice partially through knowledge work [52, 132]. Institutional medical makers offer a multiplicity of views from within organizational hierarchies. The ecosystem of healthcare professionals engage in care delivery includes physicians, nurses, and many other specialized clinical staff. At present it is unclear how some stakeholders (e.g., nurses) interact with others within these ecosystems across medical and institutional hierarchies.

Makers in some clinical roles encounter problems requiring material solutions more often than others. Nurses are motivated by patients' unanticipated and critical needs

and may respond with improvisations or workarounds in environments where no other options may exist. Gomez-Marquez and Young describe this type of improvisation in nursing work as bedside *"stealth innovation"* with a focus on materialized artifacts [67]. Most nurses tinker with existing devices, create workarounds, or adapt parts of their environment. From nursing literature, we know nurses express a moral responsibility to create workarounds in standardized procedures even when it raises ethical questions [19]. Nurses also usually undertake patient education for preventive health leading to greater ideas of integrated interventions for patient care. Asurakoddy et al.'s study innovation behavior among public health nurses to describe how "*doctors demonstrated the skills of gathering knowledge, whereas nurses exhibited the skills of new idea generation which was more important in innovating behavior process*" [9]. While nurse presence in innovation is evident, it is unknown how insights become in institutional settings without an analysis of the relationships supporting innovation.

Examining organizational hierarchies frames the inclusion of stakeholders in healthcare related making, especially for innovation. Mørk et al.'s article, based on two medical innovation projects, outlines how the introduction of new practices can contest the power imbalances in the hierarchy to change community practices. I build on their argument that *"innovation processes may highlight the political processes and negotiations already at play in communities of practice*" [132]. I focus on the overlooked roles of organizers, minimized views of nurses, and non-user perspectives to understand making situated in healthcare. In doing so, my work identifies different types of systems appropriated as infrastructure for making. I describe the three types of systems and the

labor involved in adopting systems at a scale for them to be recognized as maker infrastructure in the next section.

## 2.3 Infrastructure Theories: Systems, Infrastructuring, & Articulation Work

The traditional view of infrastructure calls to mind structures underlying an activity, for example roadways for transport. Star and Ruhleder's early work with information systems challenges this traditional view of infrastructure as substrate underlying operations [174]. They propose a relational view where *"infrastructure is something that emerges for people in practice, connected to activities and structures."* A relational view of roads as healthcare infrastructure could emerge for traveling nurses in the U.S. if it is connected to their organizational practice of portable care.

Over four sub-sections, I define infrastructure from STS and CSCW theories, then outline the maker infrastructures relevant to medical making followed by descriptions of two kinds of work (i.e., infrastructuring and articulation) undertaken by medical makers. In medical making, both infrastructuring work and articulation work are notable as labor undertaken to appropriate maker technologies for medical settings. Medical making can pose high stakes to multiple groups as described in the risk, complexity of structures, and collaborative expertise described earlier. It provides explicit sociotechnical implications as a case study for designing shared infrastructure to democratize innovation.

### 2.3.1 Building Systems & Infrastructures

> *"The emergence of an infrastructure—the "when" of complete transparency—is thus an "organic" one, evolving in response to the community evolution and adoption of*

*infrastructure as natural, involving new forms and conventions that we cannot yet imagine." [*[29]*, p 22]*

Infrastructure, as Star and Ruhleder describe it, is relational. It cannot appear as a "*thing stripped of its use."* They describe eight features of infrastructure as: (1) embedded in other structures, (2) transparently available, (3) applying beyond one time use, (4) learned as part of membership in a community of practice [109], (5) linked to conventions of practice, (6) embodiment of standards, (7) builds upon what exists as an installed base, and (8) visible during breakdown. A ninth feature in Star and Strauss's work describes how infrastructure is fixed in modular increments [175] eventually emerging in relationship to a community's practice. This definition is useful to frame healthcare systems as ongoing, dynamic negotiations between members in a community of practice.

A parallel definition of infrastructure is based on system developers' views. Edwards et al. [51] describe three phases of infrastructure development. The first phase of system design is developed with a narrow set of features for a specific site or local objectives of a group. The second phase of "*technology transfer and growth*" entails some redesign to scale up its applicability for multiple contexts (i.e., scenarios, challenges, and system performance). A third, less common, phase of consolidation leads to either forming a network of technologies or dominating the market for that system. For example, Facebook is arguably now a network of social media platforms while Google is the dominant Internet search infrastructure. Across phases, the ubiquity of a system is linked to scale of operations while the role of system users or participants are deemed passive in the development of infrastructure. Soderberg's case study exemplifies a multiple stakeholder view of a real-world open innovation community to crowdsource the

MakerBot 3D printer. Market-oriented incentives eventually concentrate the autonomy to innovate in a small group of high-skill makers [169]. Those with high-skills are relatively better positioned to make private investments to materialize profitable designs iterated upon by low-skill makers on shared, open infrastructure.

While both views recognize a shift from fixed systems to systems as ongoing infrastructure, Star's relational view is more relevant to medical making in two ways. First, it underscores the temporality of when maker technology develops into infrastructure. Second, it centers people's role in the adaptation of large-scale global systems to local practices. Ultimately, a relational view as discussed in Chapter 6 considers designers, users, and any other stakeholders as inseparable from infrastructure [30]. It emerges as an ongoing process of negotiation between the system and its user(s) create continuity of context from the global to local: "*The discontinuities are not between system and person, or technology and organization, but rather between contexts."* [174].

HCI researchers have studied the role of physical, information, and human infrastructure [87, 105, 110, 116, 180] for collaborative design iteration with novel technologies in hobbyist making. Physical infrastructure is the most visible as the arrangement of machines, materials, and space [60, 87, 161] often acting as a geographical location for community engagement [2]. Information infrastructure studies are of alignments between communication technologies and on ground capabilities, often the most studied in maker-related research [4, 32, 126]. In parallel, human infrastructure refers to "*the arrangements of organizations and actors that must be brought into alignment in order for work to be accomplished*" [110]. A focus on human infrastructure has led to understanding invisible work in collaboration [69, 175], opportunities to design

systems [91, 161, 196], and their values [5, 186]. In the next section, I outline types of maker infrastructure appliable to medical making.

### *2.3.2 Maker Infrastructures from Physical, Informational, & Regulatory Systems*

Making signals a reliance on a distributed set of systems organizing the human, information, and physical space. Human infrastructure supports caring meta-work and information infrastructure enables sharing to engage different levels of expertise [32, 106, 186]. Both are critical to maker communities working to uphold notions of open collaboration in the maker movement [18]. HCI perspectives in medical practice are bound to align with some broader insights into maker interactions with systems at the macro level in sharing information [14, 119] and micro level social interactions [60, 192]. However, workarounds and tensions specific to medical making arising from values and expertise described earlier in this document are yet to be understood when makers access physical spaces and information systems to collaborate at points of care.

#### 2.3.2.1 Physical Spaces for Material Collaboration

Healthcare professionals undertake making activities in a regulatory void. The consequences of unclear regulations around emerging technologies (i.e., 3D printing) [74, 170] are borne by individuals unless they work within an institutional framework in the U.S. The recent trend in hospitals (e.g., Mayo Clinic, Phoenix Children's hospital, John Sealy hospital, and University of Texas Medical Branch) provides clinicians the support they need to improve point of care innovation. These institutions have designated makerspaces within the hospital based on previous research experiments in collaboration with STEM practitioners [152, 178]. Such spaces now past their infancy point to the

benefits of proximity. When the makerspace is in the hospital, materials are within easy reach of clinical staff [67, 124].

Recent research suggests that maker communities at large sustain themselves in physical makerspaces because they are designed to support resource sharing and learning outcomes [32, 66]. A study on hack-a-thons shows that co-location supports technical work and enables expert facilitation [187]. Other studies on making infrastructure offer insights into designing digital fabrication spaces to engage non-experts in 3D printing processes [48, 86], but not in emerging healthcare spaces.

#### 2.3.2.2 Information Systems for Sharing

Both patient and clinician driven groups enlist shared information infrastructures to varying degrees [105, 119]. Makers share their designs online through 3D modelling repositories (i.e., National Institute of Health's 3D Print Exchange [40], Thingiverse [32]), software repositories (i.e., GitHub [202]), and project documentation (i.e., Instructables [205], Hack-a-day [179]). Through these artifacts, maker communities build a shared transfer of skills, designs, and project ideas with opportunities for makers to contribute to the community at large [105, 133]. Some stakeholders in medical making (e.g., physicians and doctors) may be encouraged to share information, still constrained by regulatory voids, because of clear liability laws in the U.S. Similar cultural practices sustain collaboration in medical makerspaces [152] with access to knowledge exchange communities exist [88], yet few studies explore how medical makers participate or become influenced by communities. Considering the distributed features of information infrastructure – shared design repositories (e.g., Thingiverse, NIH 3D Print Exchange),

code repositories (e.g., Github), and industry forums (e.g., Form Labs, Stratasys), taking a multi-stakeholder view can reveal their work in maintaining and adapting maker infrastructures to medical contexts.

#### 2.3.2.3 Regulatory, Legal, and Policy Infrastructure

Making for medical use and contexts carries greater risk than other maker domains. Central regulatory systems seek to mitigate these risks through legal infrastructure. Briefly, three structures in the U.S. govern medical devices. These are (1) medical licensure and malpractice; (2) national regulatory bodies; and (3) institutional regulation by institutional review boards and research organizations. Malpractice law incentivizes clinicians to uphold ethics of care, while the latter two regulate device manufacturing and distribution. Risk management differs in each country affecting claims to global maker access [76]. This complicates the work required for open distribution of maker artifacts through global information systems and the medical makers' work to adapt making infrastructures in local medical settings for collaboration.

Historically, clinicians have created medical devices for decades in the U.S. [55]. This tradition persists now through maker infrastructures though clinical staff generally lack adequate time, associated skill, and other resources even when they identify challenges suitable for technology-based intervention [16, 65, 71]. However, these are global systems that must be adapted for healthcare innovation [178] leaving medical makers the work required to overcome risks associated with making at points of care. Next, I describe the community's role in developing infrastructure involving at least two kinds of work: infrastructuring and articulation, often hidden in other activities.

### *2.3.3 Infrastructuring Work & Invisible Labor*

Infrastructuring work, from Star and Bowker [173] and other participatory design researchers [24, 45], highlight ongoing design, maintenance, and adaptation activities. An underlying goal of identifying such work is to highlight invisible labor that may be undermined or overlooked due to power imbalances and process visibility [175]. Recent STS and HCI researchers build on similar themes to describe invisible labor that is temporary yet essential to carry out collaborative activities [69, 96, 110]. In drawing attention to this type of work, medical making can highlight the work involved in achieving community outcomes in practice.

The continuous response to align resources may entail different types of knowledge and coordination work distributed among different parts of the community of practice. Understanding who performs these tasks reframes what counts as labor in such emerging ecosystems. Further, grounded in their activities, stakeholders' roles adapt to suit their responsibilities based on, as Erickson and Sawyer describe, the *"non-linearity of work and working"* to realistically create infrastructure where it may not exist [52]. Such work has been described as infrastructuring work in other contexts.

Drawing from work on participatory design as infrastructuring for information technology (IT), Le Dantec and DiSalvo describe infrastructuring work as *"the work of creating socio-technical resources that intentionally enable adoption and appropriation beyond the initial scope of the design, a process that might include participants not present during the initial design*" [45]. HCI studies in healthcare provide insights into infrastructuring work from the design of large scale hospital IT systems [25] and

employee restructuring to cope with disruptions in deploying IT systems [181]. Bossen et al. define infrastructuring work in healthcare as "*an extended scope and intensity of the coordinative capabilities of medication plans, and an increased vulnerability to, and dependency on events outside the immediate loci of interaction"* [25]. The significance of infrastructuring work lies in a recognition of specific stakeholders' roles in performing invisible labor to build the underlying infrastructures required for their needs. Invisible labor in maker infrastructures [175] for collaborative work hides the actual effort required to create artifacts and requires locating accountability [177] within hierarchies.

One example of such work in Gui and Chen's study [69] highlights patients' and caregivers' infrastructuring work in interactions U.S. healthcare systems. Based on interviews with parents, they distinguish such work from other patient or caregiver tasks as features of coordination with organizations and institutions, emerging from poorly designing infrastructure. They argue that patients, positioned outside a fragmented healthcare infrastructure, perform invisible labor to make healthcare systems work for their needs. Patient and caregivers' infrastructuring work does not result in long-term or large-scale impact, often arising out of a need to repair breakdowns in structures at an individual micro scale placing the burden on human infrastructure.

Nurses are another stakeholder group known to undertake invisible labor in their current practice [28]. Their work exceeds standardized professional practices [26] with an upstream-downstream effect, to borrow a metaphor from public health [193], on technology design. For example, a centrally designed technology may automate nursing work for standardized IV procedures across departments over local priorities of nurses in hospice care. The downstream effect is on nurse agency to provide high quality,

personalized care [177]. The upstream effect is on nurse insights, viewed as common sense care practices, leading to times they create workarounds or abandon technologies remaining at bedside. Bowker and Star frame similar phenomenon in classifying nursing work as complex trade-offs between surveillance and agency among nurses [26]. They caution designing technology based on externally imposed categories for nursing tasks. I explore this dual effect by centering nurses' perceptions of problem-solving at the bedside in Chapter 5. Next, I discuss how some communities undertake articulation work to enable this type of collaborative outcome.

### *2.3.4 Articulation Work & Design Remixes*

The other kind of cooperative work related to large-scale collaboration is articulation work. Articulation work takes place mainly for the purpose of structuring activities in an organization or community. Schmidt describes it as "*cooperative work to make cooperative work*" typically undertaken by members accepted within a community [163]. It is often embedded in complex cooperative arrangements around the artifact or system [104, 131, 163]. Prior work in HCI provides insights from online communities on certain types of knowledge and organization work. For example, on Wikipedia, Kriplean et al.'s case study analyses how moderators' contribution from core editing shifts to "*meta-work activities"* that ultimately build the collective reputation by overseeing participation, support, and quality of outcome [104]. Morgan et al. in their analysis of alternate WikiProjects found open collaborations abound when they maintain low barriers for participation and community-adapted social structures [131]. While wider maker communities favor a flexible, informal structure [97] to maximize participation, critical meta-work is required to ensure quality outcomes. In this context, Fox et al. observe

organizational labor involved in the care of hackerspaces when individual hobbyist efforts turn towards collective outcomes [60]. For medical makers, among other makers, articulation work ensures they can adapt designs and re-share their own versions to improve further iterations for local use. However, affordances of the digital-physical material process affect articulation work for technology specific information systems.

Moreover, hobbyist makers rarely document designs. They tend to avoid the articulation work required to re-use designs shared online [8]. For example, many novices in 3D-modeling struggle to understand the intricacies of models such as dealing with print uncertainties [100] and figuring how 3D-models interact with real-world geometries [8, 80]. In the rare case that all relevant information is included by a maker, any future variations in printer and filament can still cause prints to fail [100]. On sharing platforms, insufficient documentation is partly addressed on user forums by the community's discussion on specific 3D-models. This reactive process is not sustainable over time as users continue to remix the model. Documentation can be lost with each iteration leaving gaps for the successive author might not understand everything about the model and be unable to answer questions [4, 58]. Apart from increasing the work of articulation, the skills required to adequately express design fidelity raises questions about the role of language [163] and related processes in information systems.

In the next three chapters, I outline primary research findings to answer the three questions outlined in Table 1. The themes discussed in this document support sociotechnical implications as a case study for designing future improvements.

# CHAPTER 3 – CHARACTERIZING THE MEDICAL MAKER ECOSYSTEM

This chapter describes findings from Study 1, an exposition characterizing medical making as an activity. I describe the stakeholder networks, collaboration activity, and community norms for medical making. In the discussion, I set up the scope of medical making in routine care contexts from the perspective of a wide ecosystem of makers.

## 3.1 Study 1: Overview

I set out to understand motivations and practices of healthcare professionals with point of care infrastructure. This multi-stakeholder study examines how making for medical use engages stakeholders, other than patients and non-professional caregivers, at the intersection of maker and healthcare infrastructure. In this study, I characterize medical stakeholders and their activity at sites of medical practice. Medical making activity is defined on the basis of Hartman et al.'s description of hacking and making as "*opportunistic design*" using "*site-specific tools*" for prototyping artifacts [72, 116].

***Medical making*** is any activity to modify processes and practices in medical settings for patient care. Stakeholders who participate in this activity are ***medical makers***. I offer an in-depth analysis of the medical making ecosystem with stakeholders of varied expertise. Their strategies to organize infrastructure in traditional healthcare practice indicate functional design opportunities to support making for health. My main research question (**RQ1)** is to understand how maker technology is used in clinical practice at the point of care. I explore how medical makers resolve global—local tensions around regulated safety and liability, collaborative networks, and operational resources.

## 3.2 Study 1: Research Design

I collaborated with other researchers to conduct semi-structured interviews with makers actively involved in digital fabrication in their clinical practice. I first analysed publicly available information to identify healthcare professionals and other stakeholders. Participants, who were advocates of the maker health movement, then referred us to in their extended ecosystem of collaborators in medical making projects. The study procedures were authorized by Georgia Institute of Technology's Institutional Review Board.

### *3.2.1 Methods*

I conducted semi-structured interviews with different healthcare stakeholders: clinicians, administrators, engineers, and medical researchers with another PhD student. Between January 2018 and February 2019, we collected direct interview data and public information about interviewees' maker technology experiences, their role in the making process, and their perceptions of how maker culture and fabrication affect healthcare. We recruited makers through their public profiles (websites, blog posts, and social media) and professional events (maker-fairs and fabrication conferences) to recruit participants.

The goal was to elicit the participants' thoughts on maker culture in healthcare as well as personal stories and experiences that could elucidate their tacit beliefs on making in medical practice. The interviews explored participants' experiences and perspectives on:

- Their first and most salient making experiences in healthcare
- Their opinion of the role of making or fabrication in their practice
- Details of the maker space and technologies they use

- The community of people who use fabrication technologies and make with them
- The direction and scope for healthcare related making activity.

With one exception, we interviewed participants over the phone or through their preferred video conferencing service (i.e., Skype, Hangouts). All interviews except one (A1) was audio recorded and were between 30 and 90 minutes. Interviews were collected between May 2018 and February 2019. After each interview, the interviewer wrote a memo describing their initial thoughts. In addition to the interviews, we collected publicly available information that described participants' profiles and experiences with making/fabrication in healthcare and in the media. This included news articles, lectures, and talks, social media content, academic publications, and grant applications written by and about the interviewees.

### *3.2.2 Participants*

Participants included in this study had to meet three requirements: (1) they must be a practicing healthcare professional (clinicians, administrators, engineers, or researchers) who are involved in patient care; (2) they must be based in the US or Canada and be subject to respective regulatory agencies; (3) they must participate in collaborative activity for digital fabrication in point of care settings or as a part of clinical practice with a medical professional. Participants applied many digital fabrication technologies (e.g., 3D printing, programmable electronics, laser-cutting) but we acknowledge a majority of their discussions in this study describe the use of 3D printing as a popular technology with varied applications in the medical field [95, 111, 135].

In total, we interviewed **23 participants** with due consent, but eventually excluded five candidates **(resulting in 18**) because we learned during the interview that they did not meet the study requirements. Two candidates were excluded because they are researchers who study medical making but do not interact with patients. One candidate was excluded because he did not work in the U.S. or Canada. Two others were excluded because they do not practice medical making – their makerspace supports STEM education. The fifth candidate was excluded because she does not make physical objects in her work with clinicians. The remaining participants are described in Table 2.

In the rest of this chapter, I refer to study participants who are administrators, engineers, and researchers as facilitators. Facilitators are not medical professionals but perform integral roles in ongoing medical making activity. They wear multiple hats including management of the space.

**Table 2 Participant Demographic Data for Medical Makers**

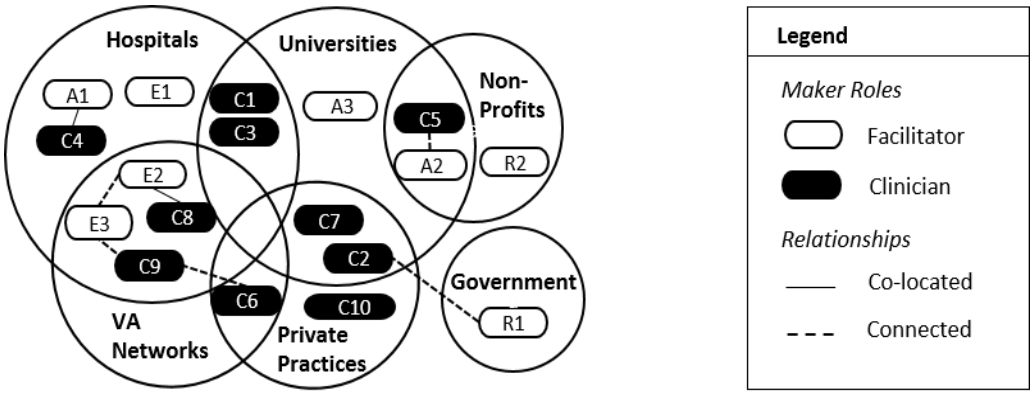
| ID | Profession | Specialty | Environment | Location | Gender | Patient Access |
|---|---|---|---|---|---|---|
| C1 | Clinician | Emergency Medicine | Academic Hospital | United States | Male | Yes |
| C2 | Clinician | Endocrinology | Academic Hospital | United States | Female | Yes |
| C3 | Clinician | Neurology | Academic Hospital | United States | Male | No |
| A1 | Administrator | Compliance | Children's Hospital | United States | Male | No |
| C4 | Clinician | Cardiology | Children's Hospital | United States | Female | No |
| E1 | Engineer | Radiology | Children's Hospital | United States | Male | No |
| R1 | Researcher | Public Policy | Government Agency | United States | Female | No |
| A2 | Administrator | Emergency Medicine | International Non-Profit | Canada | Female | No |
| C5 | Clinician | Audiologist | International Non-Profit | Canada | Male | Yes |
| R2 | Researcher | Prosthetics | International Non-Profit | United States | Female | Yes |
| C6 | Clinician | Prosthetics | Private Practice | United States | Female | Yes |
| C7 | Clinician | Public Health | Social Enterprise/Makerspace | Canada | Female | Yes |
| A3 | Administrator | Education Technology | University Makerspace | United States | Male | No |
| C8 | Clinician | Occupational Therapy | VA Networks | United States | Female | Yes |
| C9 | Clinician | Occupational Therapy | VA Network | United States | Female | Yes |
| C10 | Clinician | Radiology | VA Network | United States | Female | Yes |
| E2 | Engineer | Rehab Engineering | VA Network | United States | Male | Yes |
| E3 | Engineer | Rehab Engineering | VA Network | United States | Male | Yes |

### 3.2.2.1 Network of Community Relationships

Given the reviewed public content, we recruited known early adopters and publicly visible advocates of making for health. A relatively rare and novel activity, we anticipated a positive bias in the medical community towards digital fabrication. While we recruited further participants through snowball sampling, we did not encounter any outright dissidents or informed critics. Before this recruitment phase researchers had no relationship to the participants except for E3; two researchers met him at a conference in 2016.

Figure 1 outlines the network of memberships observed among participants. This network represents and ecosystem of the institutional (academic, medical) and professional networks that bind an emerging medical maker community in North America. Each maker is associated with different skill levels, communities, and each other to perpetuate medical making activity. These networks extend across geographies and spaces based on professional networks such as the RSNA.

**Figure 1 Study Participants and Their Network of Relationships**




Facilitators are represented by unfilled boxes while clinicians are represented by filled ones. Dashed or solid lines indicate that participants are connected or co-located,

respectively. The institutions they belong to are represented by the encompassing circles. Proximity of shapes does not imply association.

### *3.2.3 Data Analysis*

The interview data was analysed through a thematic analysis in two steps. First, I independently coded the secondary data, tangential to the transcripts (public facing participant details and interviewer memos) to inductively develop a set of eighteen axial bottom-up codes. I compared these with my collaborator who carried out the same process. Then, we discussed the interviews in weekly meetings; notes taken during each meeting led to a narrower set of themes. These became the basis for a deductive thematic analysis of the interview transcripts. We applied these codes top-down to the 18 interview transcripts. The analysis showed strong inter-coder agreement (Cohen's Kappa coefficient ($\kappa$) = .777). Disagreements were discussed during the writing and synthesis process.

We agreed on six themes derived from the eighteen top-down axial codes to organize insights from semi-structured interview transcripts:

1. **Motivations for medical making:** Medical makers were motivated to innovate or customize solutions to improve patient care.
2. **Structural support for making:** This theme includes institutional resources such as location, funding, time, regulation, materials, and space. Where structures are non-existent, medical makers find alternative means to access such resources.
3. **Stakeholder responsibilities:** The division of labor and responsibility of stakeholders is explored in this theme to emphasize the role of facilitators.

4. **Maker technology applications:** Different technologies (i.e., 3D printers, CAD software, programmable microelectronics) were used to prototype physical objects in their areas of specialty. Medical makers shared insights from prototyping customized surgical models, medical devices, prosthetic devices, and other artifacts primarily with 3D printing.
5. **Concerns around prototyping process:** Medical makers expressed concerns grounded in their project experiences. This theme addresses concerns about product quality and distribution of files within the healthcare community.
6. **Participation in maker culture:** Medical makers mostly identified making activity as an extension of their primary healthcare related work. Few others participated in maker culture outside healthcare settings.

These six themes are categorized medical making resources, challenges, and strategies to mitigate the latter in the next section.

### 3.3 Study 1: Results

I describe how medical makers create their own local systems to offset regulatory concerns. The study results and implications are organized into four sections. Each section outlines challenges and strategies (if any) to pursue activities by medical makers. The first section highlights risk mitigation from themes related to concerns around prototyping process and participation in maker culture. The second section includes a description of stakeholder responsibilities and their motivations for medical making. The third section outlines physical infrastructure accessed for medical making based on the themes of maker technologies applied in medicine and structural support for making. In

the last section, I discuss the implications for collaborative work drawing from values of safety, social relationships, and other resources described in this study.

### *3.3.1 Managing Risks to Patient Safety & Regulatory Gaps*

Medical professionals are concerned with risk, primarily related to standardized processes for making in their practice. While participants were optimistic about the role of making in healthcare, many expressed reservations. Some evaluate the risk of making devices based on regulatory guidance. In the absence of adequate guidance, each participant independently interpreted the risks. In general, participants who make devices for patient interaction were more concerned with liability arising from regulatory gaps. Clinicians become liable for their technical labor of creating patient-centered devices. On the policy front, regulatory bodies are formulating policies to manage risks faced by medical practitioners [170]. Meanwhile, practitioners have their own strategies to accept accountability in the spirit of patient protection for medical making activity.

#### 3.3.1.1 Medical Liability in Manufacturing at the Point of Care

Medical makers are aware of risks to patient safety; most clinician-participants raised these issues except for C6 and C3 who focused largely on technical details of their projects. C10 expressed her concerns about the consequences of on-demand and small-scale medical making at points of care.

> *"The whole manufacturing side of it is very foreign to medicine...It's point of care manufacturing, bedside manufacturing. We are just not trained in that, nor do we think about all of the implications in terms of verification and validation." — C10*

Liability for devices is skewed towards clinicians in medical making. Participants who operated in a DIY community and/or private practice (R2, C2, and C7) emphasized that clinicians may not fully understand the devices they deliver. C2 did not feel regulation of device quality was necessary when devices were made by and for individual patients. Such stakeholders in her DIY-AT community collaborate in peer networks that self-correct for gaps in quality of manufacture through iteration on device designs. However, she expressed a reticence to directly use the maker technology in the making process because she lacks technical knowledge.

> *"Perhaps you don't have the deeper understanding of the risks and benefits. Then someone else builds it and afterwards there's an adverse event...People who can benefit from [using 3D printing] are people who have the skill. How do you disseminate and democratize that?! Because that's hard. If you took me to a 3D printer, I'd be like "oh gosh there's no way I can do anything with it!'" — C2*

Facilitator-makers are less liable for devices. Participants including engineers with patient access (C10, C8, E2, and E3) all make medical devices and expressed patient safety concerns. E3 creates devices that clinicians prescribe to patients, but clinicians are ultimately liable for this work. They take on the risk with responsibility going to great lengths to obtain licensing to distribute their designs. C7, C2, C5, and C8 each mentioned extensive time and energy devoted to license their designs. C7 recognizes that it is a burden on medical makers to endure the licensing process, but that it is also a moral necessity.

> *"If we're looking to deploy it in global health settings, we work on getting FDA clearance of our devices. It's resource-intensive but it's the right thing to do." — C7*

#### 3.3.1.2 Concerns about Device Quality without Patient Access

Licensing design files can be useful in creating global resources for making. However, it may not fully address the challenges in process towards quality assurance for patient safety. C6 and R2, who work on site with patients, are deeply concerned about durability of materials. Similarly, C8 and C5 prefer to work with feedback from patients to improve fit. C6 shares his insight into the limited use of plastic based 3D printing models to prototype with patients for such feedback.

> *"A lot of 3D printed plastics aren't as strong as our traditional methods of fabrication and [...] we are only using these for rough draft versions right now. There are definitive versions out there, but we haven't used them yet." — C6*

Making customized medical devices for patients depends on their context. Standardized design files need to be adjusted to fit the patient in their environment. Participants who are a part of additional maker ecosystems (C1, A3), or who operate in non-traditional medical systems, such as non-profits (A2, C5) champion openly shared resources for medical maker devices. In opposition, R2 and C7 would argue that even the best documented and tested designs cannot be adapted without patient access. In fact, R2 felt strongly enough to go where the patients were to pursue her experiments with 3D printing prosthetic devices in the Global South. She began medical making through a non-profit and decided to move from her previous DIY community because it did not align with her focus on a process that prioritized patient safety.

> *"I sort of pivoted away...from the download things online and print them out anywhere, never seeing the patient sort of situation." — R2*

Both E3 and E2 are making highly customized devices for patients with disabilities and do not distribute the designs for use on other patients or in new contexts. As E2 notes, this means that their work is not subject to FDA regulation. This leaves engineering labor in healthcare in a regulatory blind-spot where it is difficult to enforce best practices for patient safety, according to E2, *"AT (Assistive Technology) flies under the radar of the FDA."* Though we found no consensus among our participants on how the existing regulatory structures can accommodate making, participants acknowledged the need for quality in device production. Some participants (C1 and A1) argued medical devices could still be made within the existing regulatory structures. C1 shares his view that clinicians can make patient-centered interventions and need not be reticent due to concerns for patient safety.

> *"Everyone thinks you need to get FDA approval...people don't even [make] because it's way too complicated...We can't just make something and tell patients that its reasonably safe...There are still many more opportunities to create something that is not going to harm a patient." — C1*

#### 3.3.1.3 Regulatory Gaps and Mitigation of Risk in Prototyping Process

Regulatory bodies are not completely immune to medical making requirements. Devices requiring highly technical specifications and greater investment guide most healthcare policies. R1 explained how amateur designs and maker creations are being explored at public health institutions. The NIH, FDA, and CDC each maintain maker spaces on their own premises to experiment with emerging maker technologies.

*"[The FDA] are anticipating the moment when they are going to be asked to regulate all these things that makers are coming up with. So, they are already experimenting themselves with 3D printers. They can start testing them in their testing lab." — R1*

Meanwhile, medical makers continue to uphold traditional healthcare ethics to the extent they can. Participants who operate in closed networks, such as the VHA (C8, C8, C10, E2, E3) or hospitals and universities (C1, C3, A1, R2, C6, A3), were more likely to support changes in regulations. The Canadian model of regulation allowed some participants (A2, C7, and C5) to limit their scope of responsibility to device design. A2 defines their non-profit's making responsibilities within the confines of one-time production and dissemination of medical grade designs.

"*Printing the pieces, distributing the pieces; that's not as much our project as testing them, validating them, publishing them…then 'here you go world!'" — A2*

Participants with patient access pursue due diligence in prototyping devices. Makers proactively seek or create tools to ensure medical grade devices are developed and distributed by clinicians. Both R2 and C7 ensure a higher quality standard of production with standardized design repositories. C8 set out to find a tool that could be applied to her work in AT and orthotics to measure outcomes and improve her custom designed devices with patient inputs. Other participants (C7, R2, C8) are developing standards within their institutions to self-regulate quality. C7 distributes a global desktop 3D printer supported by a digital repository of medical grade designs. C8 describes a set of standards and guidelines she is collating with her team at the VHA, other hospital partners, and the FDA to mitigate risks and deliver consistency to patients.

*"We are working on a 3D printer charter committee, where we are working to standardize how 3D printing is done in the VHA for various areas of healthcare. [...] I think at first it will stay more internally because it will initially come out as a draft form for getting feedback for the field... Then, it will probably go public on the site for VHA. We work very closely with the FDA and some other private hospitals that are doing 3D printing like Mayo [Clinic] but also other corporations such as GE to make sure we are following good standards of practice." – C8*

C7 summarizes how medical practitioners see their role as makers. She facilitates medical making in her space with procedures for quality checks and confidentiality agreements. Her perspective on medical making emphasizes a vigilant approach:

*"I'm not trying to be secretive, but this is healthcare. I should not lose my medical license because of a maker's project. We [makers] have to be very vigilant about protecting [patient] privacy." — C7*

### *3.3.2 Leveraging Stakeholder Expertise from Medical Maker Networks*

Unlike medical liability, manufacturing expertise is distributed across medical makers. Some medical stakeholders who specialize in relevant technical fields contribute remotely while others collaborate within co-located spaces with clinicians from many specialties, non-profit organizers, government officials, entrepreneurs, students, and hospital administrators. Irrespective of the site of healthcare delivery, clinicians and staff expressed an inclination to create solutions, similar to other studies [124, 153, 178], when equipped with adequate support either in the form of tools, skills, and other material resources. Participants shared their motivation to improve practice, deliver patient-centred

care, and impact social good. They maintain memberships in several communities and advocate making practices in their institutions to attract more collaborators.

Medical professionals and facilitators shared a consistent motivation to improve their practice. A few clinicians (C1, C2, C3, C7, and C8) and most facilitators (A2, A3, and E3) mentioned publication goals. Clinicians with patient access (C2, C7, and C5) highlighted making as a practical recourse to meet untapped opportunities for innovation in routine care delivery. C7 described their low-cost prototype of a high-precision diagnostic device to replace a market option that was too expensive to be widely adopted by clinicians. Facilitators A2, A3, and E3 mentioned 3D printing as a process to create devices unavailable in certain markets. Similarly, C5 and C7 hinted at entrepreneurial innovation in their discussion of intellectual property rights or plans for setting up a private practice. Further, the intention towards social good guides their practices. C2, C1, and R1 remarked on public health in the U.S. while A2, R2, and C7 offered a global perspective. C1 recounts his decision to adopt making as a medical professional and educator.

> *"I started thinking of the healthcare system as a whole and how broken it was and try to see how we might be able to fix it." — C1*

Clinicians act on their intentions by enlisting engineering expertise. C3, C8, C8, and E2 (in the VHA network) assert the ethos of providing holistic care with technical expertise particularly in 3D printing. Moreover, local, and ongoing technical support is preferred when it is available to medical practitioners. C3, C8, R2, C5, C10, and E3 mention clinical expertise being mediated by engineering expertise among their collaborators during their project experiences. Participants (E2 and E3) had engineering skills in biomedicine and/or

rehabilitation with advanced digital fabrication technologies. All facilitators in maker spaces (A2, C10, A3, A1, C8) referred to members with engineering responsibilities. A3 explains his staffing challenge with volunteers in a medical university makerspace.

> *"We have equipment that needs there to be a level of support for people to come in and use it. You can't just walk in and use it." — A3*

Specialized labor and technology is scarce; it is rarely available as a dedicated resource in medical settings. To bridge medical making needs, some participants (C2, C8, C6, C8, E2) use tele-health or remote consultations to share resources across locations. Engineers E2 and E3 leverage the VHA's resources to work with appropriate technology vendors for high-quality prints. Others in non-profits (A2, R2) and individual practitioners (C1, C2, C7) rely on academic partnerships to supplement engineering skill. A2 remotely co-ordinates project collaborations with engineers located in a low-resource setting and several global partners. E2 shares his role in providing support to medical makers through tele-health in the VHA.

> *"I do quite a bit of tele-health right now. The reason is there are six rehab engineers within the VA. There's probably only like three or four sites that are doing any sort of 3D printing clinically in the AT area and not all of those sites have engineers." — E2*

Apart from technical expertise, medical professionals work with other clinicians who share similar goals for medical making. C10 and C3 collaborate with other surgeons through 3D printing to improve surgical planning procedures. Participants who are facilitators (A2 and A3) and engineers (E2 and E3) shared project descriptions that include interdisciplinary teams with combinations of medical faculty, medical students, therapists,

and a range of clinical specialties. A2 explains how their non-profit is interested in medical makers who are willing to align to their organizational goal of open-source designs.

> *"We need to form collaborations with other people that are interested in the same [goal] to keep our costs low [when] we also pay for engineering costs as well." — A2*

Moreover, gaining manufacturing expertise is not a prerogative for medical makers. Instead, medical practitioners (C1, C8, C8, and C3) enlist technical colleagues to prototype artifacts. C8 explained the empowered approach medical practitioners can take as therapists towards 3D printing as *"a tool in their toolbox*" to deepen their learning. Opportunistic alliances also emerge in makerspaces with access to patients and research personnel. Participants (C1, C2, C3, A3, A2, and C8) voiced their preference of proximity to patients for feedback on prototypes. Some (C8, C7, R2, and C5) described testing multiple prototypes with stakeholders. In fact, some participants (C8 and E3) credit their inspiration to patient interactions. Other participants in learning environments (C1 and C8), and administrator A3 leverage their access to skilled research collaborators to pursue making related goals. C8 shared how the introduction of 3D printing in her private clinic required help from a more experienced medical maker in her institutional network and led to a continued professional alliance.

Medical makers foster strong relationships with relevant mentors in their practice. Participants who operate within the VHA (C8, C10, E2, C8, E3) or organizations with medical affiliations (A2, C5) mentioned mentors and membership in maker communities. C8 relies on C10 to guide her while C5 was inspired by his relationship with a medical maker who works with A2 in a non-profit. Similarly, E3 and C10 are members of national

organizations (e.g., RSNA) across the healthcare sector. E3 shares how he finds collaborators beyond the VHA network to solve problems through medical 3D printing.

> *"It's still actually pretty small I've gotten to know some of these people in the [national group] and there's a few rock stars out there in medical 3D printing." — E3*

Overall, medical makers are a small community who leverage organic global and local networks. Several participants (C7, C2, R1, C10, C8) refer to maker fairs and medical hack-a-thons as sites to build connections with other makers. A2 and C5 state that open access to their medical device designs encourage global collaboration and support. Several participants (C2, R1, A2, C5) engage with online communities on social media and personal websites to exchange feedback. C7 organized medical make-a-thons to attract members to her medical makerspace. She sums up her approach to working with a range of healthcare stakeholders based on the goal of collaboration.

> *"That's why we seek partners, we need that access. Sometimes it's with individuals, sometimes it's with organizations, and sometimes it's with aid agencies. Sometimes healthcare providers can tell us what their patients need, and sometimes you can do really good research." -C7*

Whereas collaborative environments evolve within institutions with the extraordinary efforts of some individuals. Medical makers propagate making activity through institutional advocacy to attract collaborators. We highlight some efforts to acknowledge several participants: C1, C2, C10, A2, R2, A3, C10, C8, and E3 who rally support for medical making activity in their institutions. C10 not only continues to experiment with the technology, but she also teaches a course on 3D printing. Similarly,

C8, A3, and E3 perpetuate the visibility of 3D printing technology in their institutions through their work. A3 initiates educational pop-up labs during showcases to exhibit novel medical applications of technology across their health sciences campus. C8 was introduced to medical making in training programs yet it required proof of successful application to drive home adoption among her colleagues. Others, like C1 and C10 promote making to a larger network. C1 was inspired to write a book of case studies to describe the work his medical students and faculty achieve towards patient care.

### *3.3.3 Infrastructuring Maker Operations in Medical Practice*

Medical makers are highly motivated individuals, yet they rely on access to technology and skill at the site of clinical practice. Co-located access within health institutions requires justification of setup and ongoing costs at the place of practice. The technical expertise required to adequately equip and plan for medical and operational needs pose ongoing challenges for facilitators. Some participants developed ways to organize making infrastructure around medical institutional practice and material practices [159].

Equipment in the space including appropriate maker technologies depends on the institutional medical practice's goals. Makers who prototype products (C1, C2, R1, C7, A3) and low-resource non-profits (A2, C5, R2) required generalized and consumer-friendly machines. Other makers who worked in specialized clinics mentioned specific 3D printers and materials for life-like medical modelling (A1, C4, C3, C10) or AT engineering (C6, C8, C8, E3, E2). C6 described her challenge in organizing a makerspace in her prosthetic clinic because it requires specialized 3D printers that produce stronger and more precise models than standard consumer grade devices.

*"We do not have any 3D printers now. About two years ago they were given to us by the cardiology department, but it wasn't the right kind for prosthetic devices. We couldn't use them clinically." — C6*

For some participants the choice of technology is tied to the operational costs of materials and making in low resource conditions. While C10 explains how she initially invested in machines at the VHA lab space without considering the cost of materials, others (R2, C5, A2) with fewer resources rely on constraints to guide their technology use. Participants with existing proclivities towards maker technology set up alternative spaces to support experiments. Once technology is in place, several participants fund or sustain materials for making. They employ different strategies including institutional advocacy (C10, E3, A2, A3, C1) and grant applications (C8, A3, C3, A2). Others adopt practices often seen in maker culture to lower operational costs using open-source software (C1, C5), and crowdsourcing either skill (A2, C7) or crowdfunding to meet the cost of materials (A3).

In summary, the adoption of making within organized medical practice requires participants to overcome several barriers. Several participants mobilized resources for making devices at the point of care with a pragmatic attitude. C2 expresses an underlying derision she had faced in maker projects for health.

*"There's so many barriers to the craft of design inside the delivery system that even if you are a provider and you know what the solution can be you don't have any means of actually creating or supporting it." — C2*

## 3.4 Discussion and Contributions to Collaborative Systems

Making in traditional healthcare settings is firmly situated in practice, not nostalgia. When investigating making in the context of professional medical practice, stakeholder practices in this emerging ecosystem helped characterize participation in an emerging maker culture. My analysis of findings from this study contributes to research themes on innovation [87, 116], infrastructure for community-wide collaboration, and understanding material practices in prototyping [159].

### *3.4.1 Product Quality: Streamlining Tools for Patient Safety*

Medical makers undertake making as an extension of their role as medical professionals. The ethical structure of the medical ecosystem enforces top-down regulatory structures that are, at present, unable to adapt at a pace to allow innovation while mitigating risks. Medical devices are risky propositions for patients even when they are sufficiently regulated [56]. Medical makers create new ways to guard against risks.

We found that medical makers adopt, despite uncertainty in regulatory guidelines, pragmatic approaches to mitigate risks. They ensure adequate documentation of the manufacturing process is available in text, code, video, and other media formats to invite feedback. However, such processes are currently initiated and upheld by the medical makers involved in the project. Medical makers take the additional responsibility to distribute universal designs. They differ from hobbyist makers who focus more on the pleasure of production processes and DIY makers who do not make artifacts in professional practice [13, 88, 180]. Their pragmatic approach to overcome challenges suggests a higher commitment to foster a maker mindset. Medical making, much like making itself is not the

revival of a production process [115] but the integration of a new set of tools into existing practice. It suggests the need for new systems to support medical grade and partially open design repositories.

### *3.4.2 Social Skill Share: Building a Medical Maker Community*

Medical making requires medical and technical experts to cooperate in the prototyping process. The collaborative structure of medical making is key to creating medical devices. Medical makers were quick to identify and proclaim their inadequacies, and to seek assistance from other medical experts who could resolve them. We found that consistent collaboration across institutions and individuals sustains a culture of innovation at the point of care similar to other makerspaces [87]. Medical makers maintain a global and local network of stakeholders in health to foster such collaborative sharing of skills [32]. The benefits of collaborative practices among medical makers resembles patterns in wider maker culture [97, 157, 166]. However, we found medical makers have an ongoing need to access stakeholders, either co-located or on-demand, for a wide variety of skill sets. For example, medical makers test early prototypes with patients, but it is unclear if makers engaged in iterative design activity. A recent study argues that practitioner-makers do not iterate at low-fidelity due to cost barriers and limited fabrication expertise at the point of care [82]. This suggests future research through observation of medical making to reveal opportunities to build on-site support systems for user feedback and early testing.

Several medical makers noted that they also maintained membership in the broader maker culture through engaging with maker fairs, hack-a-thons, and smaller organizations. This is beneficial because emerging medical makers meet other highly motivated

individuals who are expert medical makers. These new alliances lead to intentional digital exchanges and crowd-sourced repositories to improve process. A similar social collaborative platform for medical makers can encourage both skill-sharing and dynamic memberships to facilitate remote knowledge exchange.

### *3.4.3 The Work of Experts: Aligning Resources for Medical Maker Activity*

Recent trends indicate a preference for co-located access to maker technology inside the hospital [124, 199]. Medical makers who are healthcare providers intrinsically apply making approaches to deliver for patient care. Despite the key role of technical experts in medical making (engineers), clinicians bear the major burden of risk. The medical institution and practitioner may offset the risk by underplaying critical roles in ensuring product quality, which is not reflected in legal liability. Moreover, while medical makers prefer locally available technology expertise, it is not always possible. In such cases, resources are made available remotely through institutional networks. We found that one participant who is an administrator at a global non-profit (A2) routinely works with several remote partners using existing media platforms for collaboration. However, cross-institutional infrastructure is not always possible. There are conflicts with intellectual property protections requiring interventions to improve remote collaboration and labor distribution across multiple medical institutions.

Alternate medical maker models avoid a specialized focus on healthcare. Public makerspaces of this sort attract a diverse set of makers who enter and leave the space (i.e., C7). Their location outside restricted healthcare premises makes makerspaces ideal for rapid prototyping and interdisciplinary collaboration. These spaces are purposefully

isolated from patients who are reliant on and expecting standardized and professional care form their clinicians. Instead, when patients are involved in the maker projects in these spaces, they are made aware of the experimental nature. Medical makers make this explicit, but it is also implied by the non-clinical environments. This ultimately limits the impact designs have on individuals but reduces the risk to individuals.

To sustain such general makerspaces, makers rely on grant money from academia or the industry. The onus of regulatory compliance will fall onto the maker or the makerspace. In this case, the makerspace can be situated at the boundary of a medical institution or independent from one entirely (i.e., university makerspaces, start-ups, non-profits) to accommodate medical professionals on site. This poses two implications in healthcare practice – labor recognition and membership, which I discuss in the Chapter 6. In the following section, I recommend design tools to support findings in Study 1.

## 3.5 Implications for Designing Medical Maker Systems

This work described strategies participants use to manage risks to patient safety, leverage knowledge and skill through stakeholder networks, and bridge infrastructure needs in current medical making practice. Because such strategies rely on crowdsourced infrastructures, in our published work [108], we proposed three design recommendations centered on the core principle of widening participation in medical making. Insights based an on-ground prototyping process, medical practice, and the medical making ecosystem led to three design recommendations from this study: (1) support partially open distribution of design which meet regulatory standards, (2) develop a wider network of medical makers within and across institutional boundaries, and (3) ensure product quality before and after

reproduction. These recommendations built on the concept of clinical-CAD tools proposed by Hofmann et al. [82]. By highlighting these ideas, I **foreground the complexities of collaborative making within the medical practice.**

One idea is to document models for medical device designs in a *Medical Maker Repository* to directly enable a wide distribution of medical designs across communities of practice. Current open-source repositories for digital fabrication do not provide sufficient infrastructure for sharing medical maker designs in safe and effective ways. The NIH 3D Print Exchange in its current form is limited in its inclusion of contributions, design documentation (fidelity and testing), and quality control beyond organizational models. Based on these findings, a repository could be built with insights into prototypes, medical data, verified and tested, and/or subject to regulation.

This recommended Medical Maker Repository must, however, fit into the social infrastructure of the medical community. By contributing or using designs from a repository, medical makers assume liability for the designed artifact in the U.S. On one hand, this liability flows form a legal, political, and economic system beyond the scope of problem-solving. On the other, the material benefit relies on altruistic motives without formal recognition of maker effort. By transferring both liability and benefit onto medical makers, these tools may inadvertently exploit altruistic motives while centrally collecting their material work. Instead, this study highlights participants had their own motivations for medical making that varied between career advancement, entrepreneurship, and community shaped by their professional medical priorities. Future work is required to understand how medical making mutually shapes responsibilities, materials, and norms alongside medical priorities to become infrastructure.

## 3.6 Publication Details & Areas for Future Exploration

This study was published in the 2019 ACM Conference on *Computer-Supported Cooperative Work* (CSCW) [108]. It directs the scope for future work on how medical making infrastructure can adapt to include external communities and nurses. In the next chapter, I describe the inclusion of new communities beyond health for large scale medical supply making prototypes and products.

# CHAPTER 4 – MANUFACTURING MEDICAL SUPPLIES IN A PANDEMIC

This chapter describes two completed studies on parallel community efforts to scale up production of medical supplies. Each stakeholder group offers a unique perspective into how medical making infrastructure can adapt to include communities in collective action [44]. First, I relate salient features of the COVID-19 crisis as context. In two subsequent sections, I include results from each study to highlight the role of community norms, expertise, and standards in medical making. The first study explains how forms of expertise and norms evolve in wider grassroot communities through online interactions. The second study describes opportunities to facilitate community participation based on the perspectives of intermediaries' role in institutional makerspaces.

## 4.1 Background: Medical Equipment Needs during COVID-19

The COVID-19 pandemic ushered a medical device supply crisis worldwide. In the U.S., supply chain disruptions further interacted with regulatory uncertainties around medical device manufacturing procedures [151, 208]. Under normal circumstances, medical device manufacturing processes are overseen by central and state regulatory bodies [93]. Makers took the FDA's Emergency Use Authorization (EUA) as a call to increase the production and distribution of personal protective equipment (PPE).

In the following sub-sections, I first describe the larger supply chain breakdown, regulatory, and sociotechnical environment, and next I outline the types of PPE, shared design infrastructure, and maker communities involved in stopgap efforts.

### *4.1.1 Supply Chain Breakdown & Information Gaps*

To examine how medical makers responded in the U.S., I describe two phases of urgency: acute shortage of devices for medical use between March and May 2020 followed by a chronic shortage in devices for wider communal use between May and July 2020.

By late February, global demand for PPE escalated while U.S. based manufacturers could not supply regional stockpiles of medical devices, N95 masks. Medical manufacturing infrastructure to produce and distribute PPE broke down while health authorities updated guidelines for medical PPE use in COVID-19 treatment as the virus spread in unpredictable directions across regions [75, 204, 208]. Onsite large-scale production was restricted due to nationwide stay-at-home orders in March leading to a disruption of in-person manufacturing activities. States in the Northeast region, like New York, became epicenters experiencing more severe lockdown measures to restrict movement and transportation of equipment from nearby states.

Meanwhile, variability in scientific information about the virus affected medical manufacturing guidelines. The CDC mandated N95 masks to avoid airborne transmission and the WHO allowed face coverings to prevent droplet transmission [208]. Some states, like Washington, in the Pacific Northwest region followed guidelines from the WHO [49] while manufacturing companies in the Midwest region (e.g., 3M [200]) struggled to align their existing production infrastructure set up in compliance with traditional regulatory guidelines (FDA, CDC, and NIOSH).

By April, the FDA's EUA relaxed strict guidelines around medical manufacturing to open up ways to manufacture low risk, emergency PPE [75]. Media representation of

such maker-led responses [70] possibly catalyzed voluntary involvement, public support, and resources in the acute phase.

In May, acute needs for PPE became chronic in communities outside healthcare settings. Some manufacturing materials (e.g., filters, polycarbonate plastic) remained unavailable. Global manufacturing stabilized with transportation, new manufacturing entrants, and updated CDC guidelines [201]. Most healthcare institutions reverted to traditional sourcing methods to replenish medical device stockpiles as lockdown measures lifted in key manufacturing regions (e.g., the Midwest). However, efforts to produce PPE for general use among the public were underway in the Southeast and Southwest regions with increased demand for essential workers.

### *4.1.2 Types of PPE & Design Infrastructure*

Within days of several states adopting stay at home orders in March, numerous makers posted open-source designs for face shields, cloth masks, and respirators with significant variations in quality. In place of physical maker spaces, maker communities appropriated social media platforms to organize their efforts. A glimpse of the collective efforts to generate open source designs is visible in the NIH 3D Print Exchange: COVID-19 Response Collection [40]. This repository is typically used for collecting 3D-printable models related to biomedical science and healthcare. Submitting a design to this collection queued it for clinical review by the NIH to be classified into four areas.

- *Reviewed for Clinical Use:* implies that the designs are likely safe in a clinical environment, but does not imply traditional device approvals

- *Designs Optimized for Community Use:* not verified for clinical use, but safe for community environments such as grocery stores
- *Warnings:* denote designs that are not verified as safe or await FDA approvals
- Prototypes which have not yet been reviewed.

Face shields [154] and cloth masks [162], proven to be effective infection control mechanisms for general use, were the PPE of choice in healthcare settings. Lead innovators at the VHA, engineering, and medical innovation labs combined their fabrication expertise with equipment companies (e.g., Prusa [134]). Wider initiatives invited makers to contribute online in design repositories (e.g., NIH 3D Print Exchange, Form Labs [214]) and communities (e.g., Helpful Engineering [203]). Medical makers created device parts, for example, the head band in face shields or the valve in the Personal Air Purifying Respirator (PAPR) head. Then, they assembled the device to prevent infectious splatter onto the PPE wearer's face or body. A subset of designs mentioned in both studies in this chapter are in Figure 2.

**Figure 2 Sample Medical Maker Personal Protective Equipment (PPE)**

**Description**: Sample maker PPE (clockwise from top left to bottom left): (a) Sewn Olson Cloth Mask [210], (b) Ear-saver Mask Accessory, (c) 3D printed headband and (d) 2D printed headband for Face Shields with plastic sheets, (e) Nasal Swab holders for COVID-19 testing, (f) Personal Air Purification Respirator (PAPR) Head combines with a high pressure body protection suit, (g) Stopgap Surgical Respirator with a filter, not a N95 replacement, and (h) Disposable Surgical Gowns made of plastic sheets. All designs for PPE except (a) were collected from the NIH 3D Print Exchange [127].

## 4.2 Study 2: Overview of Grassroot Response

In the wake of the COVID-19 pandemic, early in March, expert-amateurs resolved to stem medical supplies gaps by 3D printing and sewing PPE. The rare practice of medical making transformed in reaction to three factors. The disruption of regular medical device supplies, strict oversight of medical device regulation, and atypical social-distancing requirements in real-world interactions – leading to a reliance on online infrastructure.

This study engages a mixed-methods, participant-observation of online medical maker communities' reactions to COVID-19. I worked with two collaborators between March and June of 2020 to observe 14 online maker community interaction in their efforts to make and distribute medical devices. The main research question was to understand *how communities establish norms that affect the quality, sustainability, and impact of their maker efforts for point of care use*.

Overall, this study explores how makers may be forced with align into communities biased towards action or regulation, guided by their ethos (safety, design, action), and prioritize specific forms of expertise (principled, practice, experience).

### *4.2.1 Study 2: Research Design*

#### 4.2.1.1 Methods

This mixed methods study of medical maker communities took place during the acute phase of the US response to the COVID-19 pandemic between March and June 2020. I observed public social media posts on 12 online maker communities along with two other researchers. One of us observed and participated in a local site with insignificant social media presence at a state university initiative across multiple departments (e.g., engineering, computer science, design, and hospital network).

We conducted this study in two overlapping stages: community identification and engagement. First, we connected to maker communities through our personal networks and analyzed public online content as digital traces of communities on Facebook, Reddit, and Twitter. One of us was an active poster on S3, S9, and S10's forums, and was included as an organizer in S1's community. I remained a silent observer of sites S3–S14. By separating these roles we can triangulate [42] our experiences as participants and observers. Organizers from S1 and S2 provided informed consent for researchers to participate and observe the communities. These methods were approved by our Internal Review Boards.

#### 4.2.1.2 Participants

We selected sites S3-S14 based on their prevalence on four media platforms (e.g., Facebook, Reddit, Slack, Twitter) in Table 3. We identified the largest community, S3, from mentions in media articles. Then, we searched for the terms *PPE, COVID, Do-It-Yourself PPE*, and masks to expand the community set. Starting in mid-March, we tracked

their daily online activities. On Reddit, I narrowed our focus to monitor activity on threads related to the search term 3D printing PPE. On Twitter, we followed the accounts of related communities on Facebook and tweets from key medical makers. Eventually, we decided to focus on Facebook communities based on consistent activity.

The communities met three requirements; they must (1) be open to the public, (2) involve medical making of PPE during the COVID-19 pandemic, and (3) were active for the duration of the acute phase of the pandemic (i.e., March to June 2020). The resulting 13 communities cover a range of active, public, and online maker communities reacting to the pandemic during these months. All communities applied both high-tech digital fabrication technologies (e.g., 3D printing) and low-tech crafting technologies (e.g., sewing) to manufacture medical devices.

**Table 3 Demographic Data of Maker Sites & Online Communities**

| ID | Locality | PPE Products | Platforms | Size |
|---|---|---|---|---|
| S1 | State | cloth masks, ear savers, face shields | Facebook, Mighty Networks, Slack, website | <5000 |
| S2 | City | face shields, gowns, respirators | Slack, website | <100 |
| S3 | Global | cloth masks, ear savers, face shields, respirators, ventilators | Facebook, website, Slack | >50,000 |
| S4 | Global | cloth masks, ear savers, face shields | Facebook, website, Twitter | <50,000 |
| S5 | Global | cloth masks, ear savers, face shields | Facebook, website | <5000 |
| S6 | Global | cloth masks, face shields | Facebook, website, Twitter | <5000 |
| S7 | National | cloth masks, face shields, respirators, ventilators | Facebook, website, Twitter | <5,000 |
| S8 | National | ventilator | Facebook | <500 |
| S9 | State | face shields | Facebook, Slack | <1000 |
| S10 | State | cloth masks, face shields, respirators | Facebook, website | <1000 |
| S11 | City | cloth masks, ear savers | Facebook, website, Twitter | <10,000 |
| S12 | City | cloth masks, ear savers | Facebook, website, Twitter | <5000 |
| S13 | City | cloth masks, ear savers, face shields | Facebook, website, Twitter | <1000 |
| S14 | City | cloth masks, ear savers, face shields | Facebook, website, Twitter | <500 |

#### 4.2.1.3 Analysis

We collected publicly available media articles, social media mentions, and documentation from these sites for making–virtual communities where makers convene for

their activities. Our memos multiple times a week, depending on community activity, documenting their experiences and impressions. I protect the anonymity of makers by de-identifying their posts in our notes, quoting from the largest relevant communities, and modifying the specific phrasing enough to make posts unsearchable. Each week, I met with my collaborators to discuss observations and activities during debriefing sessions [113]. Based on these discussions, we inductively synthesized themes focused on how these communities' established norms. We then reached a consensus on the presented themes of established ethos, accepted expertise, and platform limitations. In this study, I present a limited set of findings related to the first two themes on ethos and expertise.

**Description of expertise and ethos:** Observations relate to how rather than why people make for medical settings in online grassroot communities. The scope of this study is limited to prototyping artifacts through observed communication. In the process, we came across anecdotal insights into why they do what they do as drivers for their ethos and expertise. Without close, in-person observation, we would not be able to check our insights around internal constructs such as beliefs, epistemologies, and professed communal identity. Instead, we observed ethos as drawing from forms of external knowledge and expertise as a formal construct within medical institutions unlike possible internalized epistemologies that can be professional and personal.

### 4.3 Study 2: Results

In this section, I organize findings and discuss implications specific to my thesis. First, I describe the community norms determined by trade-offs between action, safety, and

design innovation. Second, accepted forms of expertise explain how communities accepted expertise in principled knowledge, professional practice, and embodied experiences.

### *4.3.1 Establishing Ethos: Action-, Safety-, & Design-driven Efforts*

We observed that many of these communities establish a shared ethos through community charters or documents, or the language and actions of members. Larger sites (e.g., S3) tended to self-align based on explicit norms: action-oriented, safety-driven, and design-driven communities. Makers frequently treated these norms as antithetical if more than one norm was encountered in their community.

#### 4.3.1.1 Action-Oriented Ethos

An action-oriented ethos is largely owed to the urgency of the pandemic crisis. These communities quickly recognized that collapsing supply chains would result in significant loss of life. In turn, makers reacted with a feeling of moral responsibility to act. Respectively, any actions that slowdown that response were immoral. In some cases, the perceived binary between do-ers and obstructionists was adversarial.

Some had periodic discussions about convincing local hospitals to accept makers' PPE. Due to inconsistent regulation and variance in local needs, facilities had different standards. Some refused non-traditional PPE; others accepted some clinically reviewed designs and procedures, while many took whatever they could find. Rejected makers within communities (e.g., S3, S4) expressed their frustration and sought action-oriented solutions to circumvent administrative policies, such as donating to less risky facilities or arguing to circumvent administrators by delivering PPE directly to practitioners:

*"Ask for forgiveness rather than permission. Less thinking and more action go directly to the doctors and nurses who don't have any better alternatives. Contact the hospital directly and you will get administrators and executives. Ignore them." – S3*

Many members of these communities (S3, S4, S10, S12, S14) saw actions taken to slow down the group, even in the pursuit of safety, as unethical. Their core argument was that the groups served a critical purpose where something is better than nothing. For example, S3 called themselves a *"do-ocracy,"* where members take immediate action and should only be obstructed when another active member raises "s*erious concerns*" by taking a counter action. This forced the community to constantly act.

While a bias towards action lead to emotionally charged discussions with a vocal minority of makers in some communities (S3-4, S11), in others (S1-2, S7, S12-13) it motivated strategic and multilateral organization. In a thread discussing S1's mission, one maker posted a document they prepared outlining a guide for stop-gap maker PPE efforts. In it, she highlights the relationship between organization and speed:

*"Get organized! I have seen many teams running with the Maker Efforts and delivering successfully. The role in each team varies with the quick pace that was needed for teams in this call to action." — S1*

#### 4.3.1.2 Safety-Oriented Ethos

Many communities retained a medical approach emphasizing caution, safety, and evaluation. Safety-focused communities saw infection risks as a significant barrier; if any makers were infected because of their making activities then that would diminish the good done by the community. In response they started by minimizing risk, then maximizing

good. Within these communities, safety became the basis for most community norms, and the safety and regulatory experts emerge as community leaders.

Safety evaluations were applied to all of S1's procedures. A team led by two medical researchers produced a document which explained how to do tasks safely by minimizing the risk of contracting and spreading the virus. This became a Standard Operating Procedures (SOP) for tasks in the community (e.g., making, deliveries). S1's safety lead, explained this approach during a publicly streamed safety session:

> *"When we designed the SOP, we built in multiple points of redundancy to allow for the possibility that every maker would not do things correct every single time, rather than relying on a single step where, if it failed, the entire thing would go pear shaped." — S1*

Other communities (S2, S12, S8, S9, S13) also followed this approach, but with varying degrees of enforcement. S9 established community values of social distancing and cleanliness. However, they had no public documentation of these procedures which caused some confusion. My collaborator asked on their Facebook Group for any documentation and an organizer responded with a brief procedure description.

> *"Once the shields are ready, we have the drivers schedule pick up and drop them all off at the warehouse for sanitation. Then the doctor liaison directs the distributions." — S9*

Safety dictates these communities' design and production processes. S2 has a safety-focused design approach. They designed and evaluated a 3D printed respirator which passed NIH 3D Print Exchange's clinical review after 13 days of development. Rather than sacrificing safety evaluations, the speedy design process came at the cost of make-ability. The design is printed with non-consumer SLS 3D printers (i.e., Selective

Laser Sintering) and cannot be readily produced by hobbyist communities. Using manufacturing processes that were known to be safe (i.e., easy to disinfect) sped up the design process. However, distributing the design to public communities remains a significant challenge since that level of safety cannot be assured. S3 makers mentioned S2's design as an example of a safe design and asked how to print it in hobbyist 3D printing filaments, implying they did not recognize the requirement to print with non-consumer machines to ensure safety. Ultimately, S3 disregarded the design because they did not have the resources to manufacture it.

#### 4.3.1.3 Design-Driven Ethos

Design-driven communities distinguished themselves from action-oriented communities by prioritizing designs over production outcomes. While action-oriented communities (e.g., S4, S9, S10, S11, S12) aimed for impact by supplying their local community, design-driven communities (e.g., S2, S12, S8, S13) desired the impact of releasing a design beyond their own community. Many communities pursued both by segmenting into design and production efforts, however this solution occasionally caused conflicts as limited resources were diverted to either design or action. For example, S2 primarily focused on creating innovative and safety regulated designs, but also printed face shields for its medical facilities. Both projects required 3D printers, and the other researcher at S2 was told to prioritize printing a part for prototyping over printing more PPE.

Additionally, S2's administrators refused efforts to distribute PPE outside the university because they determined this was not an acceptable use of grant funding. From their perspective, design is research, appropriate for grant funding, but external

engagement is not. Their designs were shared on the NIH 3D Print Exchange, but without partnership with communities who manufacture and deliver this PPE it is unclear if the designs will have significant external impact. Amongst these communities, design innovation was viewed as a foregone responsibility. Some communities (S3, S8, S13) prioritized challenges when deciding what to design. One of the clearest examples of this was efforts to create DIY ventilator designs, despite debates about the morality of pursuing such high-risk devices:

> *"There is an argument that something is always better than nothing, and that if you're literally suffocating, you'll take your chances. But the more I understand about ventilators, the more I fear building them. I have no interest in making a machine that is going to kill people." – S3*

Many makers on S3 announced their support of this warning, remarking that it laid out the risks in a useful and clear way. While it was a heated debate, most makers who responded to the post disagreed that the risks were enough to stop designing alternatives. The makers reached a consensus that, since people would presumably die without a ventilator, there was no added risk to patients. In a sense, makers believed they were not responsible, nor were the medical practitioners.

Some makers in design-driven communities engaged in conspiracies that medical device regulation is an intentional effort to slow down open-source efforts. Within threads across larger communities (S3), smaller groups exchanged these ideas in favor of specific manufacturers, halting their innovation. For example, a poster argued:

*"In this emergency the face shield is a lifesaver and any stalling by way of "approval' is only about the money and mates-rates quangos [sic]. Unfortunately, by comparison, companies are fast-tracked without such lengthy 'approval'." – S3*

Overall, design-driven communities distinguished their efforts from action-oriented communities because collective action drained design resources. On-ground, after days of prototyping, part of the S2 team wanted to start user-testing (i.e., action-oriented) and others wanted to continue prototyping (i.e., design-driven). In a community that has room for both perspectives, this led to a healthy dialogue. In others, safety was considered a valued goal but not when regulation in the form of "*lengthy*" clinical approval would obstruct efforts. Action-oriented communities valued design and safety only when it served acting with speed. Safety driven communities ultimately desired to design and act but would forgo activities experts deemed unsafe.

### *4.3.2 Aligning Forms of Expertise: Knowledge, Practice, & Experience*

To justify their positions, makers appealed to various forms of expertise. Across these communities, we observed three accepted forms of expertise: principled knowledge, professional practice, and embodied experience. Principled knowledge was derived from institutions that produce knowledge such as academia and government agencies. Expertise from professional practice was that of frontline healthcare workers (e.g., doctors, nurses) who use PPE. Finally, expertise achieved from making was embodied in experience.

#### 4.3.2.1 Principled Knowledge

Under normal circumstances, principled knowledge is disseminated through peer-reviewed publications and government agencies. By principled knowledge, we mean the

knowledge that has been produced and reviewed by institutionally recognized experts to develop disciplinary consensus, which is then disseminated to the public. Many makers across a cross-section of ethos in communities (e.g., S1-2, S11, S13) viewed this as the gold standard for guiding design processes and organizing their efforts. S13 asked for peer-reviewed research and received seven citations in the comments:

> *"I'm looking for the best scientific paper on filter materials. Comments are desired."* — *S13*

Principled knowledge about COVID-19 was being generated and disseminated unusually quickly as society attempted to manage the pandemic. Maker communities paid significant attention and scrutinized interpretations at length. Makers in some communities (e.g., S1, S4, S12) viewed unmitigated discourse amongst experts for the first time and became aware of the constant debate over various sources of new information. This led to conflicts and frustration as makers share new knowledge that appears to conflict with the sources cited by other makers. When another maker in S3 requested peer-reviewed research on related topics, the discussion traced a heated debate which compared highly technical details such as the electrostatic charge of the virus and commercially available respirator filters. An active commentator became frustrated, notable in the deterioration of spelling, after repeated defense of their insights on filtration efficacy of a chosen material.

> *"Read my above statement on filter material. Then go to my example and read the messages. I used that example to make a point. Been doing this for a while. Your info that you provided is good but there are new people trying same thing." — S3*

At times, principled knowledge was disseminated too late, which created conflicts between best practice and current practice. For example, S1 began producing face shields before the establishment of the NIH 3D Print Exchange. S1 had consistently espoused a core value of safety and clinically reviewed all their designs. However, after some face shield designs received the NIH 3D Print Exchange clinical review, makers who were not included in those initial testing phases became confused between conflicting messages from government and the S1 leadership.

During a public quality control town hall, one maker asked why the community would not accept the face shields he had printed that the NIH had "*accepted*." The moderator explained the S1 clinical review process, and that design was not compatible with the community's laser cut shields but was eventually satisfied and switched to the community design. The temporal conflict between the principled knowledge disseminated by the NIH 3D Print Exchange and S1 leadership, confused the maker until he had insights into the community's internal decision-making process. While this maker accepted this conflict, others (e.g., S3, S7, S12) saw academics and government officials as untrustworthy and corrupt. In an online exchange on S3, a request for evidence provoked distrust of scientific publications:

> *"Published? I have little respect for that. That has not helped. You just glad-hand politicians and academics while taking credit makers' work." – S3*

Makers tended to prioritize material efforts. Within S3, if a member raised concerns but could not demonstrate material, tangible participation, their perspective was devalued. For example, my collaborator identified herself as a researcher and asked a maker to clarify

their *"clinical approval."* After criticizing her association with academia, he continued to dismiss her contribution as an organizer.

#### 4.3.2.2 Professional Practice:

In tandem, and sometimes supplementary to, principled knowledge, professional practitioners were viewed as critical experts in these maker communities (e.g., S4, S11, S12). Professional practice refers to people who work in a field relevant to responding to the pandemic, primarily medical practice. Some makers viewed professional practice as a substitute for, or improvement on, principled knowledge. Practitioners are considered experts because of their experience applying relevant knowledge to medical practice, and because they are the primary users of PPE.

In some cases (e.g., S4, S10, S12), makers believed professional practice should override official guidelines. For example, "*approval*" from medical practitioners was frequently cited to justify design choices, even when this contradicted NIH guidelines. A newspaper covered one maker mask as the first "*federally approved mask of its kind"* only once noting that the NIH 3D Print Exchange had not found the design to be safe for clinical use. However, the article contradicted this assessment by regarding a local hospital doctor who had user tested the design. Makers, such as one in S10, weighted the expertise of the practicing doctor over the NIH's guidelines:

> *"Perhaps everyone printing respirators should switch to this mask?" – S10*

Some communities evaluated their designs with medical practitioners (e.g., S1, S2). For example, S2 conducted multiple rounds of user testing with medical practitioners. We

noted that the prototyping team would reach a point in the design process where they could not innovate further without feedback from those who would be using them every day.

Within other communities (e.g., S3, S4, S7, S11, S12), makers appealed to hospital "*culture*" to justify decisions. A resolution emerged deep into S3 threads when debating various mask filter materials, based on makers' observations of the negotiation between hospital needs and maker responsibilities. They described the challenges of using "*technical things*" and "*studies*" (i.e., principled knowledge) amidst shifting consensus in the scientific community by prioritizing viability in the "*desperate situation*." In this way, S3 makers ended up with appeals to practitioner's expertise to assess needs:

> *"People are treating filter materials as a "technical" thing. It's partly that, but it's also the culture of the hospital and the people who use it. We point them to our resources so they can decide on their own. If they're fearful, 100 studies won't convince them, and if they're desperate, they may not need studies." – S3*

Among cloth mask makers, a similar trend extended to personal networks. S12 opened a debate about *"medical grade cloth*" by requesting guidance from medical practitioners. Cited practitioner expertise ranged from midwives' forums with medical-professional spouses. The maker abandoned efforts to source the material reverting to recycling cloth.

> *"This isn't available to us regular Shlubs like us. Manufacturers need it more. I'm using old bed sheets." — S12*

#### 4.3.2.3 Embodied Experience

Finally, many makers (e.g., S1, S3, S12, S8, S13) valued the expertise derived from hands-on practice (i.e., embodied experiences). Practice may not make perfect, but it does generate expertise; makers learned by doing (e.g., 3D printing, sewing, engaging in forums, organizing). The expertise gained through action elevated individual makers within the community. This expertise was demonstrated best in the continuous skill-share between experienced and novice makers. For example, S13 opened membership to support makers outside their local community. A novice maker from another country posted asking for help. Experienced community members shared their expertise and guided the novice over six weeks, step-by-step, during their initial attempts to print masks with new materials.

> *"Massive fail tonight! Every mask failed. I have two printers and lots of PLA and time. If anyone has a file, they can share that would be great. I have zero skills. Thanks in advance." – S13*

Within S1, shared embodied experiences of making elevated some makers to positions of greater influence. S1 organizer was involved with 3D printing help calls most nights during the peak production period. These calls were initially intended to support makers who were struggling to manage their printers. His embodied experience using a variety of different consumer printers helped him coalesce a sub-community of 3D printing experts. Other experienced makers emerged in this group and supported others. This manifested an ongoing virtual skill exchange. Additionally, these calls served as an engaging, almost therapeutic, environment for makers to share experiences and recognize contributions.

### *4.3.3 Appropriating Information Systems: Inadequate for Remote Collaboration*

Social distancing requirements forced these communities to organize remotely, rather than physically interacting with each other. Due to a sudden reaction to the crisis all these communities seem to have selected collaboration platforms based on their founders' familiarity and availability. Facebook Groups and Slack were the two primary communication platforms in the communities we observed. These platforms significantly shaped communities and sometimes contributed to social breakdowns.

#### 4.3.3.1 Failing to Scale: Facebook Groups

The key artifacts produced by organizers are community procedures that ensure community members are aware of and follow established norms, work safely and effectively, and produce work that can be distributed by the community. This necessitates that community members find and access these procedures before taking actions that conflict with them. Online communities (e.g., S3, S9, S11—S13) pinned their procedural documents in Facebook Groups at some period. However, only one document or post can be pinned at a time creating additional labor for organizers. The S9 community stored on-boarding information in a FAQ document linked in the files tab on their Facebook Group's main page. When first entering the group, there was no link indicating that the document exists unless another maker recently linked to it. As a result, many new members repeatedly asked questions. One of these moderator's responses reveals frustration with Facebook and a conflicting feeling of necessity about the tool attracting volunteers to the community:

> *"We're constantly trying to revise the FAQs for newcomers. Unfortunately, Facebook was the easiest way to get the word out." – S9*

#### 4.3.3.2 Lost in Translation: Slack

While Slack can be more easily integrated with file management and repository tools (e.g., Google Drive, GitHub), pointing makers to stabilized procedural information remained a challenge. In Slack, content tended to get siloed across different channels and threads. For example, in gown prototyping, the S2 team struggled to develop a system where designers could leave the files for the manufacturers to find and produce them. The number of pins, linked documents, threads, and tags directed at team members was overwhelming. Over the course of two days, outdated design documents were used with incorrect gown-assembly procedures because information was missed in a thread. At times, other sources of confusion were passed on to the medical professionals who received the PPE. Without a clear chain of documentation, some practitioners were under the impression that the face shields were disposable like traditional face shields. So, they threw them away rather than cleaning them, a tremendous loss for the makers. This ill-supported information exchange ended in frustration over lost physical resources and wasted time.

Though Slack is designed to support organizational efforts, seemingly important discussions and threads were often overlooked when posted in *"#general"* channels. For example, one maker asked the S9 on Slack how to report his COVID infection and have his face shields pulled from the supply chain. The post received numerous reactions (e.g., thumbs up) but no replies. The maker re-posted the question multiple times, reiterating his concern that he had introduced COVID-19 into the supply chain. To date, we have not found a S9 policy for tracking the spread and we did not find any public conversations about how to introduce a tracking protocol despite apparent interest from the makers.

## 4.4 Discussion & Contributions to Collaborative Systems

This study elaborates how medical maker communities exist across a spectrum of internally and externally regulated efforts. In the context of the COVID-19 pandemic, we identified themes describing how makers adapt a communal ethos, develop operational norms, and prioritize various forms of expertise to shape their practice of medical making. Through this analysis, we contribute insights into the social and technical aspects which shaped the development of maker communities participating in relief efforts and the impact of disinformation on these communities. On one side of this spectrum, action-oriented, grassroots maker communities function as internally governing entities committed to producing material outcomes. At the other end, maker communities operate within hierarchical, externally regulated environments and prioritize clinically reviewed standards. No single community represents an extreme end of this medical making spectrum; however, few find a happy medium.

### *4.4.1 Implications for Participation: The Right to Help & the Right Help*

Even though medical making carries greater risk than hobbyist activities, makers asserted their right to help. To an extent, every maker community in this study expressed a belief that they had a right to act: to make and deliver medical devices. Despite their altruistic intentions, there are consequences of unregulated medical making.

These communities leveraged technologies with minimal regulatory oversight. They often compromised on regulatory standards since they slow down their action-oriented efforts which rely on embodied, hands-on experience to harness material processes. Their efforts to help became a struggle to cope with regulations that exist to

protect life but are designed to be implemented by manufactures with extensive legal and compliance capabilities. In medical making, personal liability and collective accountability are often compromised with no recourse for device recipients. Unlike with traditional manufacturers there is no clear path to hold makers or maker communities accountable for negative outcomes.

Regulation aims to push the locus of responsibility onto manufactures, but many makers viewed regulatory processes as obstructing their values of action and innovation. To slow the spread of incomplete, unverified, or unsafe designs, regulation prevents volunteer designers from releasing their work to be improved through self-correcting behavior in open-source communities. This, in turn, delays community recognition of individual efforts and stalls the communal learning process (i.e., slowing design). These regulations become exacting as the inherent risks of a design increase (e.g., ventilators require more review than face shields). However, these more complex designs are valued amongst makers who often ascribe greater value to technical challenges than positive impact. To pursue greater challenges, some communities chose to operate in the highest-risk spaces (e.g., ventilators) while abandoning regulatory efforts altogether.

When makers act as manufacturers but do not accept regulatory responsibilities, they force practitioners to bear the final consequences of faulty devices. When these communities accept regulatory responsibilities, they rely on the forms of readily available knowledge. If principled knowledge is unavailable or is contradictory, makers turn to health professionals as practical expertise is an acceptable substitute for principled knowledge. However, we note that medical practitioners, who know how to use a device (e.g., PPE), do not necessarily know how it functions; their experiences are not reliable.

Practitioners too rely on regulatory processes derived from principled knowledge to ensure that a device is safe and effective. Without access to these (e.g., principled knowledge, practical knowledge, and embodied experiences), makers are at a disadvantage.

The resulting misalignment of principled knowledge and espoused practical expertise may be exacerbated by the rapid spread of anti-regulatory sentiment and misinformation online during collective sense making. Communities that effectively limited the spread of misinformation tended to accept external regulation, while those that adopted conspiracy theories tended to internally regulate based on their own values.

Disregarding regulation cannot confer the right or responsibility to act without caution. Even as supplies of traditional PPE ran dry, many hospitals rejected products donated by makers. In some cases, makers pressured individual medical practitioners to accept and use their PPE despite administrative restrictions. We argue that the maker belief that they have a right to help can act as a barrier to provide the right help. Furthermore, makers who believe they can do enough good (e.g., if they can save one life with their ventilator while brushing aside risks for even one death) use this to justify their unregulated actions and untraceable consequences.

### *4.4.2 Implications for Systems: Safety & Speed*

Makers' criticism of regulatory structures is not completely unfounded. Regulatory systems can slow down problem-solving, stunt multifarious design approaches, and raise the barrier for entry. Established systems of knowledge production and distribution are not designed for speedy action. Regulations favor centralized institutional settings with access to more resources. We recognize the justifiable demands of action-oriented makers to

pursue unrestricted design and distribution. As a result, a tension arises between safety and speed and reveals opportunities for new ways of making and managing communities.

In normal circumstances, the public is not aware of the consensus forming debates that produce medical device regulations. However, research about the virus and the development of new PPE designs have occurred openly and concurrently, so non-technical makers could observe this sense making process in real time. It is in the public's interest to quickly disseminate and contextualize emergent knowledge. We observed community efforts to accomplish this in a context of their making with varying degrees of success. When the context remained unclear to makers, discourse broke down and action halted.

Without access to principled expertise, makers struggle to distill the requirements of medical devices regulation into actionable instructions. Decoding regulatory efforts to relax non-critical policies requires expertise beyond the capabilities of most makers, who are typically volunteers who lack domain knowledge. The NIH 3D Print Exchange attempted to create a pathway for medical makers to have their open-source designs reviewed, but designers had little visibility into this process post-submission. As a result, communities chose to either offset the significant upfront cost of design work by distributing designs regardless of formal review or divert significant resources towards design and away from distribution. While some communities chose the latter, others distributed designs without clinical review which consumed finite resources (e.g., volunteer makers, materials) in faster, unregulated, and potentially harmful production.

Despite these challenges, some communities persevered and followed external regulations though even in these safety-focused communities tangible progress was

critical. Otherwise, the momentum of maker activities is slowed as time is lost to serve redundant regulatory processes. In the end, striking the right balance between action and regulation is critical to ensure sustained collective action as explored in the next section. From a parallel study of institutional makers, I draw insights into the process of establishing safe, reliable, and large-scale medical making within healthcare settings set up with resources for small-scale prototyping (described in Chapter 3).

## 4.5 Study 3: Overview of Institutional Response

The niche practice of medical making is made feasible through collocated fabrication [124] with clinical staff at varied levels of stakeholder expertise. This staff includes people who mediate operational activities in institutional fabrication spaces. At the onset of the pandemic, such stakeholders played a pivotal role in organizing institutional stopgap PPE response. They act as intermediaries because of their distinctive position at the nexus between institutions, maker communities, and wider networks. In this study, I sought their perspectives to understand efforts to steer medical making for temporary manufacturing, or stopgap measures.

Over five months of stopgap efforts, intermediaries organized medical making around distributed manufacturing processes. These involve manufacturing digital designs with decentralized fabrication; a shared infrastructure not unlike peer-produced repositories leveraged in maker communities. Efforts to organize stopgap PPE production with medical and engineering institutions required additional infrastructure considering the litigious, regulated, and conservative environment for medical manufacturing. Organizations where intermediaries navigated transition efforts led to wider collective

action [44]. These intermediaries provide critical perspectives in lieu of clinician-makers as lead users [77] during the COVID-19 pandemic.

In this study, I explore making as repair [50, 91, 161] to understand the infrastructure required for safe medical making. Stopgap manufacturing occurred in response to a breakdown in critical supply chain infrastructure. Adopting the view described as repair orientation by Jackson et al. [22], I observe making to stem a supply chain breakdown, instead of progress, to re-purpose material design and production to widen a perspective of crisis response beyond temporal actions.

### *4.5.1 Study 3: Research Design*

Makers at medical and educational institutions in the U.S. made efforts to increase PPE supplies. I studied 8 organizations that used making infrastructure to design, manufacture, and distribute PPE between March and July 2020 (i.e., the acute and chronic phase of the pandemic) with two collaborators. The institutional identities (e.g., hospitals, academics) of facilitators impact their roles in organizing maker response from other grassroot maker community efforts. We study how those in facilitation roles adapted infrastructure to meet supply chain needs.

#### 4.5.1.1 Methods

We identified organizers at institutional maker spaces because they occupy a unique position between institutional resources, niche medical maker communities, and wider community partnerships with open-source makers, industry, non-profits, and other local experts. As medical makers, organizers represent a variety of professions in relation to their

institutions listed in Table 4. We interviewed 13 medical makers who organized efforts to manufacture stopgap PPE. These medical makers were actively involved in fabrication spaces located or related to institutions. We set out to understand how they transitioned activities for stopgap manufacturing for their institutions' priorities. We emphasize their situated activities in institutional locations across five regions of the United States (i.e., Northeast, Southwest, Southeast, Midwest, Northwest) to represent a variety of medical making responses as the pandemic spread across the nation.

We recruited intermediaries through snowball sampling starting with our personal networks. We directly emailed 7 administrators of institutional maker spaces for semi-structured interviews. These participants referred us to 6 other participants within their institution and other U.S. maker networks. We recorded all 13 interviews conducted over 30–45-minute phone or video calls. All interviews, except P11 and P12, occurred in August 2020. We interviewed P11 and P12 earlier in June due to their availability. We had interacted with P1, P3, P8–P13 prior to this study during our academic research. All participants provided informed consent before participating in the study. These methods were approved by our Institutional Review Boards.

#### 4.5.1.2 Participants

Medical makers who facilitate activities in institutions typically wear many hats. Some have specialized expertise (e.g., clinical, engineering, academic research) along with administrative duties. We sought out stakeholders who organized stopgap activities regardless of prior engagements with medical making to understand the extent of change in their responsibilities. We recruited them from our personal networks in academic

research and community participation at professional events such as maker-fairs, fabrication conferences, and later, snowball sampling through our participants. All participants in this study (1) Produced PPE primarily for medical point-of-care use and later essential workers, (2) Applied digital fabrication technologies (e.g., laser-cutting, 3D printing), (3) Functioned between March—July 2020, (4) Operated in the U.S. subject to regulatory authorities for institutional and individual manufacturing activities.

**Table 4 Participant Demographic Data of Intermediaries**

| PID | Role | Gender | OID | Institution | Region | Type of PPE | Scale; Stage |
|---|---|---|---|---|---|---|---|
| P1 | Researcher | M | H1 | Hospital | South West | Face shields, ear savers, NP swabs, Ventilator parts | <1000; I |
| P2 | Engineer | M | M1 | Academic (Health) | North East | Face shields, ear savers | <10000; I |
| P3 | Administrator | F | | | | PAPR and Ventilator parts | |
| P4 | Researcher | F | | | | | |
| P5 | Researcher | M | E1 | Academic (Tech) | South East | Face shields, ear savers, | 10000+; I, II |
| P6 | Administrator | M | | | | PAPR and Ventilator Parts, | |
| P7 | Researcher | M | | | | Respirators and more | |
| P8 | Clinician | M | H2 | Hospital | Mid West | Face shields, ear savers, PAPR and Respirators | <10000; I |
| P9 | Administrator | F | H3 | Hospital | Mid West | Face shields, ear-savers, Disposable gowns and 25 more | <10000; I, II |
| P10 | Administrator | M | M2 | Academic (Health) | South West | Face shields, ear savers | <10000; I |
| P11 | Administrator | M | N1 | Non-Profit | South West | Face shields, ear savers, | <10000; I, II |
| P12 | Administrator | F | | | | Ventilators, PAPR parts | |
| P13 | Administrator | M | E2 | Academic (Tech) | North West | Face shields, ear savers, Disposable gowns, PAPR parts | <10000; I |

**Description:** This table shows organizational details with region, types of PPE mentioned, scale of distribution, and active stages (acute supply shortage phase (I) and chronic supply shortage phase). The last column in Table 4 includes response across phases denoting a change in urgency for PPE stockpile and community wide use. In March, the acute shortage phase required intermediaries to meet an urgent demand for PPE with inadequate scientific and regulatory guidance. Around May, the chronic shortage phase marked a shift to produce PPE based on regional needs, community partnerships, and resources.

#### 4.5.1.3 Analysis

Before reaching out to intermediaries, three researchers monitored public discussions on 13 Facebook groups shortlisted on the search terms: PPE, COVID, DIY-PPE, and masks for their approach to making PPE worldwide and in the US between March and June 2020. In bi-weekly discussions, we developed a set of research questions grounded in these observations to develop our interview guide for institutional medical makers. We identified questions to understand maker perspectives unidentifiable in online discussions with the intent to probe for shifts over five months across regions. Our key questions for intermediaries can be summarized under three top-down themes.

1. **Production Priorities:** What are the choices for PPE and the production approach to organize materials, equipment, and space for institutional priorities?
2. **Prototyping and Production Process:** How does their process align materials, design, iteration, and testing activities for risk mitigation and production?
3. **Expertise and Skill Networks**: To what extend do professional networks across industry, academia, and online maker communities, existing and acquired during the process, support manufacturing needs?

We synthesized findings with top-down coding along these three themes of production priorities, prototyping and production process, and expertise and skill networks. Our stakeholders shared their priorities for fabrication process of PPE primarily with 3D printing technologies, popularly used in medical innovation labs [93] for safe, reliable production with community partner networks. Participants consistently mentioned two air filtration devices (a, g), one accessory (b), one test equipment (e), two face protection (c,

d), and two full body protection devices (f, h) shown in Figure 2. They discussed medical making infrastructure (e.g., space, materials, equipment) and overall prototyping outcomes for healthcare needs over five months. In parallel, we gathered public data (i.e., news articles and blog posts) to inform our understanding of their sociopolitical context.

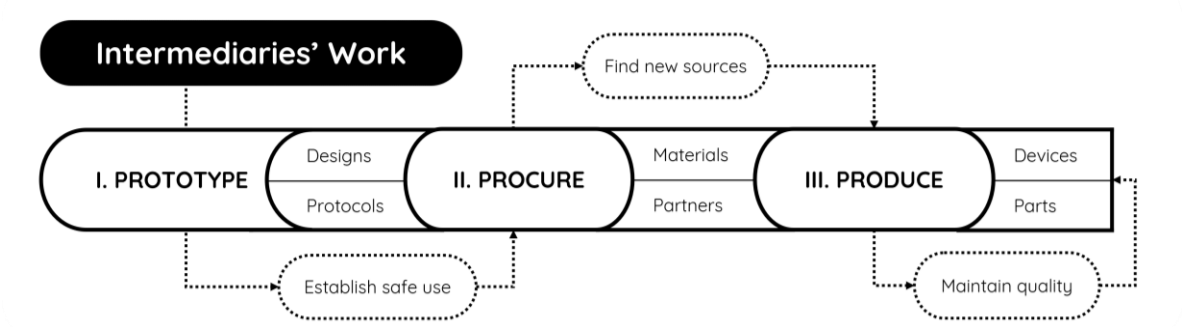
## 4.6 Study 3: Results

In this section, I describe intermediaries' efforts along themes of production priorities, prototyping or producing PPE, and expertise. The first section delves into a material-driven prototyping that reveals a larger distributed manufacturing process, where safety as a value is embedded in PPE production for distributed work between different stakeholders and locations. The second section briefly defines production priorities guiding their pivot from innovation to stopgap manufacturing. This section emphasizes how community production is made possible through extended partnerships with regional communities and peer-produced work.

### *4.6.1 Intermediaries' Role in Distributed Manufacturing Activities*

Intermediaries expanded their involvement in distributed manufacturing, a process of decentralized production, to produce stopgap PPE across inter-linked activities. The three main activities to (a) Prototype artifacts, (b) Procure material resources, and (c) Produce safe devices are shown as a visual representation in Figure 3. The diagram highlights their additional responsibilities in dotted boxes.

**Figure 3 Intermediary Activities in Distributed Manufacturing**




The next three sections explain how intermediaries prototyped safe, reliable designs with institutional affiliations and verified protocols for assembly. In parallel, they procured material and human resources through coalitions with partners in industry and community. Finally, they produced PPE for expanded use in their communities through the distributed manufacturing process set up for medical making.

#### 4.6.1.1 Prototyping: Iteration for Care Work

Speed was of essence, yet safety was non-negotiable. Unlike collective online efforts, intermediaries are medical makers who extend the medical community norm to *"do no harm."* They iterate on designs for safety, reliability, and usability in the healthcare context. However, they start manufacturing designs for institutional use when a specific iteration of the prototype adequately meets the approval of internal compliance teams (e.g., IRB, infection control). P13 describes their approach when they discovered a safety predicament in typical engineering design practice,

> *"A standard thing is to watermark 3D printed parts with indents, and that's terrible for sterilization and control. We created a variant that had no labelling on it and came up*

*with a labelling system to replace it, so [when] you distribute these in the hospital, you know that this was an approved design and not an unapproved design." — P13*

Most intermediaries started with reliable sources for design. They iterate upon files from equipment manufacturers (e.g., Prusa, Form Labs, Budman) and known makers in online repositories (e.g., NIH 3D Print Exchange, Thingiverse, Github). The Prusa's face shield [134], mentioned by all except P9, was adapted for care. Every participant in our study consulted clinical staff including nurses, to adapt PPE for usability needs. Intermediaries (P1, P2, P7–10) preferred 3D printing precisely for this speed of iteration. The face shield underwent design changes in length (P1, P9), attachments (P9–11), and material tests (P1, P13). Others like P7, directly printed parts from equipment manufacturers to iterate with the materials,

*"[Prusa was] trying to get people who have machines and networks to print device parts. It brings up a very interesting aspect of community production of these devices." – P7*

Iteration for safety invariably led to a design affiliated with institutions. Intermediaries had to adapt these prototypes to suit changes in material availability (P1, P8, P9, P13), need for re-usability (P1, P4, P8), remote assembly (P5, P9, P10) and overall costs (P4, P6). Some institutions (M3, H2, E1, E2, N1) submitted their designs to regulatory authorities and partners for wider distribution later in the chronic phase. Others partnered with start-ups (H1, H3) or volunteer organizations (H3, M1) in the acute stage itself. More significantly, some participants (P9–12) emphasized documentation of procedures for safe production of PPE. Intermediaries delivered such procedural knowledge to communities in the form of playbooks (P10, P11), videos (P6, P9), and virtual live community events. These knowledge sharing activities emerge from a safety

prerogative during the prototyping phase. P11 explains N1's commitment to create safe PPE as a non-profit,

> *"Our responsibility is being safe, not putting anything into the world that makes the situation worse."— P11*

#### 4.6.1.2 Procuring: Material and Human Resources

Intermediaries at most institutions had access to fabrication equipment, materials, and larger institutional spaces for assembly. However, environmental shifts related to the pandemic pushed participants to go back to prototyping or proceed with production efforts. Their process was driven by regional shifts in availability of material and human resources.

Stopgap manufacture was underway during the supply chain crisis. As a result, intermediaries ran out of printing materials like 3D printing filaments and filter materials for masks in the acute phase. Even when materials were available, access to 3D printing equipment varied based on the robustness each regions' technology industry. The Southwest, P1, P10, and P12, could easily send away their designs for offsite printing because of a rich technology-centered startup environment where easy access to highly skilled 3D printing expertise was more feasible. However, P3, situated in Northeast, instead needed to acquire new printers onsite to scale because niche expertise was not as widely available in their region. Most other intermediaries mentioned switching to alternate materials while material suppliers were being identified in their networks (e.g., legal team, maker communities, clinician-makers). They used alternate materials to learn about design efficacy, production speed, and developed digital files in the early prototyping stage. P1 mentioned using rayon from general store tampons for testing NP swab prototypes. This

iteration was replaced with other materials once a start-up partner took over the actual production of NP swabs. Some of these material experiments led to actual designs to meet stakeholder needs over time. P13 describes a disposable gown design made with textile machines and plastic sheets,

> *"[In response to medical team request:] We re-purposed the fabric cutter and the composite shop that's usually used to make bags and vinyl, carbon fiber cut outs [...] and we rolled out plastic sheeting on top of it." — P13*

Lockdown measures freed up institutional spaces in the acute phase because they could not be used for regular activities. Intermediaries were able to oversee socially distanced assembly with onsite volunteer staff. Participants (P8, P9, P13) mentioned conservative and restrictive institutional policies of recruiting volunteers around state or existing institutional employees for making activities before emergency guidelines were issued. This proved to be alternate employment in some cases (H2-3). For offsite community volunteers, intermediaries turned to social media. Participants (P6, P8–10, P12) mentioned social media appearances to activate interest in their stopgap efforts. P9 participated in a public virtual conference, live platforms, and put out calls for sewing face masks. P12 who raised funding for N1's infrastructure needs, offers insight into her perceptions of public reactions to making in her experience:

> *"It feels like our fundraising environment is being driven by social media or something. It's very, very reactive. It's doesn't feel proactive at all." – P12*

Unlike these unpredictable reactions, individual clinician-makers took a more systematic approach to intentionally channel resources in three ways. First, some clinicians

procured personal supplies of filaments and other materials to support intermediaries (P2, P6, P8, P10). Second, these clinicians organized lab spaces with additional equipment to scale up activities for intermediaries (P4, P5, P9, P10, P13), materials from industry partners, and actively participated in prototyping activity. Third, clinicians bridged knowledge from scientific communities to non-medical communities for production efforts through design distribution or partial manufacture (P1, P2, P10, P13). P10 mentions a clinician-maker who did all three actions for their institution:

> *"The same clinician is involved with multiple 3D printing labs with a good inventory [...] When he came up with the idea of using transparency sheets [for face shields], he went to Office Depot, very early on, and bought a pretty substantial inventory."— P10*

#### 4.6.1.3 Producing: Reliable, Safe, & Timely Artifacts for Expanded Use

Medical makers oversaw limited, small-scale manufacturing. Production of stopgap PPE required new infrastructure and approaches. Participants upheld safety in their approach to efficiently produce and assemble PPE with procedures. Intermediaries developed safety procedures for onsite and remote production. P9, P10, and P13 described rigorous onsite tracking to mitigate the risk of batch contamination. Internal infection control teams approved protocols for COVID case tracking, delivery cycles, and decontamination. Not all devices were fully assembled (e.g., face shield holders) before distribution. Participants (P5, P8–10, P13) documented these procedures for safe assembly of devices by their recipients in the destination hospitals. Documentation of procedures allowed intermediaries to manage reliable production with community partners (P9—P12). Once set, volunteers onsite and offsite were engaged in low-skill community efforts for

assembly, disinfection, or further documentation. At an academic institution, P4 describes how student-employees operate *"like a machine"* to assemble face shields,

> *"The assembly was done by graduate students [...] running this network like a machine. They were most of the reason why we even got to these large numbers. [...] They basically set up this network for students that want to come, build, and help as much as they can." — P4*

In the chronic phase, intermediaries changed their production approach as volunteers in institutional spaces returned to regular roles. Some intermediaries stopped production while others worked with community partners to simplify production efforts. Cost became a factor for some participants (P1, P9, P13). Others (P6, P8, P10) found manufacturing partners once they developed design files. These files of replacement parts or alternate materials encourage wider 3D printing efforts in repositories maintained by manufacturers [214] and NIH 3D Print Exchange. In face shield manufacture, P6, P8, and P9 switched technologies for speed, from 3D printing to a combination of laser-cutting, waterjet-cutting, and injection molding. P6, a volunteer, explains how their laser cut face shield could be flat packed with 2D cut attachments for timely delivery in remote areas,

> *"The manufacturers for each individual thing [face shield parts] could just mail it to the hospital. [...] If we shipped the face shields completely assembled, they would have taken up more space. So, we transitioned to 2D cutting and made everything flat." — P6*

### *4.6.2 Emerging Roles in Medical Making Activities for Stopgap Artifacts*

Intermediaries primarily transitioned existing institutional resources by pivoting from routine medical making to increase PPE stockpile first at their institutions and then

for the wider community. Before the onset of COVID-19 in the U.S., they were aware of global maker community efforts in Italy, Singapore, and China to make ventilators and masks. Their institutions' decisions to prepare for anticipated stockpile guided temporary measures. However, intermediaries re-purposed existing artifacts in the medical community to guide offsite production with community partnerships.

#### 4.6.2.1 Healthcare Providers Influence Stockpile Priorities

The extent of temporary production is defined by healthcare institutions' estimates of stakeholder needs. Intermediaries organized activities in the acute phase informed by the medical community. On the one hand, institutional leaders, often clinicians, influenced an understanding of urgency for PPE stockpile. On the other, regional level priorities set by external demands from communities created a different role for intermediaries who acted as procurement-buyers with the responsibility to find suppliers, volunteers, and industry partners.

Clinician-makers created an environment of trust for stopgap medical making efforts. Trust is critical because medical liability for devices is disproportionately higher on medical professionals even when they do not oversee the fabrication process directly. Intermediaries oversee such fabrication equipment to 3D print device parts or test device prototypes among other equipment for medical making. All participants with equipment access (except P3 and P12) mentioned specific clinicians in their maker networks who initiated their efforts on behalf of institutions. These clinician-makers are popular in the emerging 3D printing medical community as advocates for maker technologies (e.g., 3D printing). They also assure adoption of maker PPE by end users. P1 outlines how a clinician

stakeholder's endorsement of his prototyping efforts matters for the support of staff in the testing and later adoption of devices.

> *"We can say we 3D print or fabricate a face shield that's going to keep you as safe as a commercial one. If this doctor, a leader in her space, goes to her staff and says, 'I want you to test out their new designs for shields,' trust is now imparted through her." — P1*

Institutions set mandates for their maker facilities to produce PPE stockpiles as a stopgap measure while traditional sources can be gathered. All intermediaries except P11 and P12 mentioned that the number and types of PPE were decided by their respective engineering or medical institutions to build up supply stockpiles for their healthcare community's staff. The definition of the community depended on the institution's size and location. Some extend to rural hospitals (N1), area hospitals (E1), and citywide efforts (M1, H3). Though individuals (P6, P11, P13) initiated ideas for novel PPE, the choice of specific PPE (e.g., face shields) or parts (e.g., ventilators) was directed by gaps in stockpile rather an interest in inventing PPE. P7 describes an institutional research lab's stopgap response with 3D printed ventilator parts to replace used parts in the hospital stockpile for a clinician-maker,

> *"I think the goal eventually would be to develop a design that either, if they need us to, we can print it for them. Or, if it's a network and it's someplace else, in another hospital in [the state], they can have the design and print it out for themselves if they want." — P7*

Such focused stopgap manufacturing contrasts media mentions of PPE efforts as mass manufacturing efforts. Intermediaries had to allocate limited institutional resources (e.g., space, labor, time, materials) to undertake distributed manufacturing. We define

distributed manufacturing as a process based on peer-produced designs and decentralized fabrication, is suitable for small-scale production. Intermediaries eventually turned to communities that upload peer-produced designs and procedures (e.g., Github, Thingiverse, Reddit, Twitter) in the chronic phase. Yet, such sharing activities seemed to focus on communal learning and making efforts of volunteer partners. Within his institution, P8, the only clinician maker in our study, explains his hospital's focus on face shields for 10,000+ employee. This was judicious based on their regional network of distributed 3D printing equipment across an extensive hospital system beyond the institution's actual makerspace and research labs. He expresses skepticism about a colleagues' onsite capacity to 3D print expensive ventilator parts with the limited equipment, time, and expertise.

> *"There's no debating the power of distributed manufacturing and saying, when the supply chain goes down, you have the ability to manufacture things on premises. Now to say you're going to manufacture everything?! Well, that's different, right?" – P8*

#### 4.6.2.2 Facilitators Scale Activities Onsite with Institutional Partners

Before the pandemic, intermediaries acting as facilitators in institutional spaces primarily made artifacts in collocated, small-scale setups for innovation (see Study 1). Most intermediaries in medical making institutions (H1-H1, M1-2) remarked on the speedy ramp up to manufacture PPE. E1 and E2 gathered resources ground up with institutional support on funding, equipment, or expertise. Participants in existing institutions (all except N1) started experiments with rapid prototyping technologies such as 3D printing because they had access to the equipment and expertise. In academic institutions, easy access to volunteer student labor encouraged timely PPE production onsite. Regional urgency

overrode access to resources in locations like the Northeast that were worst hit by the pandemic's spread. Intermediaries at M1, situated in this region, started with whatever production capacity was available onsite.

Intermediaries met stockpile needs in the acute phase through onsite production to improve speed and capacity (P1, P8–10) while they prototyped for a reliable design. They developed protocols to monitor onsite assembly for infection control, decontaminated assembly, and non-medical partners for safe production. Some others could pass on these safer, reliable prototypes and protocols to manufacturing partners. P1 explains this process in the context of outsourcing Nasal Swabs to a local start-up in the Southwest region instead of onsite manufacturing,

> *"When we develop a device for another hospital, we're now marketing that device. We as an institution didn't want to produce Nasopharyngeal (NP) swabs for other sites. In [a start-up consortium], one for-profit company wanted to scale up to print swabs for us, but then also other hospitals. They went through the process of registering with the FDA and figuring out those needed steps." – P1*

Similarly, most intermediaries found regional partners to build production capacity offsite. They created coalitions with industry, non-profit, or individual partners for community participation. Then, intermediaries facilitated community efforts in distributed manufacturing of PPE parts and devices, or for assembly and distribution. We refer to these efforts as community coalitions. Some were led by some individuals (P1, P8–11) while other institutions (E1, N1) set out with regional goals early in the acute phase.

Partnerships depend on their proximity to other networks. Regional concentration of educational institutions for technology and medicine mattered as much as allied industry for start-ups, existing material suppliers, and manufacturers with factory space. P1 and P10, in the Southwest, were relatively closer to technology start-ups in Silicon Valley. They were able to partner with non-profits and start-ups with high-tech 3D printing equipment and expertise for face shield assembly. In contrast, supplier networks were closer to P9 in the Midwest because of 3M, a large medical manufacturer of critical filter materials and devices. P9 describes two material-based partnerships: a supplier and a textile company to ramp up production of disposable gowns.

> *"We worked on a pattern to make our own isolation gowns, secured some [prototyping] material from Asia, and then worked with a company just North of us to save space. They were producing gowns for us." – P9*

#### 4.6.2.3 Intermediaries Engage & Equip Communities to Participate

Intermediaries restored institutional stockpiles by producing PPE with community involvement. As a part of the medical making community, they could access healthcare expertise to establish safer approaches through materials, procedures, and partnerships. However, their efforts to transition with urgency to stopgap manufacturing across acute and chronic phases of supply shortages indicate distinct care responsibilities to engage others' efforts. We examine how intermediaries' responsibilities in the stopgap process became opportunities to equip community partners.

Intermediaries coordinated onsite and offsite activities through communication technologies. The division of manufacturing onsite into high-skill prototyping and low-

skill production allowed intermediaries to manage shift-based activities. They were able to uphold safety of people and process in the acute phase. As every participant relied heavily on communication technology (e.g., Slack), any observations of community interactions were mostly virtual. In prototyping conversations, intermediaries mentioned learning opportunities (P1, P5, P10) for less active community members.

During production, intermediaries faced repeated task-level communication around assembly, decontamination, and dispatch procedures. Some participants (P5, P9–11) described centralized procedures pinned in Slack communication channels either as playbooks or documents. However, efforts to streamline community participation required more detailed media content. P9 describes how a video tutorial of mask designed for hospital use is now serving a wider base.

> *"We actually designed that video on YouTube [...] with over 40,000 masks donated to the hospital. We were helping to supply the community and patients as well." – P9*

Volunteers engaged in production with the intent to help their community. Intermediaries recognized and described how they maintained volunteer morale by creating a supportive environment, encouraging maker pride, and ensuring visibility of impact. P1 mentioned creating special artifacts, custom branding H1 ear-savers to encourage maker pride among hospital users. Intermediaries (P5, P9, P10), who disseminated their designs early, tracked usage statistics of PPE produced through end users on social media. They communicated this impact to communities in their region with human stories of maker-volunteers and featured medical users. In collocated spaces, they (P5, P9–P13) were able to document client appreciation for PPE in the acute phase at the height of relentless

manufacturing work. P13 remarked on how the physicality of the actual device acts as a feedback mechanism.

> *"When in production, everything that came off the printer was a feedback mechanism for 'I'm doing good and I'm delivering this and I'm helping people.'" – P13*

Intermediaries withstood anxieties of adapting to the constant shifts in distributed manufacturing processes. Intermediaries simultaneously repaired regulatory gaps with protocols, re-purposed materials supply fluctuations with new approaches, and resolved volunteer attrition with community partnerships. In the acute phase, technically skilled intermediaries (P1, P2, P6, P10) worked in physical isolation till institutions approved volunteer-employees for onsite supply. P2 and P12 explicitly commented on the relentless drive to manufacture PPE with no end in sight. P12 expressed how four months of intense response required pivoting at a pace that P11 identifies as "*COVID time*" pressures. Efforts to pivot are sometimes at odds with altruistic maker expectations to participate in distributed manufacturing during a crisis. P12 describes one such concern when volunteers are asked to pivot from creating PPE for healthcare use to community wide needs:

> *"Our community didn't sign up to make face shields for hair salons. They signed up to make face shields for healthcare professionals and first responders, [...] I don't think we can ask them to work towards mushy or foggy, moving goalposts." — P12*

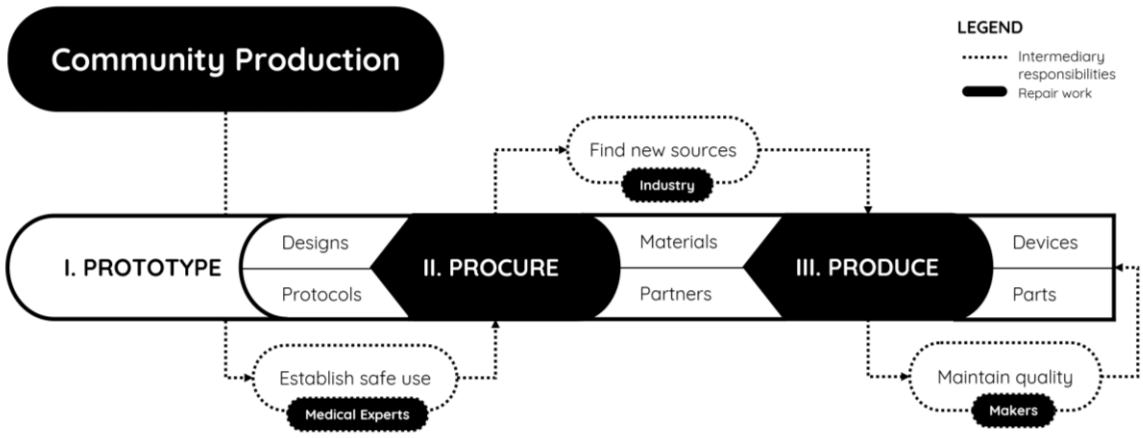
## 4.7 Discussion and Contributions to Medical Maker Infrastructure

We identify intermediaries as makers in institutions who organize manufacturing for medical use. When these intermediaries co-create infrastructure for COVID-19 PPE response. Their activities are based on institutional priorities to oversee the process of

distributed manufacturing leading to community wide efforts. We discuss intermediaries' activities for these efforts in Figure 4 to re-enforce risk mitigation in stopgap manufacturing as a comparison to Figure 3 where intermediary activities are identified earlier.

Intermediaries iterate on affiliated design and regulatory procedures to repair short-term supply chain gaps in infrastructure by working with partners in medical, industry, and wider communities without compromising safety in the process. They establish safe use with medical experts, find industry sources for materials and manufacturing, and maintain process quality in maker-led production. Their efforts to shift from innovation to repair reveals maker culture questions around ethical use of open-source outcomes, collective action, and solidarity efforts.

**Figure 4 Intermediary Activities for Community Production**




**Description**: Intermediaries (a) Prototype artifacts, (b) Procure material resources, and (c) Produce safe devices while they manage additional responsibilities shown in dotted boxes. They revisit procuring or prototyping activities. The arrows pointing right to left between activities are indicative of this reversal in the process. These reversals occur even when a

prototype is in production stage due to changes in supply chain or material realities. They cope with such unpredictable changes in regional or material needs among other repair work highlighted by filled boxes in the diagram.

### *4.7.1 Making for Care: Re-purpose Design for Safe, Medical Use*

Medical makers engage with design extending from care for others unlike larger maker communities motivated by novel technologies. Intermediaries in our study cope with the escalating demand for material-driven designs in uncertain supply conditions. They re-use internal protocols and prototypes to guide non-medical stakeholders in safe, reliable making for medical use and community needs.

#### 4.7.1.1 Iterate on Affiliated Design with Experts

Medical device manufacturing laws typically restrict institutional distribution of PPE. We observe the development of affiliated designs as prototypes affiliated with institutions in the prototyping activity phase indicated in Figure 4. We found intermediaries start with design files affiliated with organizations where clinicians may be involved. Such affiliations indicate diligent process quality due to the medical liability on organizations (e.g., VHA, university, hospital) and market players (e.g., Prusa, Form Labs) by existing regulatory bodies. Additionally, they document protocols for safe assembly of manufactured parts at destinations without access to onsite fabrication equipment. Intermediaries iterate on these designs and process with medical experts for healthcare use. In contrast to low levels of iteration observed in routine clinician led making [82], medical makers iterate for material availability and point of care usability. Every intermediary enlists healthcare professionals to adapt designs developed by engineers with inputs from

both nurses and doctors. Then, they create low-scale prototypes [99] with their respective local, regional, professional, and personal networks to re-purpose affiliated designs and protocols for production.

#### 4.7.1.2 Improve Usability for Healthcare Practices

Healthcare workers wear PPE to protect them during care delivery. Their task efficacy in terms of communication, movement, or routine use cannot be compromised using PPE. Intermediaries, who iterate for innovation at points of care, prioritize testing for such usability while upholding safe, reliable healthcare use. We found most participants could iterate for healthcare use quickly in the acute phase by experimenting with available material alternatives, and then identifying partners for production. However, some intermediaries responded with more urgency by printing parts to be added to existing devices already in use. Such replaceable parts, re-usable features, and workarounds are essential to quickly replenish high-cost ventilator stockpiles at hospitals. Industry partners released designs of parts (e.g., Form Labs) to encourage maker networks at large to print parts while intermediaries contributed to these libraries with alternate designs for efficient production. We found that intermediaries focused on reaching wider communities in the chronic phase by changing manufacturing methods (e.g., injection molding) and formulating protocols and procedures for safe assembly of PPE offsite.

### *4.7.2 Manufacturing Momentum: Recruit Community Partners*

Medical makers in our study largely represent institution-based making with access to critical medical making infrastructure. Over five months, they re-purpose small-scale distributed manufacturing infrastructure to create roles for community partners in medical

making activity. Their response reveals clinicians initiate support yet collective action through making [78] requires special community partnerships.

#### 4.7.2.1 Clinician Role for Mobilizing Institutional Support

Clinician-makers are lead innovators [77]. Their authority confers credibility to medical making efforts creating trust. They ensure adoption of makers' devices at the institutional level and validate infrastructure use. In early March, when emergency guidelines were not yet in place, clinician-makers exert influence in their institutions to initiate stopgap plans. With fluctuations in material supplies and sociopolitical complexities, maker experiments are critical to understand materials, technology efficiencies, and organize efforts to meet urgent mandates for safe PPE. Clinician-makers can manage conservative expectations around risks of innovation in healthcare settings [5] including failed prototyping costs. Without their support, intermediaries risk interruption in their activities of procurement, prototyping, and production.

Intermediaries rely on specialized medical expertise for infection control, legal compliance, and other internal regulatory authorities. Gaining prioritized support for the combined expertise of these stakeholders establishes safety in medical making. As indicated in Figure 4, they help articulate quality control processes in protocols while evaluating prototypes for safe use. Moreover, access to infection control teams in the acute phase alleviated uncertainty in the selection of materials due to a lag in peer-reviewed scientific data. Once material reliability and safe protocols are in place, intermediaries scout for safety-oriented partners who carry out high volume production. By the chronic phase, consistent production of PPE by industry startups or non-profit makers could use

protocols that lower the risk of contamination. These actions extend the medical community's safety ethos throughout community production.

#### 4.7.2.2 Community Partners to Scale for Community Needs

Most intermediaries met institutional mandates for PPE by May before the chronic stage (Table 4) and continued with stopgap efforts to enable community production. Initially, onsite social distancing constraints led to the recruitment of volunteers, graduate students, and clinical staff who may have been furloughed. Intermediaries' process engages volunteers in low-tech and low-skill work of PPE assembly, decontamination, and dispatch. Intermediaries maintain quality of maker efforts indicated in Figure 1, by defining a process for low-skill work without training [169] in large institutional areas for production activities. Volunteer employment is governed by institutional regulations for use or distribution of PPE when produced by clinical, student, or research personnel.

By the chronic phase, most intermediaries replace employees or students with local partnerships except for N1, which transitions to produce larger volumes. This procurement activity leads to startups, supply companies, or non-profits taking over production. We found these partnerships depend on the institutions' regional proximity to high-tech communities (e.g., Southwest) or material suppliers in local industry (e.g., 3M is in the Midwest). Others distribute affiliated design prototypes and protocols on social media, online websites, or open-source repositories to ensure wider circulation for safe community production. Through these efforts, intermediaries unintentionally restore missing regulatory guidance around medical manufacturing by makers.

### *4.7.3 Making as Repair: Hidden Labor in Community Production*

Medical makers prioritize safety based on their institutional liability and medical responsibility. Both are community norms [169] guiding their reliable maker response to a public health crisis. Yet this response placed expectations on participants in our study to keep pivoting their efforts to repair critical care infrastructure. The extent of their individual responsibilities in pivoting to cope with changes is visible in the activities (see filled boxes) they revisit in Figure 4. This shines a light on the role of altruistic maker efforts and implications of overstated maker efforts in mainstream media.

#### 4.7.3.1 Misrepresented Repair Work

Makers are not manufacturers. Individual makers organize collective action [44] as acts of resilience [123] based on maker community values of care and altruism. Along these lines, we found medical makers re-use material knowledge and re-purpose institutional infrastructure to create opportunities for community partners to produce safe PPE. Their repair work [91] highlights breakdowns across regulatory, material, and cultural design orientations to coalesce community roles in medical supply manufacturing. Intermediaries work with open-source maker communities, institutional design networks, and sustain collective action with distributed manufacturing for low volume production. Yet, we found our participants valued community partners outside technical fields by engaging in care for communities and creating communal learning in open infrastructure.

Overall, we found medical maker response repair infrastructure breakdowns as a stopgap measure through social systems for collaborative action. Identifying and creating such social systems were part of our participants' work. It is not surprising that we found

some intermediaries who openly express skepticism of news and social media mentions where PPE efforts are presented as mass manufacturing alternatives. We highlight their experiences of medical making with distributed manufacturing in contrast to technology centered narratives of PPE making efforts during the acute phase to offer a more holistic view of maker infrastructures.

#### 4.7.3.2 Relentless Crisis Mode Response

Safe production of medical devices requires establishing, then maintaining quality of process. As intermediaries do both and manage real-time feedback within their communities. Intermediaries leverage existing platforms (e.g., Slack) while non-medical institutions (E1, E2, and N1) concurrently document their safety processes to monitor infection rates and material reliability. While intermediaries can access healthcare information formed within closed scientific communities, their process documents convey such information to inform community efforts across the digital divide [34]. Their systematic response to create standardized processes, cope with regional material shortages, iterate on new designs, and protocols upholds safety across each of the three activities seen in Figure 4.

#### 4.7.3.3 Misplaced Labor

Stopgap PPE design artifacts moved between open innovation on peer-produced networks to closed innovation within institutional networks. This poses two ethical challenges. First, a decentralized means of production increases responsibility, in this case intermediary or clinician-maker duties, to document, organize, and communicate information. Second, it underplays the role of consistent crowd work in open communities that is critical to

manufacturing at scale. Without a realistic assessment of labor, individuals bear the disproportionate cost for infrastructure creation and maintenance.

As manufacturing labor, ethical concerns around open-source innovation arise when it becomes unpaid labor in a market-driven environment in the U.S. as studied in other maker communities [169]. Jackson et al. offer a means to examine such creativity [90] that highlights maker response to repeated breakdowns in supply chain, regulatory lags, and pandemic conditions succeeded due to their decentralization efforts. Undertaking these responsibilities indicate the resourcefulness and resilience of those engaged in collective action in the face of relentless pressure match pace with *"COVID time"* (P11).

### 4.8 Implications for Future Infrastructure Design

Makers in intermediary roles introduce medical community norms into distributed manufacturing. Wong et al. describe lifeworlds as places where artifacts are defined by their "*social, perceptual, and political environment*" [196]. Maker practices and relationships exist in a lifeworld largely focused on innovation. This study uncovers makers' efforts to design when situational constraints in these lifeworlds create breakdowns for temporary or sustained periods of time. Makers iterate for reliability when regulatory, material, and cultural infrastructure fail to exist. This re-purposing of innovation infrastructure suggests design opportunities for future acts of resilience during crisis to broader implications for interdisciplinary research discussed in Chapter 6. In this section, I suggest two speculative exercises to decentralize and diversify participation to expand on how medical making offers a case study for healthcare transformation from the bedside through nurse makers.

### *4.8.1 Decentralized Prototyping among Medical Makers*

From our stakeholders, we learned prototyping involves iteration for safety. The process involved adapting available designs further to suit material reliability, design feasibility and device usability. Most maker communities at large engage technical expertise for the first two. Though each iteration occurs at an intersection of all three factors, it may be possible to create affiliations to share knowledge at each phase. We found that makers for medical purposes iterated on prototypes released by hospitals, academic institutions, and industry manufacturers.

While the NIH 3D Print Exchange is one official source of affiliated design in the U.S., participants released their designs on open-source exchanges and hospital websites to quickly disseminate their designs. The variability in materials, designs, and differences in iterations can speak to social use and re-use activity. Such evidence can inform policy revisions to decentralize affiliation and the relevant authorities for each phase within communities. For example, material reliability for medical use can be carried out by an infection control team in a health sciences lab. The documented iterations at each teams' level can contribute to community learning.

### 4.8.2 *Material-Human Networks to Support Healthcare Priorities*

Healthcare systems are rife with technologies that prioritize operational expertise over people's needs. The motive for innovation shifts to meet institutional and communal needs. We found that when intermediaries prototype, they adapt to materials that can be sourced through local networks with maker technologies. However, purely technocentric design repositories or general-purpose repositories like Thingiverse are inadequate for making

when for community needs. Viewed from a sociocultural lens, these repositories exclude the efforts of some makers such as nurses.

As seen in study 2 and 3, there is a place for craft, expression, and design for maker values (e.g., customized ear-savers). Nurses as a stakeholder group have previously created other workarounds with alternate materials. Widening repositories to include design alternatives for part production, alternate materials, local procurement partners, and protocols can diversify collaborative efforts in rural areas for applications in care. Going further, a design experiment with expansive rather than extractive design goals can guide research on critical making.

### 4.9 Publication Details & Areas for Future Work

Both studies were published at CHI 2021 as separate papers [84, 107]and received honorable mentions for Best Paper in their respective sessions. The parallel analysis of medical makers' design process indicates hidden efforts in widening collective action within a situated context of crisis-related medical making response. In my future work, I extend my inquiry of stakeholder understudied inside U.S. healthcare institutions: nurses.

## CHAPTER 5 – CREATING WARM SOLUTIONS AT THE BEDSIDE

In my fourth and final study, I turned to a missing voice in my research: nurses. Though my work so far describes a wide ecosystem, clinicians were disproportionately represented by physicians as emerging medical makers (see Table 2). The under-representation of nurse participants in my previous studies signals a corresponding absence of nurse voices in healthcare related research in HCI. Noting this absence led me to question what barriers and opportunities nurses encounter to participate in present-day medical making as a form of innovation in hospitals.

The term nurse making is increasingly linked with nurse innovation over the last decade [207]. From nursing literature, we know nurses express a moral responsibility to create workarounds in standardized procedures even when it raises ethical questions [19, 21]. They are motivated by visceral demands to care for patients' unanticipated and critical needs. Most nurses tinker with existing devices, create workarounds, or adapt parts of their environment. Nurses also usually undertake patient education for preventive health. Their prolonged interactions may lead to ideas that are better integrated into the patient's individual lives while informing best practices for such interventions involving artifacts. Asurakoddy et al. study innovation behavior among public health nurses to describe how *"doctors demonstrated the skills of gathering knowledge, whereas nurses exhibited the skills of new idea generation which was more important in innovating behavior process"* [9]. With nurse presence in hospital settings, their participation and collaboration in innovation centers like makerspaces is understudied.

Extending from a social construction of technology approach, I included non-users of maker technologies and non-linear "*technology frames*" in my two-part study [23]. In doing so, I took a wider approach to identify present-day nurse makers indirectly through a network of makerspace facilitators. However, I first surveyed the historical influences in nursing innovation and practice. I then re-oriented my methods based on feminist theory [35] by changing my description to nurse problem-solving, a term free of techno-optimistic notions around innovation [10], at points of care.

Correlating histories of nursing innovation in U.S. helped me factor influences on present-day participation in medical making, oriented towards innovation. Hidden within structures, seemingly inherent nursing professional and organizational hierarchies became more apparent. In this chapter, I discuss key lessons for HCI's goal towards democratizing participation by outlining the nursing community's position in technology design as innovators, users, and participants.

## 5.1 Overview: The History of Present-day Nurse Innovators

Nurse contributions, and nursing work itself, have a complicated past as gendered work in the medical hierarchy. In 2017, there were 3 Registered Nurses (RNs) for each physician employed in U.S. healthcare workforce [168]. Nurse absence is conspicuous in the literature with largely physician-led point of care innovation [3, 16, 124]. Studies in nursing journals suggest nurses collaborate within their community of practice to innovate too [9, 101, 209]. Yet nurses are seldom invited to participate in wider technology initiatives in institutions beyond the scope of evaluation in design [144, 178]. Instead,

nurses are known to appropriate technologies in ways that support nursing work at the bedside [21, 67].

Historically, nurse resourcefulness at the bedside was considered integral to routine nursing work, at least per literature in the U.S., as evident from improvised hospital equipment dating back to World War II [55, 67]. A prominent example of nurse-led innovation during wartime can be seen in Florence Nightingale's organization of patients by severity of condition, creating a model for the modern intensive care unit [191]. Framed within the maker movement, nurse perspectives within current medical practice offer insights into understanding participation within maker ecosystems. In this study, I investigate the following research questions:

**RQ3.** What factors impact nurse inclusion in medical making at the point of care?

a. How do historical influences *shape* nurse roles in problem solving and innovation?
b. How do current institutional structures *affect* nurse participation in innovation?
c. What are opportunities to *engage* nurses in future medical making?

I argue for the relevance of nurse-led activities as an understudied HCI domain based on three factors: the historical role of nursing work in care [27, 175], gender norms in making [60, 192], and community norms of care [5, 97, 186]. Nurses use alternate materials, face unusual constraints in their practice, and act to solve problems at the bedside. In situations they face, nurses encounter opportunities to respond to breakdown developing into larger opportunities. I argue that nurses' everyday creativity, often associated with low resource contexts in HCI [50, 90], introduces a new dimension of participation in creating solutions.

I build on my previous studies to characterize crucial, understudied stakeholders in the medical making ecosystem. Additionally, in the reflexive tradition of other HCI researchers [5, 15], understanding nurse participation in technology can reveal methodological limitations when recruiting historically overlooked participants in interdisciplinary research. When I conducted a literature review, a close reading of nurse innovation experiences in the last decade helped me reframe my view of nursing roles. In the next section, I describe briefly how findings from a literature review (study 4a) directed my primary data collection around present-day nurse innovation (study 4b).

## 5.2 Study 4a: Historical Review of Innovation in Nursing Work (U.S.)

I revisit nursing innovations to reframe them from historical themes in nursing work. I analyzed past and present-day nurse innovation discourse to understand maker technology adoption among practitioners today. Instead of product outcomes, this literature review approaches nurse innovation as a vital response to sustain patient-centered design through medical making. I performed a Google search on *"nurse innovation"* for media articles over the last decade. The year 2010 coincides with the Robert Wood Johnson Foundation's initiatives to possibly support key committee recommendations on the *Future of Nursing* at the Institute of Medicine [41]. The foundation offered financial and media resources to nationwide healthcare institutions invested in encouraging expert amateurs [105] with public media coverage. Some private hospitals in the U.S. mirrored this move internally with a focus on nurses (e.g., the Mayo Clinic, Phoenix children's hospital, John Sealy hospital). A few partnered with Maker Health, an MIT Media lab initiative to set up makerspaces – the first one at the University of Texas Medical Branch, inside hospitals [198]. Notably, the Maker Nurse initiative

reflects individual nurse efforts to create solutions within each partner institution [207]. It is unknown how supporting structures support nurses beyond these sites of innovation.

Underlying this trend to organize nurse-led innovation are notions of novel and scalable solutions. Both notions draw from a prevailing definition of market-oriented, technology-led innovation to maximize creative ideas as products [38]. However, Gomez-Marquez and Young draw attention to another trend in history, that of *"stealth innovation*," a longstanding practice among nurses who create bedside improvisations [67]. I build upon their work in this section to investigate how nurses describe solutions.

### *5.2.1 Literature Review & Analysis*

In Spring 2020, I shortlisted public mentions in social media and blogposts by searching for the terms *"nurse innovation"* or *"nurse innovator"* online. I identified three institutional sources: academic nursing journals, nursing blogs, and social media. Articles in academic nursing journals [184, 194] offered institutional insights into nurse innovation. However, rare first-person accounts from nurses (e.g., *Rebecca Love: A Nurse's Guide to Becoming a Successful Entrepreneur*, 2019) who are entrepreneurs or make artifacts offered more insight into the challenges nurses face when they undertake innovation in routine nursing work.

In parallel, I collected accounts from the nursing community – nurse leaders, nurse innovators, and facilitators. I also referred to three books on nursing philosophy, the nurse training act, and women inventors in technology [129, 150, 171]. I will organize my findings from this literature review to approach *RQ3a How historical influences shape nurse roles in problem solving and innovation?* I examined nurse engagement

across two arcs. First, how nurses solved problems, and in what ways was this choice supported by the medical community as nursing work? Second, how did market pathways for innovation become an alternative outside mainstream nursing practice? To answer these questions, I note the operation of power and language [35] in nurse descriptions.

### *5.2.2 Gendered Norms: Labor & Participation*

Nurses in the U.S. are largely women (88%) representing an intersectional and marginalized group engaged in gendered work [168]. These factors influence the visibility of nurse contributions and recognition in the medical hierarchy. Butler's work directed my attention to how nurses perform their roles, repeatedly adapting and creating within their routine work, to deconstruct, and eventually question gendered norms around innovation. In *Undoing Gender*, Butler proposes that *"through recourse to norms, the sphere of the humanly intelligible is circumscribed, and this circumscription is consequential for an ethics and any conception of social transformation"* [[35] p222]. The ethical prerogatives of nursing work are essential yet hidden. The constraints in recognizing its impact on healthcare become visible when the norms of novelty, scale, and innovation itself are seen from the nurses' act to intervene. I argue that understanding constraints and contexts within which nurses enact care can reveal opportunities to encourage and integrate nurses in activities they may find relevant to care practices.

My aim is to distill these performative acts of problem-solving hidden within nursing work regardless of prevailing notions of technology-led innovation. I started with bottom-up codes developed along three themes: historical agency, community resources,

and barriers to innovation. My analysis led to an understanding of how and why nurse solutions are undermined and undocumented in the history of medical innovation.

### *5.2.2 Undermined Contributions: Gendered Nursing Work & Erasures*

The nursing community, in the U.S., stands witness to the historical erasure of its contributions to healthcare. Bowker and Star's observations when classifying nursing work in the 1990s [29], provide a brief background of the dual erasure of nurse activities within a hospital environment. They observe how hospitals systematically discard traces of nursing work ranging from the act of expunging their patient notes to subsuming nurse services under other hospital services in accounting records. This deepens gendered norms of overlooking the efforts of perpetually "on call" nursing staff. However, this external erasure within the medical hierarchy, the lack of recorded data, creates gaps in understanding how nurses exactly perform in a clinical capacity or what they achieve, though physicians' records are retained for reference in medical research.

In parallel, a trade-off is undertaken by nurses themselves. Nurses conserve the time required to catalog the variety of tasks. In doing so, management is unlikely to standardize and override a nurse's practical freedom to adapt their workflow. Experienced nurses may overlook their knowledge, as a language developed from experience, inadvertently withholding the definition of a process or specific solutions from other nurses. This behavior creates a more pervasive internal erasure in nursing work. Moreover, nursing in Western medicine is oriented to an ethics of care (to do good), as described by global nursing scholars [150]. Nursing philosophy according to these researchers is often incompatible with practical expectations placed on individuals at points of interaction (i.e.,

the provider or patient). This leads to nurses actively hiding their processes [21] to offset surveillance that may lead to curtailing a nurse's agency to act on more urgent information.

Patricia Benner, a nursing scholar in California explains how *"Nurses are required to engage primarily in clinical reasoning, and only in times of complete practice breakdown, novel problems, or confusion are nurses required to engage in critical reasoning"* [19]. Clinical reasoning, rooted in practice, relies on social relationships and concerns to inform clinical decision making [19]. While nurses use clinical reasoning in administering procedures, they apply critical reasoning rooted in practice – a type of puzzle-solving based on more recent developments in their environments. At times, critical reasoning may conflict with clinical reasoning [67]. As a nurse educator, Benner outlines how critical reasoning in practice, is overlooked within a standards-driven healthcare practice that is more aligned to treat the pathology. Towards this end, nurses are expected and trained, to perform universalized procedures that may deprioritize immediate needs.

However, in situations of breakdown, novelty, or confusion, nurses act. As women, nurses perform care work in medical situations in ways normalized to their gender. Women's work, historically performed as invisible domestic labor, extends from child rearing and caregiving roles. Studies on classifying work show this invisibility, to some extent, may be due to nurses' perception of their efforts as an extension of routine care [175]. If their actions to materialize artifacts attend to patient care, then these actions count towards innovation, eventually becoming a part of practice at the point of interaction. I investigated these erasures in study 4b to understand how they define the expectations in the nursing community to participate in present-day nurse innovation. Primarily, I focused

on the additional labor performed in medical making as repair and innovation (discussed in Chapter 4) and the organizational hierarchies supporting nurse ingenuity.

### *5.2.3 Undocumented Inventions: Articulation Work for Historical Archives*

My hypothesis, based on both types of erasure in nurse inventions, correlates the professionalization of nursing practice around the 1960s with present-day barriers. In this section, I focus on how professionalization intensified two main barriers: first to articulate material artifacts for scientific archives, and second to obtain formal support to convert patents into products for market presence.

#### 5.2.3.1 Professional Nursing Practice and Scientific Archival

With its emphasis on practical or applied reasoning [19], nursing practice in the 1960s left little room to participate in a documented form of contribution to medical history. Homespun nurse innovation in the early 20$^{th}$ century indicates a different context when nurses were required to care for patients in their homes (The Nurse, 1915 c.f. [11]) not hospitals or at the literal frontline during wartime efforts. The terms *"nurse improvisations"* and *"workarounds"* appeared in several articles in the *American Journal of Nursing* (AJN) to invite open experiments shared with a larger nursing community. Nurses invited feedback in professional trade magazines [55, 67]. Their inventions primarily took the artifactual form necessary for material practice. In this sense, the skill of writing to contribute to a scientific archive did not extend to all members of the medical community. In medical practice, this power was vested in physicians while nursing was still a technical trade-based vocation in the U.S.

With the growth of the U.S. hospital sector in the 1920s, nursing shifted from a central role in holistic care to passive support within institutional healthcare [129]. Coinciding with this period after World War II, Gomez Marquez remark on the recognition of nurse ingenuity through AJN's *The Trading Post* for the next 15 years [67]. The article highlights how improvisations were judged on practical execution and provision of patient care over financial imperatives. Nurse training was imparted in 1938 at the New York chapter of the Red Cross to improvise hospital equipment with a limited archive on nurse creativity at patient bedsides (Farley, 1938). The Nurse Training Act in 1964 formalized and streamlined options for nurses in training across in the U.S. [129]. By the 1990s, when *"the profession began to formalize and align itself more closely with science"* [62], some nurse researchers and educators became more adept at skillsets required for scientific publication. Nevertheless, a nurse articulates her inventions for practical use. Invention in medical research either as patent or as a scientific publication requires scientific collaboration for credibility, well out of a nurse's reach. Other sources show that nurses simply made artifacts at home instead [67, 171].

**A Case Study on Archives: Anita Dorr's ER cart**

A registered nurse in the emergency department, Anita Dorr, noticed an opportunity to organize her work by crafting a wooden prototype by first cataloging various medical supplies with her colleagues and her husband's help at home. A precursor to the now ubiquitous crash cart, the "crisis cart" [164], formally appears in medical invention archives credited to Dr. Joel J. Nobel. The patent held by Dr. Nobel is based on his prototype, Max the Lifesaver, which appeared in LIFE magazine and can be found in *The Smithsonian's National Museum of American*

*History*. Anita Dorr is a legend associated with the now robust and influential organization, *Emergency Nurses Association (ENA)* [136, 164]. The invention of the cart, culled from practical use, materialized from a nurse's practice. The records do not mention the invention because it was not articulated in the form of a document within the network of medical institutions acknowledging the original idea based on a nurse's contribution in medical history.

Anita Dorr's crisis cart, a wooden prototype, represents the potential of nurse problem-solving. When developed from iterative use in nursing practice, it could become useful in wider emergency care [164]. It is a marker of nurse capabilities previously showcased in AJN's column ["Ideas that work", 1964 from [67]] such as improving geriatric patients' movements with roller skates on rocking chairs, newborn babies' prenatal care with inventive tracking mechanisms, and other incremental yet essential workarounds [67]. When professional nursing practice prioritized hospital employers' demands, there seemed to be an eventual decentering of nurses as key actors in care innovation.

To some extent, nursing education adapted to meet the needs of hospitals while conferring streamlined licensure and accreditation of nursing work. Today, the term "nurse" for most patients can mean a registered nurse (RN), a nurse practitioner (NP), and may include a Licensed Practical Nurse (LPN) and additional qualifications of a bachelors, masters, or doctorate in nursing. However, the power to act in a medical capacity varies with each of these accreditations within nursing practice. Some nurses, deeply entrenched in practice at the bedside, have little visibility into the large-scale implications from the practical use of their artifacts. An RN may not be able to articulate her invention, or even

attract collaborative interest from scientific experts. It is unclear how other positions innovate within nursing practice [9, 64].

#### 5.2.3.2 Nurse Entrepreneurs and Marketplace Patents

Historical accounts of nurse entrepreneurs are rare, but there are some who set out to articulate the value of their innovations for the market [171]. Physicians who seek entrepreneurial routes in the market with present-day 3D printing technologies (e.g., for profit [68] or open access [149], operate within power structures that were historically unavailable to nurses. As clinicians, nurses are vulnerable to risks of both litigation and unethical interventions yet they are subjected to greater scrutiny than physicians at least in the U.S. [21]. The work required to scale nurse innovations exposed them to other challenges outside the healthcare system.

Innovation became conflated with notions of scale with the rise in technologies. First introduced, at least in literature, by the economist Thorstein Veblen as the collective effort to meet the essential needs of societies towards communal development [188], it was only in 1974 that Christopher Freeman's *The Economics of Industrial Innovation* introduced notions of scale with different forms of technology to solve problems of an entire society [61]. In recent times, Clayton Christensen [38], a Harvard business professor, describes innovation in terms of market disruption achieved by technological artifacts. In fact, it is not technology that ensures scale but a complex network of infrastructures.

In a recent study, Avle et al. describe how the techno-optimistic vision of scaling up or dominating markets is employed in nation-building rhetoric around technological production [10]. Based on their background, nurses might need support in carrying out a

specific kind of cooperative work for large-scale collaboration: articulation work [163]. Embedded in complex cooperative arrangements, missing articulation work around nurse ideas or insights can impede efforts to either contribute to incremental innovation or realize innovative products within the medical hierarchy. I found that nurse innovations, despite their articulation for scale in the market, remained at outside formal innovation efforts because of limited community support.

### A Case Study on Market Pathways: Bessie Blount's Patent

Bessie Blount, an African-American wartime nurse and physical therapist, successfully patented her "Portable Receptacle Support" device to feed amputee veterans in 1951 [171]. Blount received initial support from her hospital administration but met with challenges manufacturing the patent at scale from the U.S. Government. Without the VHA's support, she eventually gifted her patent to the French government. While Blount continued to invent other gadgets and interventions from her practice, this feeder is the only invention in the archives resurfacing in the recent work tracing inventions by extraordinary individuals [22, 171]. An understanding of this instance of nurse invention points to a deeper, more pervasive trend around the support structures required for nurse participation.

Blount's example is one of many nurses operating at the intersection of race, gender, and professional margins [171]. Though the details are lost to history in her case, the fact that her patent was voluntarily renounced signals a lower anticipated exchange value, a type of withdrawal, of an inventor's expectations from the public. Relying on the prerogative of individuals traps nurse innovators to perform in ways

aligned with the norms of care at a personal cost, such as Blount, or accept a place in oral history, like Dorr, for their roles in technical invention that remain unrecorded in archives.

### *5.2.4 Understanding Current Nurse Innovation: Making & Recognition*

In this section, I analyze excerpts from interviews with nurses with access to hospital makerspaces. These nurses enroll in programs with funding, research collaborators, and management advocating for their invention as an innovative product. While a physician is outnumbered by 3 nurses in the U.S. today [168], collaborations in academic medicine [156] between a physician and a nurse are rare. A blog entry on career advice titled *"Nursing Innovation"* by an ER nurse asserts that nurses do not recognize their creative potential [139]. Laura Kinsella, a nurse educator describes how nurses solve problems: *"From innovative wound dressings to re-purposing gloves or hospital socks for off-label uses, we are always thinking outside the box. We just* ***never realize it****."* The mindset to constantly adapt their environments is also a mindset essential for creative problem-solving at the heart of both design and engineering processes. A nurse educator and innovator, Marion Leary at Penn Nursing in [137] explains how, *"Especially in the healthcare system and in the community, nurses do workarounds all the time. We just* ***don't call it innovation****, but that's what they're doing and that's what they've always done. Now we're just looking at making it more formalized."* The act of realizing and formalizing then correlate to creating visibility around nurse creativity with innovation within hospital environments.

Studies show that nurses solve problems out of *"great responsibility towards the most vulnerable populations"* [176]. Within institutions, like Driscoll Children's Hospital

in Corpus Christi, Roxanna Reyna explains how she got the idea to improve wound care dressing for children. The interview mentions how the "product" applies only to a specific group of patients, *"and there's not enough demand for it to be manufactured on a large-scale basis"* highlighting a sensitivity to the scale of innovation at the problem identification stage [130]. Reyna's solution improves the healing process for children with a birth defect affecting their skin after children undergo surgery. However, *"experimenting with bandages, sponges, and tape"* does not count as a relevant activity towards innovation unless Reyna is able to articulate its value as insight at a scale commensurate to and impact the hospital's goals.

While most publicly available posts, most likely sponsored by institutions, indicate optimism around innovation, nurse frustration with breakdowns show up on social media and community discussions. A curated set of letters to the editor of American Journal Nursing (AJN) reveals the frustration of nurses: *"Have you ever tried to correct or update the problem that spawned a workaround? It never happens. Bureaucracy and hospital administration never respond."* The article urges nurse leaders and hospital administration to identify when nurses resort to *"working the system to relieve system flaws or to help their patients*" to improve engagement and retention of nurses in patient care [21].

Within a centralized system, performing a formalized set of protocols, nurse insights are extracted as a resource. In a nurse entrepreneurship article, Thomas Clancy, a clinical professor at the University of Minnesota School of Nursing states that "*Nurses really have a wealth of knowledge about how products work. The biggest problem is that knowledge hasn't been tapped"* [73]. Institutions approach nurse participation guided by standardization of practices for improved efficiency with limited insight into practice-

driven insights (see section 2.3.3). Because nursing work exceeds standardized process [27], a nurse's insights into opportunities for design are keenly oriented to emerging healthcare practices. While the approach is necessary, it can ignore the interests of nursing as a profession to perpetuate care work at the frontline. Healthcare technologies have repeatedly tried to automate nursing functions in an integrated system of healthcare system to create passive mechanisms that deliver reliable care overriding the validity of personalized services required in patient care. Nurse inventions however are intertwined in nursing work at the center of care delivery. With a focus on such care delivery, nurse improvisations could return agency to nurses who attend to anomalies in care systems if recognized as legitimate labor. Understanding the value of these insights could further improve possible concerns within the nursing community of practice with an impact ranging from nurse retention, satisfaction, and learning over time to benefit nurse stakeholders. I explore the scope and potential of these concerns in the final study.

## 5.3 Study 4b: Current Barriers to Institutional Making

Based on my analysis in study 4a, I designed a study on nurse engagement in present-day makerspaces. In previous studies, I explored the norms, values, and expertise related to stakeholder participation by first locating where physician-led making originates at the bedside to create safe, reliable, small-scale prototypes, and then re-framing the importance of medical making, with lessons from the COVID-19 pandemic, when grassroot and institutional makers' efforts repair temporary manufacturing breakdowns with reliable medical supplies. The historical literature explored in study 4a provides a background for study 4b focused on re-centering the role of nurses in medical making. Historical nurse contributions in routine care (in the U.S.) highlight three themes around

innovation: formal collaboration, articulation work, and practice-driven prototypes. I develop insights along these themes from current nurse experiences in hospital innovation settings to understand how making may or may not support nurse innovation today.

Within the scope of this final study, I argue that making creates (and relies on) more than artifacts; it creates a dynamic environment with new hierarchies. An environment, where social infrastructure, not technologies, afford opportunities for ongoing innovation. At the outset, study 4b contributes a perspective from an understudied stakeholder group in medical innovation to further characterize *who participates in* the situated activity (i.e., medical making) in healthcare practice. Towards this goal, the study's findings address **RQ3b how current institutional structures affect nurse participation in innovation** and **RQ3c opportunities to engage nurses in future medical making.** This study highlights how medical making privileges contributions of a few medical makers over others. Further, the minimization of nurse problem-solving in practice is contrary to nurse training for care roles in the U.S.

Finally, the exclusion of nurses from making in institutions perpetuates their work's invisibility in long-term policies – FDA guidelines, recognition of labor, training for future roles in healthcare. Findings from this study impact infrastructure design for nurse inclusion by articulating informal design efforts, relating the role and extent of training, and recognizing low-tech innovation in care with implications for continued nurse learning and training.

### *5.3.1 Study 4b: Research Design*

#### 5.3.1.1 Methods

Nurse participants in my study represent a subset of professionals in active nursing positions in the U.S. Within the scope of this study, I recruited 16 participants between October 2019 and September 2020 to understand nurse contributions in maker technology initiatives. I shortlisted five existing healthcare facilities (e.g., hospitals, academics) from public media mentions and my pre-existing network of medical makers from previous studies. In addition, I reached out to nursing professionals in our personal and academic networks to survey wider perceptions of makerspaces and making within the nursing community. I began by approaching nurse participants who self-identified as makers or innovators. Two participants explicitly stated that they did not make physical prototypes. I include their perspectives in this study as non-users of maker technologies.

#### 5.3.1.2 Participants

I recruited 10 nurses associated with five of these spaces in the in the United States described in Table 5. During interviews, I found two did not use maker technologies despite awareness of such spaces on their hospital premises. I retain their perspectives as they were considered problem-solvers by others in the study. They offer insights into their experience of non-use to inform boundaries of technological capabilities in practical contexts [17]. All others were actively involved in fabrication spaces located or related to institutions sharing four characteristics: (1) collaborated or directly prototyped solutions for training or point-of-care use, (2) applied craft or digital fabrication technologies (e.g., laser-cutting, 3D printing, electronics), (3) worked as or with nurses on at least one prototype, and (4) were subject to U.S. institutional or other manufacturing and regulatory frameworks.

**Table 5 Participant Demographic Data of Nurses**

| ID | Profession | Specialty | Role | Environment | Identity | Experience |
|---|---|---|---|---|---|---|
| E1 | Nurse Practitioner (PhD) | Neonatal, Maternal care | Educator | Health University Makerspace | Female | 5+ |
| E2 | Nurse Practitioner (MS) | Critical Care, Surgical | Educator | Private Hospital, Makerspace | Female | 5+ |
| E3 | Nurse (BS) | Critical Care | Educator | Hospital Makerspace | Female | 10+ |
| E4 | Nurse Practitioner (MS) | Prenatal Care, Midwifery | Educator | Hospital Makerspace | Female | 20+ |
| E5 | Nurse Practitioner (PhD) | Gerontology | Educator, *Non-user* | Hospital Makerspace | Female | 30+ |
| N1 | Nurse (PhD, Masters) | Endocrinology | Entrepreneur | University Maker Program | Female | 5+ |
| N2 | Nurse | Midwifery | Entrepreneur | Hospital Maker Program | Male* | 25+ |
| N3 | Nurse | Prenatal Care | Prototyping | Hospital Makerspace | Female* | 5+ |
| N4 | Nurse | Cardiac, Midwifery | Prototyping | Hospital Makerspace | Female | 35+ |
| N5 | Nurse Practitioner | Pediatric care | *Non-user* | Hospital Innovation Lab | Female | 45+ |
| F1 | Lab Manager | Education Sciences | Facilitator | Health University Makerspace | Male | 5+ |
| F2 | Project Manager | Management, Education | Facilitator | Hospital Innovation Program | Female | 10+ |
| F3 | Researcher | Graphic Arts, Engineering | Facilitator | Hospital Innovation Lab | Male | 5+ |
| F4 | Branch Manager | Library Sciences | Facilitator | Health University Makerspace | Female* | 5+ |
| F5 | Nurse Practitioner | Education, Leadership | Facilitator | Hospital Makerspace | Female | 3+ |
| F6 | Design Engineer (PhD) | Arts, Design | Facilitator | Hospital Makerspace | Female | 2+ |

**Advanced Nursing and Educators:** Nurses achieve seniority as they advance in their professional practice by shifting into managerial and educational roles. In our study, based on facilitator insights, I identified two groups of nurse stakeholders: educators and bedside nurses. At least half our participants operate in teaching hospitals contributing to a higher number of nurse makers who are educators in our study. However, the nursing profession requires nurses to undergo recurring certifications to update process-related and specialization-specific knowledge with implications for senior nurses. This is somewhat represented in how all 10 participants had part-time or full-time experience as nurse educators. Table 5 has details of 10 certified nursing professionals who are registered nurses. Some have advanced degrees and others specialize in critical care, pediatric care, and other areas.

With institutional review board approval, all participants provided informed consent. I recruited participants through snowball sampling methods starting with our personal networks. I emailed 6 administrators of institutional maker spaces for semi-structured interviews. These participants referred us to 10 other participants within their

institutional and other U.S. maker networks. I interviewed 2 non-users: N5 moved to a rural area from an urban area like N6 where they each had access to maker technology. I offered flexibility in research methods – a survey, emails, and interviews to suit our participants' availability, though I rely mainly on interview data in this paper. I recorded all 16 interviews conducted over 30–60-minute phone calls. All interviews were conducted between October 2019 and September 2020.

I situate this study from perspectives of nurses who have access to technical capabilities on-premises. I referred to their activities in these spaces as problem-solving in our recruitment email and interviews. I intentionally chose a less value-laden term than innovation, prototyping, or making to counter any underlying notions of novelty, engineering, or scale that nurse might associate to discount their work [175]. I first asked for their definition of problem-solving, and then probed for instances where they created physical prototypes (i.e., making) to understand the role of materials and technology use in their process (see A.1.3 Study 4: Nurse Makers). The nurse-driven definitions are contrasted with the commonly accepted notions around innovation, problem-solving, and prototyping in institutions based on previous studies [124, 152, 189]. I was then able to collect and shortlist an integrated set of results from participants' challenges in problem-solving generated from descriptions of physical prototyping experiences and their perceptions of maker technologies to innovate for nursing as a profession.

I sought non-user perspectives to explore nurses' perception of their role in shaping and using maker technologies in nurse-led problem-solving. I added one COVID-19 related question enquiring about *the state of medical supplies and its effect on their daily work as a maker*. I received reflections from (F6, E3, E4, N3) due to their

availability for interviews in September 2020. I also received email responses to the same question from (N5, N2, F4, F1) when I reached out to all the participants after the interviews in July 2020. I had previously interacted with all the facilitators prior to this study for academic work.

#### 5.3.1.3 Analysis

Interview audio data transcripts were generated with Otter.ai. Two researchers independently developed bottom-up codes from a subset of interviews for initial themes around *motivations, barriers, process, materials,* and *innovation*. In bi-weekly discussions, as we conducted more interviews, we iterated upon these themes to synthesize axial codes around three categories. First, different stakeholder *motivations* for solving problems they faced in their workflows, typically in enhancing nurse training or direct patient care. Second, their prototyping experiences with descriptions of physical infrastructure (e.g., space, materials, equipment) to highlight *barriers, process, materials*. Third, when describing the status of their ideas, they conveyed self-perceptions as makers and reflections on wider *innovation* activities. Each of these categories were refined further based on iterative coding of interviews as described in:

- **Contexts for Problem-solving:** Situations described by nurse collaborators when they observed peers' actions to intervene by solving problems with physical solutions. They identified specific materials, technologies, and resources in healthcare settings.
- **Perceptions around Innovation:** Concepts mentioned by participants when relating their experiences of problem-solving within their routine work that guided decisions to persist or desist when faced with challenges. I focus on

perceptions of the nursing profession, their individual role, and the use of maker technologies within the scope of this study.

- **Skills, Resources, and Capabilities:** Mentions of makerspace resources (i.e., materials, training, policy, and other forms of support) as reflected by participants when they identified gaps in skills to help them realize ideas. This includes challenges in existing technologies and infrastructure for healthcare innovation.

In the next section, I map key findings in each theme to describe relevant problem-solving contexts, conceptual beliefs, and prototyping capabilities for nurses to persist in prototyping solutions.

### 5.4 Study 4b: Results

A nurse (N5) must *"figure out how to problem solve"* in her daily work. Nurse problem-solving closely maps to the process of design starting with the problem identification stage confirming findings from other medical makers on motivations to prototype, a collaborative ecosystem, and challenges discussed in Studies 1-3 as well as other studies [82, 108, 167]. In this section, I organize thematic findings around practice-based contexts, perceptions, and capabilities across from three new stakeholders: facilitators, nurse educators, and nurses. Each stakeholder is linked to maker initiatives in their primary healthcare institution though their problem-solving activity may occur elsewhere describing the experiences of prototyping, innovation, or making regardless of formal outcomes. These insights extend from Study 4a's themes around undermined and undocumented nurse contributions.

I organize insights into nurse contributions across three sections. The first section confirms that nurse capacities for solutions originate at patient bedsides like others in Studies 1—3. It may at times lead to changes in the larger environment or nursing practice. The second section delves into new insights around nurses' underlying notions about innovation, collaboration, and support required to further shape their capacity to pursue prototyping solutions. The final section combines the influences of contexts and concepts on the gaps in sociotechnical capabilities to find resources (e.g., materials) to realize initial insights into innovation.

### *5.4.1 Caring at Bedsides Requires Innovation*

> *"Because nurses are amazing inventors, when we don't have the exact tool that we need, we will make it available. With our close interaction, at the bedside, we know exactly what we need."* — E3

A nurse's insight grows at points of interaction with patients in her role as an educator, manager, or specialist. E3 describes her reasons to introduce nurses that she trains to making through an exercise re-thinking IV holders in the hospital makerspace to create a foundation and expectation among nurses to adapt at the bedside. Nurse challenges in performing routine work often required adapting their environments.

Participants described their compulsion to prototype in two contexts at the bedside. One context expands on practice-wide impact when nurse leadership is involved in problem-solving to build prototypes from patient-centered insights. They may improve training with tools for specialized nursing practices or devices to improve standardized workflows. The other confirms a wider perception of MacGyver nurses [67] at the

frontline of patient care – a nurse responds to patient discomfort and care needs. Notably, these two descriptions of physical prototyping at the bedside often overlook a more pervasive trend of repair activity among nurses who adapt technology to meet their own practical needs. For example, a nurse may create shorthand codes for in-person patient notes [197] that need not be recorded yet help organize her workflow.

#### 5.4.1.1 Bridging Workflow Gaps

> *"It's not really much help to solve the problem if it's not being implemented on a wide scale [...] If I designed something like this [redacted], it would be a device that is hands off. It would work in the flow of a hospital birth." — N1*

Nurse solutions can expose overlooked gaps or outliers in patient care not yet included in standardized workflows. N1, a nurse who holds an advanced nursing degree, speaks of her prototype developed during her doctoral research. A Doctorate in Nursing Practice (DNP) involves a practice-based intervention in nursing based on observations in practical workflows. Her observations of an unregulated process workaround among midwives in postpartum care included the use of a basin to monitor the rate of blood loss in pregnant women to forecast possible time of intervention. By attaching a digital meter, her thesis research project developed the insight into a possible medical device. N4's effort to achieve a scale of deployment in the hospital was guided by her insight into standardized workflows. Alongside other nurse educators in our study, such beliefs that scale justifies effort highlights how nurses need to be equipped two-fold, first to identify a robust solution from practical insights and second to articulate its impact in line with institutional priorities. F4 explains how a nurse maker in her lab space could reserve

resource time and materials for her prototype on managing pressure wounds because it aligns with departmental goals.

> *"The lead nurse on [redacted] said she's made this one of her personal goals […]. Improving pressure wounds [management] is one of the strategic goals for the medical center and the nursing department." – F4*

The dual capacity of articulating insights and visibility is vested in nursing researchers. Nurses with advanced degree (E1—E3, N1) had the educational training and time to argue their case for institutional resources to create, adapt, and advocate solutions. Additionally, F6, F5, E3, N1, and N3 mentioned how they had more time and flexibility when making prototypes in their academic stints as researchers. Educators have a similar capacity to advocate for resources because in E4's experience, the department is likely to *"trust that you're presenting them with evidence-based practice."*

Apart from educators, all participants had part-time teaching responsibilities at the same or local nursing colleges. In these roles, according to facilitator F6, they seem to gain insight into procedures to innovate on their specialized practice as nurse leaders. Educators with such visibility into standard operational procedures can scope their problem space to independently adapt insights into prototypes. Their efforts lead to support and eventual integration into the hospital's practice, as F6 describes:

> *"The hardest part of innovation is finding the right problem. It's less about the solution and more about understanding the problem, because you can create a solution that, down the line, creates other problems." – F6*

Artifacts to ensure more consistent nursing performance (E1—E4) are no doubt welcome in a litigious healthcare environment. Educators who collaborated with facilitators (F1, F4, F6) recreated patient skin (E1, E2) and fashioned midwifery tools (E4), wound detection (E3), patient education models (E1) as training tools for process-based learning. With repeated practice, a nurse retains procedures better to avoid clinical mistakes especially when unusual patient symptoms occur at the bedside. For example, E2 makes models of unusual sutures with her learning tool made of silicone to create lifelike fake skin draped over a mannequin to build *"nurses' capabilities to apply that process"* for neonatal care complications they might someday see it in the real world.

> *"[Educators] are more invested in innovation within the practice, and understanding standard operational procedures, and making them better." – F6*

#### 5.4.1.2 Creating for Patient Needs

> *"If the patient is sick, the nurse is still the one taking care of that patient, so I think they become innovative more because of desperation than time in the in-patient setting." – F2*

Nurses may encounter problems in an outpatient or in-patient context. The latter created a more visceral response in nurses across participant groups. In the quote above, facilitator F2 muses, along with F4 and F6, how desperation sometimes propels action among in-patient nurses. At other times, nurses witness individual patient's discomfort to intervene with short- and long-term solutions.

Short-term prototypes seem to coincide with device failure in meeting specific patient needs. F2, F4, F6, and nurses (N1—N4) mentioned patient cases where a standardized medical device caused pain, inconvenience, or risk over time. F3 at a pediatric

care center explained how most medical artifacts designed for adults need to be adapted for children's needs. For instance, a ventricular assist or an artificial heart may be available for adults though developing a pediatric version is considered an innovation worthy of NIH funding and incentives. This may lead to intellectual property concerns around medical devices. F3, like every facilitator in this study, works with internal departments or external partners such as a local startup consortium, engineering schools, and a country-wide network of makers in surgical 3D printing to make this a reality for nurses stating that the purpose of facilitation is to "*leverage the interest in creating a solution."*

Similarly, others (F4, F6, N1, and N3) pointed to devices unsuited to women patients' needs. F4 describes an instance where two nurses noticed a female external catheter, a standardized design made by a non-medical person, did not adapt well to an obese woman. It caused her pain and increased risk of infection from prolonged use. The two nurses iterated on a solution made of vulcanized rubber with patient feedback to develop an attachment. In the context of another project, N3 explains how iterating on her low-tech maternity gown design with F6 solves a recurring problem in prenatal care when new mothers' struggle to sleep when strapped to a baby,

> *"It was really unsafe, even though we tell them you need to really put the baby back [on your skin...]. There's many devices actually available out there to do skin-on-skin, but not a hospital gown." – N3*

Nurses prototype solutions to prevent recurrence of the situation for future patients. All nurse participants in our study approached facilitators to brainstorm approaches once they had a solution in mind though facilitators (F2, F4—F6) shared instances where they helped refine the problem space as well. Unlike patient bedside

interventions (N1—N4), nurse educators E1–E3 drew from repeated patient observations to create training tools. These tools improved wider process knowledge in nursing practice. E1 mused that all her tools are from in-patient insights to explain why sometimes the *"acuity of the patient"* referring to medical acuity, or severity of illness symptoms, that prompt her to improve training procedures for greater retention of unique cases. Other educators explained how a nurse's perceptual acuity to patient conditions in situ can equip nurses with enough insight to act on the ethical imperative to intervene.

#### 5.4.1.3 Repairing to Perform Routine Tasks

> *"Nurses alleviate problems by using tape to create a better catheter bag […] It's just that it's not documented the same." – E3*

Nurses balance conflicting priorities to care for patients, caregivers, and clinical processes. Echoing E3's remark above, participants (F4—F6, N2, N4, N5) mentioned instances where problem-solving alleviates temporary conditions in nurses' work. They were unlikely to openly discuss bedside ingenuity based on perceived censure among nurses for their deviations from standards. Participants reflected on how others in their department adapted devices, process flows, and created temporary environments in crisis situations (N3, E3, E4) motivated by an immediate need to cope with their responsibilities. Such improvisations help them perform nursing tasks in ways that may circumvent standardized practices.

As indicated earlier, not all nurse-led problem-solving is sanctioned by institutions [21, 67]. Nurses at the frontline are forced to deviate from manufacturer instructions for use at times. In this study, I found this was because the device design seemed to

functionally fail in supporting nurse work at the bedside. Sometimes, they worked around procedures based on their values for speed, efficiency, or patient engagement. N5 explains how nurses in her unit worked around using a barcode scanner designed for safer prescription entries. The tags placed on the patient's arm interfered with nurses' efforts to maintain eye-contact to establish trust in the short time available with patients during the discharge process leading to questionable deviation from procedures.

> *"On each piece of medication that have the same kind of barcode on it, everything has to match up and be scanned. [re: the scanner] It's a safety thing to keep people from making errors, but that's one of the things we nurses learn to work around. They'll print real bar codes, tape it down on a desk, so they can handle it. […] They have like a little cheat sheet with the extra barcodes already loaded on there, but it'd be very easy to click on the wrong one." – N5*

In relating this example, N5 did not condone risking patient safety. However, she reflected on the need for workarounds when technologies were designed without nurse inputs or insights into nurse workflows remarking on the risk nurses seem to accept in performing their routine tasks within their roles in the medical hierarchy. At other times, breakdowns occur due to unpredictable in-patient conditions. Participants (F3, E2, N2, N4, N5) explain, that could not be foreseen while other ideas emerge from nurse specific concerns. For example, E2 described a nurse's initiative to create a baby apron with pockets to carry seven or eight babies in case of a fire going on to explain that *"sometimes nurses create things just with what they have in the closet."*

When nurse-led problem-solving occurs under the radar, they seem to engage in repair work to adapt devices to their specific needs in the form of customization. F6

describes how nurses *"were putting these scrunchies on their feet, so that they wouldn't trip over"* standard issue personal protective equipment (PPE) during the early days of the COVID-19 pandemic. PPE worldwide is sized for male bodies, unsuited to a 90% female workforce kept mostly on its feet. Though minor, oversight in universal design of essential medical supplies prompt nurses to adapt or create workarounds to perform tasks specific to nursing work at the bedside.

### *5.4.2 Becoming Innovative is a Challenge*

> *"I thought I was going to invent something, I was going to build it, and I was going to help a lot of people. But there's a lot of due diligence that comes with starting a business. I didn't know any of that information from the beginning." – N2*

A nurse's perception of what counts as innovation is influenced by concepts around scale and, reflexively, of herself as an innovator. N2 shares how his perceptions underwent a change when he decided to set up a product-based business in a region with fewer medical manufacturers. When he developed his prototype at the bedside, he had institutional support yet failed to attract formal collaborators within the medical community as an individual nurse entrepreneur. While nurse resilience could fuel an adaptation mindset, scaling up from prototypes to innovation demands nurses to overcome more practical and systemic barriers to explore innovation pathways in medical communities or the wider market. Each pathway entrenches the notion of resilience in nurses learning to use technologies, document processes, and the myth of a lone inventor.

#### 5.4.2.1 Reticence to Collaborate

> *"Nurses as professionals are going to be more likely to trust another nurse and maybe open up in different ways than they are with somebody who they're not familiar with." – F5*

Even before nurses attempt prototyping, they seem to operate from a position undermined by historical erasures in nursing work [27]. F5, the only nurse-facilitator in our study reflects on how a "*trust thing"* pervades nursing practice as her observation of reticence in a community. However, medical making requires collaboration as it occurs at the intersection of legal, regulatory, and medical institutional policies. Most participants (all except N3, F1, and F3) alluded to reasons for skepticism about working with others in institutional systems. Some mentioned instances of overlooked contributions (e.g., F4 on doctors taking credit, N1 on institutional ownership claims) and others referred to historical inventions or forgotten nurse contributions (F2, F4—F6, N1, N4). Of relevance to this insight is nursing's shift towards a research-driven science from a practice-driven technical profession in 1950s [55]. E2 shares her insight as a nurse educator on how a turn towards evidence-based practice may have required nurses to describe and collect evidence to support their prototypes at the bedside. Without adequate direction, it is likely they exclude nurses because their ideas were not recorded in formal literature:

> *"In about the 1950s and 60s, [nursing] started practicing more evidence-based practice, which kind of pushed some of the inventions that nurses were making out because out of the literature, because they weren't researched." – E2*

On the other hand, internal erasures exist in nursing work [27]. F2 who developed programs in her hospital for grassroot collaborations mentions how nurses speak about their ingenuity as *"what I have to do to do my job."* Observing creative opportunities required a facilitator or a leader, according to participants (F2—F6, E2, N3). Self-censoring or opting out was more common among senior nurses with more experience and training in our study. They were risk-averse in technology experiments while admitting to improvisations at the bedside. As N4, with 44 years of nursing practice, asserts, *"nurses are very rule following people"* but need *"some ego because you need to nurse"* at the bedside to contain the chaos of caring for patients. Often these actions and insights are seen as an extension of nursing work, a part of their organic routines. They rarely register as innovation without evidence to support nurse insights to begin prototyping experimental solutions.

#### 5.4.2.2 Risky Unregulated Technologies

The risks of experimentation with medical making are more unclear for nurses. The visibility into risks either of liability or material reliability are different for other stakeholders who innovate medical devices [132] while nurses tend to adjust and adapt medical supplies. For example, IV holders as medical supplies are not regulated and therefore not standardized. F1, F2, E4, N2, and N4 each mentioned workarounds or fully implemented solutions they made (F6, E2) in their departments. F6 explains how these perceptions are changing within a healthcare makerspace,

> *"The space matters, and who is involved matters, simply because in the U.S., medical manufacturing laws seem to mandate some things, but not some other things." – F6*

When regulatory gaps exist, medical professionals perceive risks differently leading to varying levels of participation. F4 points out how regulatory gaps in medical making seemingly stop nurses far more than doctors who "*surge ahead anyway."* This is echoed by F6 who draws a line between bedside problem-solving and innovation as separate modes with the remark that nurses are "*not necessarily always tinkering."* In her experience, echoed by some nurses (F5, N1, N4, N5), nurses innovate when they start thinking of implementing solutions at scale, which invariably requires justifying the use of institutional resources at least for prototyping artifacts in healthcare settings. Then, they may decide to develop their prototypes to explore one of two pathways for formal scientific research or market-oriented production. It is notable that this motivation to explore either pathway is similar to other medical makers [108], yet the challenges for nurse innovators vary in practice as seen in the next two sub-sections.

#### 5.4.2.3 Articulation for Scale

Development of ideas and insights into forms for institutional support entails effort to document, argue, and describe in ways like other novel research in scientific work entrepreneurship. Articulation of ideas entails the effort to document, argue, and describe artifacts for collaboration and recognition in scientific collaborative efforts [52, 163]. Such articulation work is key for generating resources to attempt scalable solutions. Facilitators, often also project managers (all except F3), translate scope of work and connect nurses with adequate expertise either to leadership, internal partners, or external partners.

Administrative foresight can ensure funding and material support within the institution. Facilitators in our study wrote grants with all nurse participants except N1 and

N2. Others applied to programs outside the hospital (N1, N2, N4) for mentorship, expertise, and explored market-driven pathways. F1, F4—F6 explained how they communicate and direct nurses to learn about institutional policies around intellectual transfer, innovation safety, and expectations of support for makers overall. F4 provides a glimpse into how the university expects part of the profits when a prototype becomes a product when the inventor takes it to market at their own cost.

> *"Anything that is made here or is created using any of [F4's university] resources, services or anything like that, belongs to [them....If] you will pay for marketing and I believe manufacturing, they say looks as though it's going to be big and make money, [redacted] does not own it, but they do get 40% of the profits." – F4*

Branching out of institutions requires nurses to engage in formal networks like startup consortia, academic conferences, and communities like maker fairs. These sociotechnical networks prepare individual innovators to negotiate and pivot their solutions for market needs. Participants (F3–F5, N1–3) expressed concerns establishing mentoring or coaching relationships outside their immediate nursing community. N1 and N2 who became entrepreneurs cited challenges in scaling up. N2 noted his region's lack of investment in medical devices leading him to write an NIH grant for his patent-pending device. N1 highlights her choice of a startup to raise money as a signal that *"something is worthwhile"* in her prototype. She identifies a range of specialized experts and material resources but looking back over two years sees a need for formal support.

> *"I was looking for funding, but really mentoring, training. I'm having a hard time finding it [...] I've connected with people who connected me with people. I've been learning a fair amount. But it's informal." – N1*

#### 5.4.2.4 Scientific Boundaries

In formal medical research, evidence, and the systems to generate scientific data are bounded by specific standards for what counts as research. While this rigor is necessary for medical research, problem-solving of the kind nurses seem to undertake may not be easy to translate into formal methods. Healthcare professionals have accessed emerging technologies through *"innovation labs"* in public and private hospitals long before to the maker movement. We found traces of innovation-centered language across participants associating scientific notions of measuring quantitative effects to justify qualitative improvements in care. Facilitators (F2, F3, F5, F6) think such strict notions of innovation could deter nurse participation in experimentation. They adopt a more casual approach in their makerspace pop-ups and lab sessions to imbibe wider maker communities' values of openness. However, F1 and F4 describe how their academic makerspace only attracts nursing students when educators bring them in. Unless they make one-off prototypes (E2 and N4), institutional sets the tone for nurse participation. F3 captures how his lab in a pediatric care center attracts institutional support because it carries connotations of a scientific research center with resources resembling makerspaces.

> *"Maker is [a term] barely utilized in hospitals. More often the terms of innovation lab, or printing lab…because that term "lab" has the connotation of a higher science approach." – F3*

Not all nurses want support because they are less amenable to creating solutions at scale. N4 and N5, both older nurses, weighed in on judicious use of 3D printing material when a device needs to be created instead. They would rather transfer

responsibility to a different community of biomedical engineers. Younger nurses (N1—N3, F5) seemed interested to actively participate in the research pathway based on their role in practice or explore the market pathway with wider partnerships.

#### 5.4.2.5 Individual Resilience & Relationships

Nurses, in the U.S., operate at the intersection of gender, racial, and socioeconomic pressures either directly or indirectly on behalf of vulnerable patients. Though we did not frame explicit questions to probe these sociological influences, it is possible nurses in our study faced biases on one or more fronts in their situations as persons of color performed gendered work [175, 177]. From their experiences, F2 and F4 as well as nurses (N1—N3) direct experiences attribute external reasons for stalled projects including but not limited to stopped funding, inadequate mentorship, or formal collaboration to see their prototypes through the required institution- or market-defined process. N1, N2, N5, F4, and F5 expected to balance personal goals with a demanding job towards a greater goal to benefit nursing practice. F5 describes her extraordinary transition from a nurse practitioner who spearheaded two years of projects with a grant she wrote, then worked with hospital management to advocate for a makerspace and continued to fundamentally create her position with others to build a culture of innovation.

> *"We would prototype, and at the point of care, we would start trying it, whether that was with cardboard, or scissors, or glue, all the way up to 3D modelling. [...] We built this culture, people were engaged, they're excited about their work, they had the 'we can' attitude." – F5*

The larger story of F5's success lies in the personal time she spent at conferences, online communities, and management meetings with the external support of mentors in a health-focused maker community outside her institution. Despite facilitators' view of culture and other apparent challenges discussed in this section, I noted a consistent reference to personal grit. However, the myth of the individual inventor or heroic designer [177] was evident especially among facilitators with design training (F4—F6) and entrepreneurs (N1, N2). From N5, the most experienced nurse in our study, and other senior nurse educators, nursing work requires resourcefulness, dedication, and constant learning on a routine basis by *"sharing tricks of the trade."* As innovators, regardless of the pathways, extending their capabilities seems to re-enforce this narrative of resilience to materialize their insights as lone crusaders first though every participant in this study had collaborators. When asked, participants rated nurse willingness (F4, F6, N2, N4), persistence (F1, F3, N2, F5), and duty to share learning (F2, F4, N1) as the three most influential reasons nurses innovate. In short, a nurse's individual resilience is viewed as a prerequisite though experiences indicate a higher reliance on relationships to participate in medical making.

### *5.4.3 Overcoming Constraints for Person-, Patient-, & Practice-centred Solutions*

> *"I see solutions where doctors try to automate some of the processes in nursing, because they see there's not a lot of reliability. [Doctors] already have a standpoint of liability and safety for the patient and not necessarily a warm solution for the patient." – F6*

A nurse's capabilities are enhanced by technology to perform nursing work centered on the whole person, specific patient conditions, and specialized nursing

practice. As F6 observes in the quote above, physicians may prioritize different values in their technology-based innovation because of a tendency to focus on the practice. This leads to prioritizing norms of safety and reliability in their activities. Though no one in our study contests the need for caution, most facilitators (except F1) mention how nurses tend to account for patients' lived experiences to create, as F6 eloquently puts it, a *"warm solution"* for the human being. This person-centered approach to problem-solving leads to insights that could inform changes to recurring patient-centered solutions, and further evolve into process level changes in training to become practice-centered solutions.

Other stakeholders, such as physicians, are equally motivated to intervene on behalf and in the service of patient care [82, 108]. However, the urgency and immediacy of deploying physical devices is different among nurses due to their practical orientation. The few nurses who looked to advance novel research, specialized practice, or make a social impact, at least in this study, started with an insight at the bedside. In this, nurses differed from most other medical makers in how much they iterate, at which points they seek expertise, and when they seek formal collaborators.

#### 5.4.3.1 Low Tech Iteration

When prototyping their ideas for devices, nurses used low tech materials to iterate on form and function. In contrast, most collaborators (F1, F4—F6, E1-E4, N2, N4) noted other stakeholders prototyped high tech solutions to manage the pathological condition. Nurses invariably used readily available materials suited to their solution (e.g., wood (E1, F4), cloth (N3), velcro (F4), foam (E4, F4, N1, N4), Play-Doh (F2)). Nurses who made physical artifacts looked for experiential feedback loops with other nurses and facilitators as primary collaborators. N2–N4, E3, E4, and F6 each shared instances adapting IV

holders (N2, N4, F6), face shields (E4), and surgery environments (F1–F4, E3) with better equipment. F4 describes how a team of 4-5 nurses improved a recliner for spinal surgery patients by testing different blocks of foams cut to be "*much more ergonomic"* with patient feedback over four iterations of their initial idea. Once they developed a low fidelity prototype, nurses could look for ways to adapt it further.

Nurse (N1—N4) descriptions highlight how their iterations are based on practical use (e.g., maintenance or re-use). Some added technical features with electronics (N1, N2) and digital fabrication (E1—E3, N2, N4) with technical expertise from facilitators. Educators adapted low fidelity prototypes for workflow integration with facilitators (F3—F6) who mention these project materials are selected by the nurse educators to serve multiple purposes. E1 explains how a cervical dilation tool to train midwives who learn to accurately assess dilation by making a board with cutouts of responsive silicone materials all while ensuring group bonding.

> *"The tool was conceived by me only because I didn't want a wooden or plastic board. I wanted something that mimics what the cervix might feel like at different valuation. Again, and again, I was trying to figure out something that they [students] could do together as team building. But I also wanted to have utility." – E1*

More importantly, nurses (N2—N4) seemed to perceive a more nuanced view of the patients' life to extend their solutions' effectiveness for patients. When a person-centered approach could be adapted into a hospital wide initiative, it often led to a patient-centered solution. F4—F6 who oversee collaborative projects, shared nurse insights that placed the person at the center of solutions even with high tech materials. For example, a nurse solution of a 3D printed IV holder took on animal shapes for use in

the pediatric ward. At other times, this leads to changing the environment for care delivery. E4 describes working with F6 and nurse leadership to rally resources for a solution to humanize the pediatric ward with portraits of providers to soothe isolated children during the COVID-19 lockdown.

> *"Putting the patient in the center and helping with their fears and frustrations with not being able to have visitors and connecting with nurses. And that's how it started." – E4*

A person-centered approach, described in the previous example, could eventually grew into a hospital wide initiative when the nurse received formal support. Others, like N2, could pivot an existing patent-pending prototype of an IV-line organizer to specific constraints faced by ICU nurses who needed to reduce PPE usage. However, participants invariably handed off their prototypes to technical experts in their maker spaces.

#### 5.4.3.2 Hands-on Expertise

> *"It's not obvious to them [nurses] that they're supposed to be doing the making themselves. […] We're sort of learning this the same time as they are." – F4*

Most facilitators in dedicated hospital makerspaces (except F4) have technical expertise and project management skills. Without such skills, as F4 in her academic maker space shares, nurses often expect to hand-off technology use to offset the learning curve. Though F1, F3, and F6 also work with engineering students in their local communities, on-premises support widely affected the extent to which nurses developed their prototypes based on insights.

Nurse educators offered a contrasting perspective on how and when they used prototyping to create learning experiences in their curriculum. E1 and E4 speak from a leadership perspective of hands-on learning. E5 who does not use the makerspace expected nurses to absorb learning challenges and efforts within their schedules *"to construct something that they know in their head that they need for patient care."* However, E2 explains that nurses may have a solution for problems but may be wary to invest in creating a device with unapproved equipment.

> *"Most nurses will work to solve a problem. It just might not always be streamlined or be a device." – E2*

Unlike educators, nurses are typically overseen by nurse managers. Nurses in our study overextended themselves to develop prototypes on their own time. N2 and N3 developed their projects during educational stints with flexible schedules. Technology iteration is time-consuming, so it is understandable that nurses with little time to spare will minimize its use. F1, F3, and F4 shared times they either handled or handed off actual printing time despite expectations of a hands-on maker approach. F1 empathizes with nursing students' low participation in his collaborations with the department,

> *"The biggest challenge for the nursing students is time and that has absolutely nothing to do with the makers lab space, or how it's done. [...] It's really hard to take on yet another learning process." – F2*

#### 5.4.3.3 Formal Collaboration

One alternative to time and technical skill is collaboration with others. Nurse solutions seem to lead to collaborations between nurses when makers align proof of

contribution to departmental goals. Yet formal collaboration is difficult because of structural barriers within the medical system. Participants mentioned informal collaboration within the nursing community across problem-solving stages.

Though some nurses overcame their expressed reluctance to formally collaborate by seeking nurse leadership first, N1—N4 all mentioned how mentoring across a wider network helped them make progress. N3 who was granted a short-term award stopped working on her prototype once her nurse manager was indisposed and eventually passed on. N1 looked for informal mentors outside her university finding them in a national association of nurses. F3 and F4 also mentioned their partnerships in local communities with other makers as does F5 who is deeply embedded in both local maker communities and hospital management. N2, the only male nurse in our study, described his challenges in obtaining formal collaboration with facilities within the medical community (e.g., private physician-led practice) to formalize the data collection on his prototype without much progress towards such partnerships.

> *"I went to physician-owned facilities; they have the same amount of red tape as corporations. But I'm not giving up. I'm going to continue and hopefully one of these facilities will allow me to do a pilot study." – N2*

The permission sought to participate in medical innovation indicates an underlying need for persistence. Nurses in our study, who had made any progress to scale solutions, relied on formal support from hospital leadership, grants, and programs. F2 and F5 each spearheaded a short-term innovation program in their hospitals for grassroot ideas. Without such structures, nurse insights circulate among individuals (N1, N2) who must find ways to surface their insights. Facilitators can be critical to build the trust

required to make nurse insights more explicit; to articulate the insight into a prototype. With nurse participation, they create proof of concepts with materials that are best suited for nursing practice. F2 shares her view of why nurse involvement in traditionally defined innovation projects conflicts with nursing prerogatives to care for patients:

> *"You have to find an efficient design, take the time to make it, do research on it. It takes a very, very long time. For a lot of nurses that just doesn't necessarily hold their interest, like patient care does." – F2*

## 5.5 Discussion: Transforming Healthcare Organizations from the Bedside

I set out to identify nurses' adaptive problem-solving in innovation spaces at the point of care. My findings confirm that a practitioner's role influences visibility into procedural improvements in quality of care. Unlike other frontline workers, nurse interactions require them to manage these situations for each patient creating ongoing tacit knowledge, a type of organic wisdom from experiential improvisations of the patient's life [1, 59]. Nurse contributions originate from tacit knowledge often implicit in practice. Such knowledge can be made explicit when realized with formal support as arguments and/or low-fidelity prototypes for temporary or long-term improvements.

Based on making as the context, I discuss how creating opportunities for overlapping perspectives between nurse and physician perspectives in innovation projects allows a wider, collaborative asset-based approach to problem-solving. More importantly, encouraging organic and tacit improvisations on-ground can work alongside top-down, managerial action by overcoming challenges in employee driven innovation [7, 143]. Especially in medical innovation, I argue that nurse participation can update care

practices and long-term procedural knowledge by negotiating alliances between social actors in the healthcare organization [132]. Medical making is in fact a case study for episodic future transformation of healthcare organizations.

In this section, I discuss how nurses face constraints in present day makerspaces leading to insights into three challenges: concealing solutions and sequencing resources for innovation, ultimately falling short of anchoring for future transformation [7]. At makerspaces, nurse participation relies on specific allies to craft arguments and create prototypes. I contribute insights on the supporting sites of organizational innovation [7, 143] with a focus on makerspaces towards themes of negotiating expertise in medical innovation and understanding wider participation in making as collaborative design.

I set out to identify how a nurse's adaptive mindset manifests in design as problem-solving at the point of care. All 16 participants reveal how a nurse's insight can manifest as improvements for patient-centered care beyond devices to improve healthcare environments. However, nurse problem-solving remains peripheral in institutional medical making collaborations despite most participants' view of problem-solving as an extension of nursing work. In this section, I discuss how nurses face constraints around their capabilities in present day contexts shaped by underlying concepts around a nurse's role in innovation.

### *5.5.1 Allied & Assisted Innovation: Fostering Trust*

Healthcare institutions favor consistency and reliability over risk in care practices. While this upholds safety, standardization inadvertently overlooks insights from nurse's practical reasoning applied at patient bedsides. Nurses, as clinicians, are known to bring

perspectives of prevention, recurrence, and oversights in design of devices or environments from their practice [1, 47, 102, 197]. Moreover, nursing philosophy places the prerogative on professionals to uphold ethics of care (i.e. holistic well-being) resulting in short- or long-term interventions to alleviate pain and prevent future harm [19]. I confirmed findings from nurse insights that accommodate improvements both in their own task flows and patient care. For example, E2 in our study adapted a wider training protocol to practice wound sutures based on observations of nurses in her unit. When nurses engage in *"stealth-innovation"* recorded elsewhere in literature [67], their tacit knowledge remained within their community of practice due to a lack of historical trust in existing systems. Fostering trust through visible and formal support can alleviate this challenge in employee-based innovation observed as the concealing stage in other studies [7].

The role of nurse leadership and on-premises technical experts suggest a model of *allied innovation* to encourage nurse prototyping and participation. Facilitators in our study unequivocally note that nurses need help recognizing opportunities for innovation. They oversee medical making in institutional makerspaces and innovation labs [107]. Facilitation invariably creates awareness of interdisciplinary legal facets along with engaging design and engineering expertise to develop collaborations across the medical organization required for formal innovation [63]. Educators and nurses further indicate formal support from nurse leaders or managers is central to nurse-led activity at least within the institutional setting to align resources and create visibility. I hypothesize further expanding human infrastructure through community roles, non-profits, and administrative hand-offs can supplement expertise involved in tasks for sequencing resources for innovation [7] that maybe unavailable on site. In the absence of such facilitation,

participants like N1 and N2 shared challenges finding adequate support for technical needs and mentorship outside their primary institutions. Nevertheless, to make progress towards organizational innovation, I found a need for formal roles within the nursing community to navigate challenges discussed in the next two sections.

### *5.5.2 Seeing, Creating, & Telling: Crafting Arguments*

In my study, nuances in nurse orientations to problem-solving are visible in the person-centered solutions they create based on perceptual acuity and proximity to specific patients. While their visibility into patient experiences is unparalleled, advocating for material resources understandably requires articulation work [163, 175]. The articulation of labor required for sequencing long-term resources for innovation [7] is complicated by power structures marginalizing nurses based on historical [67] and current organizational hierarchies. I found few nurses were able to generate preliminary evidence, supportive leadership, on-ground technical experts, and proof of ability to scale before nurses begin to prototype solutions. Though these socio-technical challenges are not unique to nurses [7, 87], their experiences show how explicit organizational support is required to encourage the kind of political shift observed in organizations in other medical innovation projects [132]. When nurses get visibility into institutional priorities (e.g., F4's remarks on how a nurse justified time on a project based on the hospital's quarterly goals to reduce pressure wound instances), they could advocate for resources such as time for on-ground problem-solving. Recent studies indicate there is a finite scope for rapid prototyping process in healthcare settings with low tech materials [79] unless we develop remote and shared systems to support collective innovation.

At present, participation in innovation through medical making increases the burden of articulation work on nurses and their early collaborators to justify experimentation in institutional settings. While nurse insights arise from proximity and perceptual acuity, fabrication and other technologies serve to expand on-ground nurse capabilities in institutional settings when they have time to experiment through allied roles as educators or learners. Once they create prototypes with low-tech materials, they must develop evidence per internal standards for evidence and accepted forms of nursing research [62]. Here, creating formal roles in nurse innovation and opportunities for collaborative reflection [182] may be useful to help craft arguments, write grants, or form research collaborations. These are skills currently concentrated in nurse educators and researchers who perform articulation work; a criterion of inclusion for some nurses deepening the hierarchy between those with advanced degrees and nurses at the bedside. Those with advanced degrees, as seen in this participant group, tend to be employed in urban or private hospitals [168] representing a widening digital divide in nursing.

### *5.5.3 Labor of Iteration: Prototyping Solutions*

Nurses face challenges that occur at the *"point of interaction"* (E4) with the technology typically when they are with patients. Ideas to improve prenatal, maternal, and pediatric care indicate how bedside interventions rarely scale up to become standard medical devices despite practice level implications. Few nurses developed low-fidelity prototypes into products, even with on-ground technical expertise, without receiving additional institutional support.

From my study, I understand that nurses iterate more than physician-makers [82] precisely because nurses develop solutions from in-patient observations unlike process- or technology-led solutions focused on specialized treatments. Nurse solutions then may be tacitly formed based on appropriate scale of intervention for temporary yet immediate patient needs or chronic yet overlooked process gaps [9, 101, 138]. To prototype physical solutions, the additional complexity of materials requires nurses to engage in experimental processes which Baruch et al. describe in the cost of failed prototypes, sunken time in iteration, and technology experimentation as challenges making in hospitals [16]. The three nurse stakeholder groups in our study identified similar conditions affecting technology and materials used in prototyping process. Some participants mentioned working with materials to collaborate with nurses to define the problem space beyond the bedside by adapting their practice.

Alongside the two non-users of maker spaces in this study, participants expected to invest personal time in their projects till they could hand off technical development to facilitators limiting the time they spend developing expertise from the project. Depending on their stature within an organization, apart from resources (i.e., mentors, materials, funding) for prototypes, nurses at the bedside had little room in their daily work to do more than make adaptations when technology design fails. I contend that nurse experimentation with one-off low-fidelity prototypes cannot be scaled to current notions of technology-led innovation. In fact, making with its promise of customizability and personalization is suited to this need in nursing work for patient care. Even when nurses are unable to streamline resources, they can be encouraged to improvise with adequate training and recognition of their labor. Their contribution is not only creative resilience,

within private institutions, it is also invisible labor in nursing practice. A narrow focus on novelty, reliability, and advancing clinical efficiency overlooks the hidden labor of nurses who improvise anyway in their routine work.

A psychosocial perspective around innovation emerges from participants who believe nurse resilience will tide them over barriers when they seek to sequence and anchor organizational transformation [7]. On one hand, *"all nurses are problem-solvers"* and on another *"nurses don't want obstacles"* revealing the tension between individual commitment to innovate and the collective need for formal organizational support. Integrating nurse participants' view of problem-solving requires healthcare organizations to recognize their activities as potential nursing work centered on patient care. Within the scope of our work, we suggest implications for systems aligned to short- and long-term problem-solving in medical making infrastructure for innovation.

## 5.6 Implications for Centering Nursing Work in Technology Design

Understanding nurse challenges in the niche context of medical making is not adequate for insights into organizational features for healthcare innovation. Nurse participation in making [102, 138], and nurses themselves, can however be centered in technology design by creating formal systems to reverse visibility into improvisations and remote systems to support ongoing innovation.

### *5.6.1 Reversing Visibility for Collaborative Reflection*

Revisiting how technology is designed and implemented within hospital hierarchies can encourage nurses to collaborate in technology design as observed in other contexts[182]. One method of introducing on-ground alliances for prototyping is to

appoint facilitators and leaders across communities of practice or departments. For example, F2 in our study mentioned putting together teams with at least one nurse to diversify the project team regardless of the person initiating the project. Visibility, even as a participant, can create intra-professional alliances over time. Otherwise, nurse participation remains enmeshed in other gendered care practices that undermine on-ground insights. Systematic focus through programs, showcases, and formal positions can incentivize nurse participation with clear pathways. In addition, creating role models for nurses across intersections of specializations, age, experience, and extent of solutions creates a more accessible landscape of innovation for nurses.

Makers are amenable to sharing ideas through forms, pop-ups, showcases, and psychologically safe spaces. I recommend creating levels of expertise in nursing within the hospital environment to create upstream visibility in healthcare to impact technology implementation with realistic insights [197]. In medical making, technologies are more likely to invite prototyping collaborations with nurses if it directly supports roles to craft material arguments. To carry out this responsibility, a formal recognition of its value in healthcare practice is necessary either in training or nurse professional roles. Such policy recommendations are beyond the scope of this paper. However, communication technologies can be designed to express and translate existing nurse-made workarounds, prototypes, and bedside interventions with remote collaborators instead of the current focus on sharing finished technology-led prototypes in wider repositories like the NIH 3D Print Exchange.

### *5.6.2 Notions of Scale for Repair*

Not all nurse insights can be applicable beyond singular situations or a specific patient's needs. Yet technology-driven innovation in a privatized healthcare system (U.S.) is skewed towards scale of impact. This notion of scale is aided by remote systems such as design repositories and shared infrastructure for making tuned to artifacts. Instead, we call on technology designers to expand on the potential of maker technologies to support local, small-scale artifacts through shared community resources Exploring features of digital platforms and entrepreneurship can suggest future design to support medical innovation for actual use. Nurse problem-solving in other emerging sites of repair [90], crisis [107], and community-led innovation [165, 206] suggest untapped creativity to be leveraged through large-scale communities distributing parts of the problem-solving process.

Arguably, material-based expertise is required to resolve a conflict deep in nursing work wherever applicable in their practice. De-linking scale of implementation from problem-solving may encourage nurses to come forward to design healthcare innovation. However small in scale, as acts of repair and reuse, nurses' everyday creativity suggests necessary innovation for care. Further, nurse participation in technology ensures their perspectives are introduced in their own future roles in long-term telehealth and short-term crisis management in healthcare settings. Technology may automate or standardize healthcare functions to become more reliable, accountable, and comparable, but moving towards a future with personalized care relies on the resolution of nurse contributions to improving healthcare.

## 5.7 Publication Details & Areas for Future Exploration

Study 4b is currently under review for the 2021 ACM Conference on *Computer-Supported Cooperative Work* (CSCW). It directs the scope for future work on how medical making infrastructure can adapt to include stakeholders within institutions in technology-led innovation centered on nurses.

In Chapter 6, I discuss how systems expanding technical capabilities are unlikely to be adequate to encourage nurse participation in group work. However, human infrastructure and training are more likely to support wider inclusion of stakeholders within and outside healthcare institutions. Overall, I develop implications for designing human-material infrastructures to enable wider participation to include multiple stakeholders in medical making.

## CHAPTER 6 – CARING & CAREFUL COLLABORATIONS

Aligned with a rise in maker culture, HCI has been concerned with the study of user empowerment, widening participation, and technology production. As Bardzell et al. outline in their survey, "*making confronts us with both the potential and unintended consequences of our own work*" because HCI and making share a commitment to democratization [15]. An underlying notion of such democratization lies in the promise of ongoing innovation of sociotechnical infrastructures, which other scholars [10, 118] explore at global sites. An explicit goal of making as innovation is to offer novel, scalable, and transformative solutions [37]. My work shows how makers use technologies to fundamentally repair broken healthcare infrastructure. I do this by unmasking hierarchical structures of power and unpacking the on-ground process of making.

Making for health, as discussed in Chapter 2, largely characterizes DIY patient ecosystems. In Chapter 5, I showed how nurses remain understudied in HCI though they adopt maker technologies, continuing a rich history of innovation that precedes a recent trend in hospital makerspaces at points of care. Making in medical institutions differs from other applications and environments because of its inherent risks to both the maker and the user of the made artifact. Medical makers then operate within existing care infrastructure ranging from physical spaces and regulatory frameworks when appropriating open maker infrastructures. From four studies, I contribute to an understanding of sociotechnical systems at the intersection of policy, professional practice (medicine and design), and collaborative work (see Table 6 for relevant chapters). The first study delineates the medical maker ecosystem for healthcare settings from maker culture. In response to a pandemic, two studies contrast medical making communities' efforts in a crisis to provide

an alternate, critical view of maker infrastructures for collective action beyond innovation narratives. My final study with nurses describes how nurses in U.S. undertake innovation activity historically and in the current healthcare ecosystems to enhance perspectives in HCI around nurse inclusion in design collaborations.

## 6.1 Overview of Discussion

I initiated my research with a focus on understanding how stakeholders in healthcare settings innovate care infrastructure with maker technologies. Instead, I investigated how relational structures change with medical makers' activities across four studies framed by relevant theories. I took a non-linear approach to develop an ecosystem of stakeholders' technological use and non-use [17, 23]. Apart from prevailing notions around open innovation [43, 77], I framed activities through the lens of collective action [44] and repair [92, 161] to account for the larger context of a public health crisis. Lastly, in this section, I examine how medical making can become a means to innovate care infrastructure when social, technical, and relational factors are identified as infrastructure [51, 174].

So far, making in healthcare settings has been studied in limited contexts of digital fabrication [83, 167] at least in HCI. Instead, I characterize medical making activities, stakeholder ecosystem, and relational structures [174] required to uphold the community's norms of safety, reliability, and accountability. The work required to uphold norms while aligning multiple forms of material and technical expertise ensures risk mitigation in collective efforts to repair care infrastructure, which I discuss in this chapter. Previous chapters (3—5), summarized in Table 6, show stakeholders' adoption of maker technologies to accomplish the point of care: patient wellbeing. Their activities uphold

safety and empowerment of both end-user reliability and other makers by instilling wider accountability through institutional efforts.

**Table 6 Overview of Four Studies with Medical Makers**

| Study | Description | Participant details | Year | Referred in |
|---|---|---|---|---|
| 1 | Medical makers and their activities at the point of care (RQ1) | N = 18<br>(10 clinicians, 4 facilitators, 2 researchers, 2 engineers) | 2019 | Chapter 3 |
| 2 | Grassroot makers' norms when engaged in medical making (RQ2a) | N = 14 communities<br>(12 Facebook; 2 in person) | 2020 | Chapter 4 |
| 3 | Institutional makers' repair work for community production (RQ2b) | N = 13<br>(7 facilitators, 2 clinicians, 4 researchers in 8 institutions) | 2020 | |
| 4 | Nurse perspectives on inclusion in medical making (RQ3) | N = 16<br>(6 facilitators, 10 nurses including 2 non-users) | 2020 | Chapter 5 |

In this chapter, I argue that maker technologies could fundamentally alter healthcare infrastructures to deliver care when the work of medical makers, especially intermediaries, is supported with adequate systems for long-term impact in healthcare settings. To support this argument, I set up two contrasting models of medical making processes: an artifact-centered model (see Figure 5) and a human-centered model (see Figure 6). I contrast these models to show how the first, developed from theories of innovation, hides the work of human stakeholders. The latter model builds on relational structures emerging from ongoing activities within relevant contexts. From the second model, developed from Star's infrastructure theories [173], I show how different types of work offer opportunities to fix the gaps identified in Chapter 2, with in existing care infrastructure, to adapt centrally standardized technologies at the point of care.

In the next four sections, I describe how my work directs attention to systems that support the medical making ecosystem to create environments for future care infrastructure. First, I explain how medical makers do not innovate care infrastructure drawing on Star and Ruhleder's and others' work [44, 69, 91, 174] to analyze medical makers' use of technologies in healthcare settings. I discuss two models of how makers' activities shape outcomes primarily as repair more than innovation and collective action. Second, I describe the affordances for systems currently embedded in the work undertaken by facilitators and clinical educators. As human infrastructure, stakeholders created environments for others to participate at different stages of medical making. They performed two kinds of cooperative work: articulation work [163] and infrastructuring work [44, 69]. Third, I discuss the overarching process of medical making emerging from four studies to highlight the stages where stakeholders participated, appropriating information or material systems for medical making in safety-driven activities. In the final section, I draw implications for researchers adopting a wide lens for cooperative work, technology designers of appropriate systems, and related fields.

## 6.2 The Relationship between Medical Making & Care Infrastructure

Maker technologies, introduced in healthcare settings, created visibility in the literal sense for participants in my studies. An environment for collaboration and appropriation relies on other types of infrastructure as discussed in my work. To understand structures emerging for the use of technologies, I study social arrangements apart from technical systems required to support artifact-based activities. While activities in this space became visible based on artifacts (Studies 1—4), I found that an artifact-centered process revealed few insights into the work I had observed in Study 4. Instead, framing activities from a

human-centered process revealed relational structures leading to deeper insights into medical making activity's impact on care infrastructure.

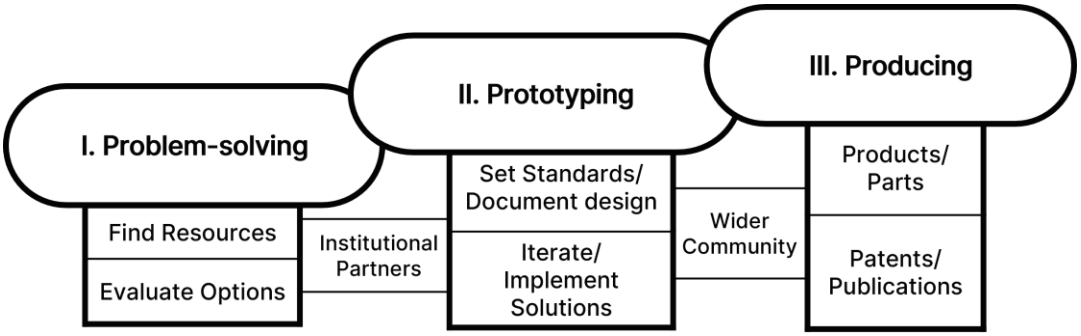
In the following four sub-sections, I first contrast two models as an overview of my analysis to then outline my analysis of Star's framework of infrastructure to describe how I arrived at my conclusions that medical making within institutional makerspaces does not innovate care infrastructure yet and offer insights into future system design.

### *6.2.1 Existing Structures Shape Medical Makers' Activities*

I foreground my analysis by contrasting two models of medical making activities. Based on previous chapters, I developed an artifact-centered model abstracted from a collaborative network (see Figure 1) and a community production process (see Figure 4). The second model is human-centered, framing how relationships emerge around stakeholders who may collaborate to create artifacts.

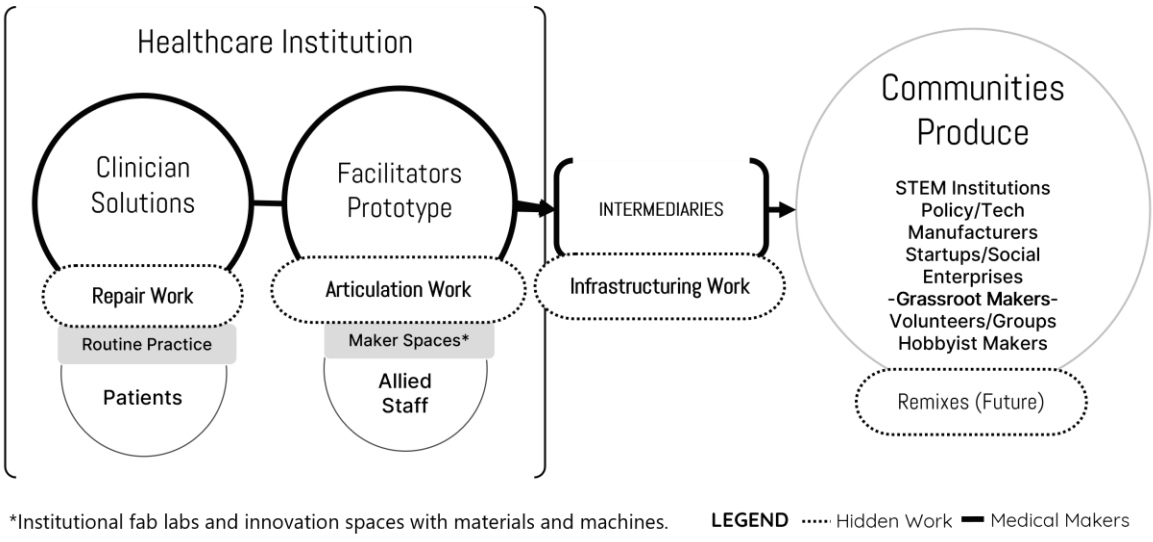
In this sub-section, I briefly describe how each model reveals different insights into scale, expertise, and types of labor. These models summarize insights from my work across four studies is to re-orient an understanding of medical making as an on-ground practice supported by an ecosystem. My aim with both models is to provide an overview or a snapshot for visual reference of the deeper discussions in later sections (6.4, 6.5).

**Figure 5 Artifact-centered Model of the Medical Making Process**




The artifact-centered model indicates a linear process that progressed from left to right to realize increasing scale of production. The diagram illustrates how activities described in section 6.4 approximate different outcomes and responsibilities observed in my research. However, these activities appear static with little visibility into multiple structures indicated in the data. Another limitation of this model is that it could be interpreted as a one-time process focused on artifacts in the short-term. Instead, I explored a model based on relationships to center human stakeholders seen in Figure 6.

**Figure 6 Human-centered Model of Medical Making Activities**



Building on stakeholder perspectives, this dissertation calls attention to the work of some individual medical makers (e.g., facilitators, leaders, and others) creating the environments and artifacts underlying medical making activities. In the diagram (see Figure 6), the relationship between different stakeholders within a single healthcare institution situates collaboration within their contexts including facilitators who operate in a fabrication lab or innovation space. This model highlights relationships and approximates the involvement of each stakeholder in each activity. However, depending on the temporal context (e.g., a pandemic), more stakeholders could be involved in the activity as seen with temporary production activities in Study 4. I discuss the work shown in the human-centered model and the artifact-centered model respectively in in section 6.3 and 6.4. In the next sub-section, I describe how I analyzed relational structures in medical making.

### *6.2.2 Medical Making is Repair of Care Infrastructures*

Star's view of infrastructure as an ongoing set of relationships that "*occurs when local practices are afforded by a larger scale technology, which can then be used in a natural, ready to hand fashion"* [174] suited my investigation better than other frameworks [51] describing the unintentional appropriation of systems into infrastructure. I turned to studies set in routine care contexts, discussed in Chapter 3 and 5, to understand how findings map to the nine features described in Section 2.3.1 [174, 175]. I found that medical making does not count towards changing care infrastructure in three ways. First, it is not fully embedded in other structures, occurring in a regulatory void at the prerogative of the medical maker willing to risk and arrange resources. Second, though it is transparently available, most makers rarely apply it beyond one time use subject to their visibility into practice, membership in networks, and position in the institution (discussed in Chapter 3

and 5). Finally, medical making requires an optional set of skills to articulate details of solutions beyond the makerspace environment that is not learned as part of professional practice, especially in the case of nursing (discussed in Chapter 5).

Maker technologies empower stakeholders to repair missing healthcare infrastructure at a micro scale within their practice or environment. They do not innovate at a scale that influences care infrastructure. Clinical stakeholders who create at points of care may not have the time to perform the tasks required to ensure long-term change through articulation or infrastructuring work. In this discussion, I offer an analysis based on both types of work currently performed by intermediaries, enmeshed in medical making activities, as invisible labor. My aim is to highlight the necessity of their work across medical making activities (see Figure 5) to resolve tensions in opposing values, gaps in expertise, and sustain collaboration across global communities. Understanding their activities allowed me to examine how they re-orient whose participation is made possible in medical making and how computational systems can support care innovation.

Maker environments present two options in healthcare practice. The first appears as an option to repair breakdowns, either temporary or recurring, in care infrastructure. Repair involves attention to when structures stop working as intended or create barriers in workflows requiring urgent re-use, temporary maintenance, or repurposing of materials [92]. The second presents itself, to those who can innovate [132], as an option to experiment with technologies and materials. Literature in medical journals [65, 95, 124], often frames maker technologies, especially digital fabrication, in the latter context of innovation to signal novel approaches and outcomes in patient-centered care.

#### 6.2.2.1 Medical Making as Small-scale Repair

The four studies presented in this thesis demonstrate that innovation is rarely the sole outcome of medical making activities. To support innovation, additional systems to support shared knowledge, skill exchange, and remote support are required. Few such system currently exist in the form of a design repositories [127] that meet a narrow set of prototyping needs. Awori et al. describe how healthcare professionals make and modify without complete control over the cost of failed prototypes, sunken time in iteration, and other emerging challenges of making in hospital environments [11]. These barriers were amplified in standardized clinician roles, such as nurses discussed in Chapter 5, for whom making is often an act of repair at the bedside. I found the involvement of clinicians in the problem-solving stage (i.e., before material prototyping) led to iteration to create the device directly applicable in their routine practices (see Figure 5). They do not engage with further activities because their commitment is aligned to repair and maintenance [91] where they appropriate maker technologies to fix, hack, and adapt their environment in ways existing technologies or devices are unable to meet their needs.

#### 6.2.2.2 Medical Making as Opportunistic Innovation

Within the U.S., collective action underway during a pandemic, as discussed in Chapter 4, can be seen as social innovation. However, it did not influence long-term care infrastructure because the classification of medical devices or supplies for regulatory purposes remained unchanged. When making is framed from the lens of innovation, particularly the promise of open innovation [76, 78], it is likely to obscure stakeholders' positions of urgency in the short-term or the potential of evolving long-term solutions. The

multi-stakeholder perspective in my research shows that medical making is repair, not innovation, precisely because of its adaptability in temporal, ephemeral, and urgent contexts (Chapter 3 and 5).

The key implication of recognizing medical making as repair is its revelation of underlying priorities for novelty and scale in HCI research. Hospitals invest in innovation infrastructure when the potential and on-ground use of maker technologies is in the repair work required by most practitioners on an ongoing, small-scale, and unpredictable basis. It changes the expectation of scale and subsequent investment in training and infra around supporting who/why/how tech is used in medical settings. Avle et al. expose the inherent techno-optimism in conflating scale as a natural feature of technology-driven innovation where powerful decision-making inevitably turns to "*scale as a logic of action*" in nation-building through technology investment [10]. A more local vision of such techno-optimism is visible in HCI studies of making and within healthcare institutions' rationale for supporting making as a form of activity [11, 65, 178]. While there is a place (and time) for scale, makers adopt maker technologies as instruments for temporal repair. The scale of their efforts is defined by their visibility into care infrastructure and expands their responsibility to care for those who depend on their continued ingenuity. Medical making then extends from professional responsibilities more than novelty; it arises from moments of opportunistic discovery.

### *6.2.3 Future Sociotechnical Systems Could Integrate Medical Making*

In collaborations within healthcare communities of practice, medical makers need fewer systems to disseminate professional standards. However, for wider collaboration

with different experts, they need to reinforce a culture of ethical responsibility in non-medical makers. Tuned to mitigate risks, and without adequate scaffolds to manage the designed product, medical makers may forego wider collaborations unless dire circumstances leave them with no recourse. Occasionally, making in moments of repair lead to insights into healthcare practice, some makers may find adequate collaborative support to create prototypes for their institution, their community of practice, or even the wider community. For example, as discussed in Chapter 4, an alternative face shield design to the popular 3D printed design became necessary to enable easy assembly in remote areas far from the original location. Future studies can expand design repositories' scope to support repair work onsite. Additionally, a more integrated set of remote collaboration tools need to be explored for opportunities arising at the bedside in routine times focused on empowering stakeholders and not institutional outcomes through design speculations for infrastructure [196].

Medical makers can modify care infrastructure by developing and designing tools that meet their standards of professional care. The process of design and development relies on maker technologies and related information systems. In my work (see section 3.5 and 4.4), I refer to information systems including design repositories like the NIH 3D Print Exchange, because these large-scale technologies connect distributed networks of consumer grade technologies in local healthcare settings. My observations do not extend to other large-scale technologies like social media platforms discussed in Chapter 4, which are inadequate for medical making activities in the specific context of a public health crisis [84]. The concerns discussed in Chapter 4 around misinformation and coordination, align with studies in crisis informatics when general-purpose platforms are appropriated during

crisis for wider collaboration [6, 54, 195]. Instead, I focus on the intentional design of a shared set of structures for knowledge and design exchange as observed in other general sites for entrepreneurship and social innovation [87, 118].

Systems to support processes of documentation for publication and patents (discussed in Chapter 5) can offset the burden of articulation work [163]. While some medical makers' insights have a limited application within the practice, when the need for action exceeds the healthcare institution or the related communities of practice, makers could engage in collective action [44]. In studies 2 and 3, it became clear that the unusual situation of a pandemic created conditions for temporary openness in medical making. The interpretation of FDA emergency use authorization tended towards wider collaborations with non-experts, though not all efforts were accepted by hospitals.

As deeply discussed in Chapter 4, the temporary response to care infrastructure breakdowns revealed the extent to which medical making could scale up by democratizing participation. The atypical rise in medical making during a public health crisis exposed the work required to fulfil social innovation as stated by some makers (e.g., A2's view of their non-profit's interest in distributing designs under a Health Canada license) in study 1 and 4. Even when medical makers attempted to clarify safety and reliability through protocols, the risk of interpretation by non-experts remained unresolved. Recent work describes how the review process can expand individual maker contributions to medical making efforts by adapting features of the NIH 3D Print Exchange [121]. Future work is needed to understand systems that extend beyond a narrow part of the process (i.e., prototyping) for medical making to impact care.

In summary, understanding relational structures in medical making leads to two sets of insights around the appropriation of systems. First, the temporality of *when* makers rely on maker technologies to repair care infrastructure, as in the case of a public health crisis, depends on *how* they channel onsite or general-purpose information exchanges (e.g., on social media platforms). Second, the potential of *what* makers seek to influence in care practices, for example nurse educators' visibility to develop training tools, leads to centering technologies in small-scale prototyping then sourcing materials. Some studies describe prototyping software to embed clinician perspectives in digital fabrication for assistive technologies [83, 167]. However, future work is required to understand how these systems re-enforce hierarchies and increase the burden of activities on some makers. Though maker spaces and material processes could offer a flexible set of systems for healthcare needs, prototyping activities are so deeply influenced by healthcare values and expertise that producing devices at scale with non-medical experts offers a glimpse into the explicit labor undertaken by some medical makers. Supporting collaboration is currently vested in the role of facilitators as key intermediaries (described in Chapter 4) and others, who perform additional work discussed in the next section.

## 6.3 Human Infrastructures Reveal Hidden Work in Medical Making

Medical making within healthcare institutions was distributed across different stakeholder networks. Together, these networks and arrangements align expertise, resources, and information to materialize ideas into identified solutions. As human infrastructure, they appear as *"the arrangements of organizations and actors that must be brought into alignment in order for work to be accomplished"* [110]. Directing the

adoption of maker technologies within healthcare institutions required the ongoing alignment of resources for collaborative work as discussed in Chapters 3 and 4.

In the human-centered model (see Figure 6), I outline the stakeholders as human infrastructure for medical making within and outside institutions based on data observed in four studies. I focus on facilitators in this section as organizers with a varied background in engineering, project management, design, library science, and other related domains. Along with some clinicians, facilitators occupy a unique position in creating alignments within organizational hierarchies. They supported priorities within healthcare institutions, as discussed deeply in Chapter 4, bringing in external expertise to create or disseminate the solution. These are not static arrangements because resources were appropriated based on the solution or missing skills within institutions. Internal coordinators and advocates become essential to create a larger network of institutional partners and grassroot makers outside institutions. They become intermediaries in roles, noted primarily from findings in Chapter 4, emerging in relation to the scale of *"work to be accomplished"* [110]. I highlight this role to describe their work to enable collaborations and outline how information systems can support towards widening collaborations for medical making.

While physicians mitigated risks extending from their professional capacity, and not as makers, facilitators must learn to act in a similar capacity to mitigate risks. The work of risk mitigation for facilitators who are rarely medical professionals themselves is additional to material and technical expertise in medical making. In the next section, I discuss the specific types of work undertaken by facilitators as an exemplar of invisible labor to draw implications for information systems. By highlighting such work, performed

mainly by facilitators and others as intermediaries, I delineate how their labor in the health context could transfer to other forms of expert—non-expert collaboration in design.

### *6.3.1 Infrastructuring Work Upholds Norms of Safety & Reliability*

Medical making occurs amid tensions, as seen in my findings, between norms in local healthcare practices, regulatory frameworks, and wider maker communities. The range of tasks involved in creating consensus include resolving risks of experimentation, forms of expertise, reliable design distribution, and open sharing of artifacts. I identify these tasks as infrastructuring work in medical making with, as Bossen et al. define, "*increased vulnerability to, and dependency on events outside the immediate loci of interaction"* [25]. Within institutional settings, the locus of interaction may be problem-solving or prototyping subject to professional ethics and medical liability. Facilitators perform invisible labor [175] in distinct ways from other stakeholders when they act to protect clinicians' and patients' safety. They resolve norms arising out of tensions between global and local contexts in three areas: medical making environments, collaborative alliances, and accountability in process.

#### 6.3.1.1 Facilitators Shape Collaborative Environments

In the physical spaces available to clinicians and others within the institution, facilitators were typically appointed as technical experts responsible for the innovation space or fabrication lab. However, depending on the hospital management's expectations, facilitator skills included project management, art, and other interdisciplinary expertise (see Table 5). In Chapter 3, medical makers engaged in collaborative work in a variety of physical spaces either within healthcare institutions or partnering with makers' facilities.

The onsite physical space can be intimidating to internal stakeholders when it carries connotations of rigor associated with *"higher science"* as described by F3 (in section 5.4.2.4.). A physical space became an environment for collaboration with facilitators' organizational labor including advocacy for specific processes, building alliances across departments, and maintaining an open culture for participation as described in other hobbyist sites [60, 185].

Guiding the key stakeholder involved also required facilitators to learn how to approach solutions in a way that do not *"cause problems down the line"* as a F6, a facilitator describes in Study 4 (see Table 6). Though the risk of liability on clinicians with a medical license is higher, as expressed by participants in Study 1, facilitators were ultimately responsible for material risks inherent in the end-use of the artifact. For example, R2 who initially worked with a DIY community stopped using open-source designs to fabricate prosthetics when she became a facilitator in a non-profit because the original design was unlikely to have prioritized patient safety (see section 3.3.1.2). To some extent, this addresses the burden of iteration studied elsewhere among clinicians who fabricate in routine care practice [83]. Facilitators had a greater influence on the alternatives generated towards solving clinicians' observed gaps or problems. As seen in Chapter 5, facilitators worked with educators to develop training tools for specific nurse training needs in neonatal care with technical, material, or other experts.

#### 6.3.1.2 Facilitators Engage Varied Sources of Expertise

Facilitators are more than the default collaborators; they shape relational structures between experts and non-experts. A facilitator's domain of expertise shapes the medical

making activity. For facilitators to *"leverage anyone interested in the solution,"* as noted by a facilitator F3 in Study 4 (see section 5.4.1.2), they had to first recognize the potential scope of the problem based on their own individual skills, in this case the creative design background in art to implement a practice wide solution involving photography. Then, they create wider connections to relevant experts in regional and global networks. While systems may not be able to foresee or create opportunistic connections, they can support human actors in making, at any scale, who are critical to creating access to external and internal partner networks in local practices.

Communities valued different forms of expertise, as discussed in chapter 4, based on their access to information and collective sense-making abilities. When partners included communities with academics and medical professionals, grassroot communities tended to favor principled knowledge, even when sources offered conflicting insights, and the advice of practitioners. This may be the default source of expertise in medical making within institutions but requires intentional collaboration with end-users in mind. In making, separating the roles of designer, and producers [115, 180] could widen participation. As seen in times of a public health crisis, the separation of these responsibilities raises a more urgent question about relaying the consequences of acting with limited expertise.

#### 6.3.1.3 Facilitators Create Accountability in Processes

Given the ambiguity of manufacturing regulations, facilitators drove clarity around individual makers' motivation when they chose to scale. This work affected the eventual openness of distributing medical making prototypes. When facilitators and some clinicians

became intermediaries, they help structure action *"beyond the initial scope of design"* [45] depending on the larger context or stakeholder priorities.

In routine times, facilitators create clarity based on the intentions of clinical stakeholders to openly distribute or profit from market distribution. As F4 describes in Study 5, the location of the medical maker space within institutions carried implications of ownership for the use of infrastructure for prototyping or problem-solving. However, from most participants in Study 1, it was clear most clinicians volunteer time and skills to realize their solutions. Others in Study 4, expressed a motivation towards open innovation [78] or entrepreneurship [87]. Facilitators help them to first define these goals and then align internal legal teams to support individual stakeholders, as discussed in Chapter 3 and 4.

In times of crisis, facilitators created action plans or discovered the most plausible approach. Their existing partnerships with external partners became evident in Study 4 when some medical makers were able to quickly forge additional informational and material partnerships to produce large scale medical supplies. They organize videos, protocols, meetups, and other formats to supplement wider communication on Facebook Groups and Slack. As discussed in Study 2, grassroot organizers' initial attempts to use Facebook were eventually replaced by external tools (e.g., websites, email, phone, Slack). In the limited contexts I could observe these activities, intermediaries between healthcare institutions and these grassroot communities managed to enforce limits through informational protocols, which when unavailable creates confusion among partners. For instance, grassroot medical making was dominated by active makers and hobbyists who tend to favor skill-exchange based on embodied experiences of makers. In these situations,

facilitators become arbitrators for their original community of practice, medicine, to perpetuate values of safety and reliability.

In summary, the types of artifacts and solutions generated within a space extend as much from the facilitator's individual skillsets as the clinician collaborator's insights. However, facilitators' efforts may seem incidental to the end outcome as they do not result in long-term or large-scale infrastructure. Similar to patients' and caregivers' infrastructuring work to repair breakdowns in healthcare structures at an individual, local, and micro scale [69], facilitators' work to repair missing regulatory processes, breakdowns in manufacturing processes, or unclear organizational pathways for stakeholders remain hidden within local practices. Visibility within a community of practice is currently achieved through showcases and knowledge exchanges for these ideas at different stages of medical making activity among facilitators in medical making spaces. Understanding the process and extent of intellectual labor involved, especially at the prototyping stage, can protect stakeholders' interests [89, 169]. Future work in this area can further help recognize the pivotal role of systems to support facilitation as infrastructuring work.

### *6.3.2 Articulation Work for Shared Design Activities*

Apart from infrastructuring work, medical makers describe solutions and processes in ways that enable peer medical makers to iterate on future designs. As Schmidt describes, the "*cooperative work to make cooperative work*" is the articulation work required for communal knowledge [163]. Articulation work is performed within the larger medical community or specific practices like nursing to make solutions' value explicit to organizational stakeholders. However, in healthcare, it can also act as infrastructuring work

as discussed in the earlier section to embed medical making values between communities of practice. For instance, the review process in open-source maker repositories, like Thingiverse, have fewer requirements for design submissions while the NIH 3D Print Exchange has a review process to ensure some level of rigor in describing designs. The express intention of sharing relevant information through articulation work is to encourage and inform future innovators or designers. Studies on similar short-term coordination work to generate descriptive details among hobbyist or knowledge communities indicate the relevance of these details for *"remixing"* shared designs or information [57, 58].

The relevance of articulation work in making leads to diverse creative solutions. Medical makers publish their designs for use, reuse, and distribution in wider repositories. In these systems, as Alcock et al. describe in hobbyist communities [4], details required for alteration and iteration are lost in documentation eventually restricting the future versions of the prototype for other contexts in healthcare. The loss of detail carries greater implications on individuals' lives in medical making, without which safety and reliability may be overlooked in favor of other maker values of action or novelty. Most general-purpose maker communities favor a flexible, informal structure [97] to maximize participation, especially from volunteers, over defined roles for critical meta-work [131] to ensure quality of submissions. Depending on the complexity of material processes, articulation work resulted in a digital artifact, introducing a layer of complexity in describing the relevant details involved in future iterations of the design. Unlike physical artifacts, digital artifacts are generated as approximations mandated by the repository's review process. Eventually, this leads to inconsistent information on core properties, evaluation methods, or use cases, leaving most digital fabrication repositories riddled with

insufficient documentation of design files. It is not surprising that time constrained medical makers avoided adopting open-source designs, as discussed in Study 1. Repositories can offer an alternative to access requisites details, protocols, and standards for design.

Producing a coherent record of the safety-focused designs ensured collaboration largely between institutions through global repositories like the NIH 3D Print Exchange. The skills required to create adequate accounts varied with the design process, material alternatives and rationale, protocols, and iterations. Most times, the many layers of risk can disincentivize medical makers, described in Chapter 3, from openly distributing their prototypes to partners outside healthcare institutions. A few medical makers performed the tasks required to validate designs [149] for distribution under a global open access license to transfer accountability to the maker while most others embed accountability through documentation to ensure small-scale artifacts do not inadvertently cause harm to end-users.

The need for accountability simultaneously increases the specificity of design documentation and upholds the agency of medical makers in collaborations. The first, documentation, limits the future collaboration of prototypical artifacts as seen in a upcoming publication analyzing design convergence in the NIH 3D Print Exchange [121]. Capturing such details increases the work on some medical makers. Clinicians making at the point-of-care (e.g., hospitals) act on an ethical obligation to apply the same risk mitigation techniques clinicians would apply to other aspects of their work. While these risk-mitigation efforts help uphold patient safety, mitigation mechanisms only add to the known concerns around invisible organizational labor [60]. Organizers, in external grassroot communities, who may already be overworked and undervalued are left with the

task of enforcing strict quality and safety procedures which do not align with makers' innovation-oriented practices.

The second need for accountability arises from the case of deeply embedded practical workarounds and possibly undermined contributions. As seen in the case of nurses, articulation work may cause harm to the individual because of a loss in translation. It is adequate for workarounds to stay on ground because it increases labor on people who are already repairing for free. Additionally, as in the case of automation efforts, they are unable to see or participate in nuanced conversations about their role or labor. Acting to solve problems is a form of agency that requires some non-standardized critical thinking especially among nurses. It creates resilience in the human infrastructure for healthcare against hierarchies that may arise from top-down automation for efficiency over individualized holistic care.

In summary, medical making requires facilitation exceeding that of general-purpose makerspaces. Facilitators as intermediaries open participation through work observed in other close-knit communities [57, 169] for healthcare technology design beyond the healthcare industrial complex. However, it is not yet known how other human infrastructure interacts with facilitator roles that are currently restricted to single institutions. Future work can uncover if articulation work upholds other values in institutional making. It may reinforce existing hierarchies implicit in healthcare organizations' accepted norms without the explicit attention to articulation and infrastructuring work required to negotiate power structures in traditional organizations [132]. Both types of work underpin medical making activities, either for institutional use

or market wide distribution, to reveal conditions for participation in three stages described in the next section.

## 6.4 Medical Making is Partially Open for Wider Participation

Making at the point of care is rarely a linear process, much like design. The progression of a solution from an insight into a product is even more constrained in a healthcare context. Nevertheless, aligned with previous literature [31, 105], my studies (see Table 6) show that medical making and the activities involved relied on varying kinds of expertise. Clinicians, both nurses and physicians, faced multiple challenges when they appropriated making in their routine practice, developing workarounds to address quality and safety of material products (Chapter 3—5). The increased use of medical making in healthcare setting indicates gaps that technology designers may never perceive [11]. Here, medical making creates an environment of opportunity to design pointing to potential innovation at scale or solutions applicable beyond a single instance. By describing these activities, this dissertation calls attention to the need to 1) design information systems supporting small-scale prototyping on site, and 2) recognize human labor in managing ongoing scale and collaborations.

In this section, I discuss how the extent of collaboration with internal and external partners depended on the scale of their activities supported by information systems and material repositories. I described three overlapping stages (see Figure 5) encompassing actions in medical making, which I describe in this section to show how stakeholder participation could shape information systems and maker technologies for fabrication, craft, or low-tech materials.

### *6.4.1 Stage I: Problem-solving*

Clinical experts encountered gaps prompting their problem-solving activities as an extension of their primary responsibilities. As Lindtner et al. describe, making is not the revival of a production process [117]. Clinical stakeholders often focused on closing the identified gap depending on their own or onsite collaborative material expertise [158]. Some areas of clinical practice require 3D printed artifacts (e.g., pre-surgical planning in radiology) on a regular basis while others need low-tech interventions (e.g., foam for patient comfort in surgery), as discussed in chapters 3 and 5. When material tools and materials are available in their onsite space, clinicians were still guided by the solution and not the *"hedonistic"* use of specific technologies [180].

A solution-centered approach guided their adoption of making as *"a tool in their toolbox*" in clinician-maker C8's view (see section 3.3.2). For example, a nurse educator's repeated observation of a gap in midwives' knowledge on cervical dilation led to a more hands-on training tool for the department (discussed in Chapter 5). Problem-solving may lead to changing the workflow or the environment as discussed in Chapter 5. However, when making requires engineering and design expertise (e.g., iteration), medical makers perceive it as a different set of skills tied to prototyping the artifact. C2 in Study 1 shared a commonly noted sentiment among clinicians: "*people who can benefit from [using 3D printing] are people who have the skill. How do you disseminate and democratize that?!"* (See section 3.3.1.1). It is possible to supplement or learn these skills through the cohesive organization of work through online systems as discussed in Chapter 4.

Time-constrained clinicians invariably solve problems with onsite collaborators within pre-existing networks (discussed in Chapter 3). Without onsite support, depending on the scale of the solution, medical makers undertook one of two options to proceed with: (a) small-scale prototyping or (b) invest in preparing for large-scale production.

### *6.4.2 Stage II: Prototyping*

While Hofmann et al. describe limited iteration in clinical care settings [83], I found a multi-stakeholder view shows that iteration may occur when prototypes need to be scaled for internal practice or community production (discussed in Chapter 4 and 5). Such scalability occurs along pathways noted in other maker communities around academic publication [112], entrepreneurship [87], and open design distribution [149].

Notably, prototyping activities led by clinicians were largely within institutional partner networks (see Figure 5). Given the popularity of medical 3D printing, physicians may partner directly with industry players like Prusa or Stratasys. However, facilitators were the ones who often iterated on prototypes building new partnerships. These collaborations can be essential when technical expertise is unavailable onsite, turning to asynchronous forms either online [33] or offline [149]. Regardless of partnerships, prototyping in clinical spaces is inherently a risky task. It directly exposes individuals, especially physicians, to malpractice risks [213]. In routine times, medical making remained within institutional networks, as discussed in Chapter 4 and 5, to retain a modicum of accountability across collaborative networks.

The extent of collaboration with grassroot communities directly depended on how well their operations align with medical values as discussed in Chapter 4. The adoption of

Facebook, Slack, or other communication networks like YouTube became necessary in these times to supplement non-existent systems for medical makers to collaborate with wider communities. While such appropriation is typical in times of crisis, collaborative networks that were previously closed became open to the wider community of makers, who also lack access to scientific information within general purpose information systems. In effect, the diversity of solutions is partially open to those makers with membership either through an institution or professional affiliation implying ethical responsibilities.

### *6.4.3 Stage III: Producing*

In collaborations beyond healthcare communities of practice, these standards reinforce a culture of ethical responsibility in non-medical makers who begin producing for wider communities. Physicians invariably view making as point of care manufacturing [108], but they do not expect their activities to sustain a larger scale of production. Manufacturing devices with maker technologies is an experimental process; it is not completely reliable even if it is the only alternative to meet patients' custom device needs. Instead, most stakeholders, especially physicians, partner with market players in the industry (e.g., 3D printing companies like Prusa) to pursue entrepreneurial or open distribution pathways for their prototypes. Other partnerships with local start-ups can help create resources unavailable in grassroot networks. The resources required to achieve scale may be materials, machines, and expertise. Medical makers then engage in documenting patents or publications (discussed in Chapter 3–5) and even directly collaborate with external partners to produce devices or parts.

Rare situations of crisis prompt medical makers, with access to maker technologies and materials along with established expertise in prototyping, to undertake actual production towards hospital or community needs. Studying the temporary shift in scale provided insights into the different ways maker technologies can adapt making, and its limited applications, within healthcare practice. More importantly, it indicated the need to design repositories, information systems, and remote collaboration tools.

In summary, medical making can create an environment to include non-experts to contribute to 3D printing, craft (e.g., sewing), and other hi- or low-tech artifacts for healthcare use. As in the case of hobbyist spaces with non-experts [48], environments can be a hybrid of online and offline resources often structured in specific ways [97]. However, future research is required to understand how these hybrid spaces meet healthcare needs based on ethnographies or deep dives into institutional makerspaces. Digital fabrication technology can be helpful in realizing these solutions at a small, urgent scale at least for material artifacts. At present, manufacturing reliable and safe medical devices is too resource intensive for the small-scale activities of innovation labs or makerspaces to support on an ongoing basis.

Beyond the scope of my work, there are other missing stakeholders who are present but do not collaborate at the point of care. In healthcare ecologies, as Jeong and Arriaga explore, a wider approach creates more clarity around factors influencing the use of technologies [94]. Expanding perspectives to include more non-users and users with access to healthcare settings can help shape workflows, environments, and wider collaboration in different activities. Future work could explore how systems can support specific parts of the collaboration between members within communities of practice and non-experts. In the

next section, I summarize implications from previous chapters to uphold activities without compromising values of safety regardless of the end objective in the final section for researchers, technology designers, and related fields of policy and regulation.

## 6.5 Future Work: Implications for Systems & Infrastructure Design

Towards values of democratized participation, medical making offers possibilities for caring and careful infrastructure design for healthcare. A critical view of making further identifies the limits of technology systems in addressing communal needs for emerging contexts. Based on the role of facilitators, and key advocates of making in my studies, participation requires clarity and transparency around the process, human infrastructure, and work involved in collaborative medical making. I highlight implications for related areas and stakeholders invested in medical making.

### *6.5.1 Implications for Healthcare Institutions*

Innovation-centred rhetoric around medical making in institutions may attract certain clinicians. My findings show that not all clinicians want to engage in every activity, even less so lead the overall process, because medical making may not fully speak to their professional identity, time, opportunity, or other orientations to ensure reliable use of artifacts. Explicit expectations of learning and collaboration required for the adoption of medical making will direct stakeholder attention to calibrate collaborative work. Making these efforts directly visible as valuable contributions in healthcare work can lead to eventual creation of roles by investing in training and human infrastructure. In this context, the exclusion of certain professionals implies the gradual automation of roles where individualized care is necessary. Nursing work especially with critical care patients is one

such situation where speed of response overrides the standards set. The stakes are higher in these situations leading to prompt, decisive action using workarounds.

The interconnected work of individual medical makers to create person-, patient-, and practice-centered artifacts (see Chapters 3 and 5) further creates opportunities to speculate how spaces need to be designed if we were to support innovative infrastructure for a community, in this case healthcare. Once the validity and scale of medical making is understood within an institution, material hand-offs can be better aligned instead of relying on the lead innovator model [76]. Moreover, lowering the emphasis on short term iteration and encouraging long term experimentation can be more appealing to innovation-centred clinical stakeholders who have few incentives to persevere through longer cycles of prototyping. Centralizing clinicians' role in problem-solving, even when it does not lead to an artifact or scale, can create an institutional memory.

While my work shifts the site of technology design to the point of care, democratization through medical making can only be complete when other stakeholders (e.g., patients and caregivers) are invited to collaborate in solutions that affect their lives. The overall implication of this shift is on the U.S. healthcare system, which is currently focused on protecting the interest of the institution and not the patient. Re-orienting the purpose of innovation spaces as liminal areas of intervention – spaces where providers adapt devices, design solutions, and collaborate across specialized spaces can exponentially improve patient-centered care. Medical making then becomes a hybrid space for iterative development of innovative ideas even when if it originates as repair.

### *6.5.2 Implications for Information System Design & Research*

I discussed design recommendations for information systems such as design repositories, skill-based forums, and local design tools in previous chapters. In this section, instead of a prescriptive approach, I outline possible agendas for researchers to understand the dynamics of human infrastructure and information needs emerging in new contexts. When suggesting a partial open repository (in section 3.4.1), I was only aware of the routine context of collaborations observed in Study 1. By study 3, it became evident that medical makers need a wider set of information systems for skill share exchange and coordination. The need for partial openness of a repository was validated by the tensions arising between grassroot makers' orientation towards speed over safety in Study 3. However, the designs found in the only medical making design repository [127], showed additional articulation work for large-scale outcomes [107]. As an online resource, the repository became a sort of virtual showcase and forum for more than 3D printed artifacts. In a follow up study, when I worked with my collaborators to take a closer look at the diversity of designs generated in this period [121], we found that this partially open repository attracted mostly makers affiliated with institutions. One implication is that the burden and ability to undertake articulation work does not extend to grassroot makers. It revealed that participation in these design repositories evolves a new hierarchy around the expertise to uphold safety. Additionally, future work is required to understand how physical access and material expertise influences the last mile reach for medical making. For example, at home nursing solutions could leverage public libraries for such technologies if they are trained to do so. Further, systems can be designed based on intermediaries' work when they led

such adoptions of technologies or choice of systems ultimately defined the boundaries of collaboration within hierarchies in multiple communities.

Apart from systems, my research approach offers a holistic approach for other HCI researchers interested in understanding stakeholder roles in making. Applied to other communities, a wider lens can clarify the need for aligning access, needs, skills, and norms. A situated, multi-stakeholder view of the process further explains evolving norms and exposes hidden work involved in creating the required environments in healthcare to develop a multitude of use-contexts to create large scale technologies. In effect, such views ensure HCI research does not suffer from techno utopian notions of what these systems can achieve and instead centers the people who are already doing work.

### *6.5.3 Implications for Non-technological Infrastructure (Policy & Regulation)*

Medical making is not widespread; in fact, its applications are mainly in repair because it lacks the infrastructure to easily scale for social innovation. Instead, systems may end up deepening digital divides where benefits of tech innovation remain concentrated on novelty (experiment) when it has the adaptability potential to repair (more urgent). Understanding this phenomenon even at this nascent stage is necessary because designers cannot be where design opportunities are, especially in closed environments like healthcare. Instead, systems can become infrastructure in ways that enable collaborations.

The Maker Movement owes some of its visibility and popularity to political support in the last decade. Without corporate players and political agendas, makers are unlikely to have the resources, membership, or expertise to set up the systems. The design of systems

with the intention to eventually become infrastructure matters to ensure a wider impact beyond urban healthcare institutions. The importance of these shared systems raises future questions around the role of medical experts to solve problems remotely with the increasing decentralization of healthcare, through telehealth, at-home hospice, and peer-driven healthcare practices.

Making at the margins requires policy to sanction this kind of collaboration. Along these lines, policies need to be usable enough to scaffold interpretation in material processes. While articulation work, to create a record of the solution online, helps medical makers gain enough momentum to create long term change in policies; it places the burden almost completely on the community. For example, Nightscout, a DIY patient-caregiver community continues to bear scrutiny for their Open Artificial Pancreas (OpenAPS) system, yet it remains a unique case for community-led change in regulatory acceptance of their devices as mainstream alternatives [206]. On the other hand, with larger infrastructure in place, The Glia Project took the academic route to publish a peer-reviewed report of tests on the efficacy of the stethoscope along with distribution under the Health Canada license [149].

Overall, interdisciplinary research and design collaboration are critical to developing emerging ecosystems instead of inadvertently restricting ideas to local practices. Such infrastructure in regulatory and policy domains encourage institutions and individuals to approach medical making in their practice as a valuable extension of care delivery through technology adoption.

## CHAPTER 7 – CONCLUSION

What makes making a significant phenomenon in HCI research? As recent HCI scholars and others [32, 141, 185, 190] describe, making is rooted in the collective efforts of a caring community to create solutions for its own needs. Oulasvirta and Hornbaek describe a research problem in HCI as a *"stated lack of understanding about some phenomenon in human use of computing, or stated inability to construct interactive technology to address that phenomenon for desired ends"* [145]. When makers collaborate, they create environments that could divest the power to create solutions where problems arise. My research decenters technologies to cast sociotechnical infrastructure in sharper relief [118]. In this sense, the *"human use of computing*" mentioned in the quote above encompasses medical makers' use of many systems – human, material, and informational – to support design related activities in care practices.

I use qualitative research methods to collect participant experiences of applying medical making at the bedside, in institutional makerspaces, and across online communities. I analyze how stakeholders shape relational structures to enable participation in making for care. The long-term empowerment of medical makers to innovate care infrastructure rests on supporting the efforts of key stakeholders and their labor, specifically the infrastructuring and articulation work of intermediaries to support collaborative work. In my dissertation, I study medical making activity at the point of care where patients interact with care providers. I found collaborations between medical makers are limited by hierarchical relationships defined by norms leading to the exclusion of some stakeholders in healthcare settings. For instance, despite creating patient-centered "*warm*

*solution*s," nurses are rarely at the forefront of technology use or innovation because medical making requires adequate support through articulation work.

Participation in medical making requires makers to overcome barriers to collaboration resolving opposing values, forms of expertise, and access to material resources. I examine these barriers form on-ground experiences in medical making to unpack how (and when) participation can be enabled by designing systems. I contribute an understanding of relational structures to show how makers adopt a partially open process to repair care infrastructure with the hidden labor of some stakeholders. In doing so, my research has shown how techno-optimistic visions of maker technologies, arguably technology itself, as tools for innovation are in fact used to repair breakdowns in healthcare settings. Further, my work shows how long-term goals to democratize technology-led innovation are deeply vested in an ecosystem influenced by social, material, and temporal contexts. I center relationships formed around and with maker technologies to understand the systems required for such collaborative making for healthcare use.

Overall, medical making as a case study for expert—novice collaborations is meant to inform the careful and caring design of sociotechnical infrastructure for any community interested in the use of maker technologies. In organizing this body of work, I present a research approach that represents a multitude of perspectives from lived experiences of makers who work towards solving their community's needs through creative, collaborative, and committed effort. In doing so, I hope my work aligns the interests of technology designers, researchers, and other related experts to critically examine how we contribute to HCI agendas of stakeholder inclusion.

## APPENDIX A. INTERVIEW GUIDES

This appendix includes the interview guides for three of four studies described in my dissertation; study 2 does not use interviews as a method.

### A.1.1 Study 1: Medical Maker Ecosystem

Thank you for taking the time to participate in our study.

Our research aims at understanding how people, particularly medical practitioners, craft health-related tools by making their own healthcare solution. Through this interview we hope to understand your experience and views working with the community of makers in healthcare. I've sent over the consent form on your email. The information we collect in this study will be used only for research purposes.

**Background**

1. Tell us about your background, and your introduction to the maker movement.
    i. What is your training - formal or informal?
    ii. What was your first experience with making?
    iii. In what way were you involved in the making process?
    iv. In what way do these experiences relate to your current initiative?

**Theme: Maker Identity**

2. What are the maker technologies you have come across in the healthcare context?
3. Were clinicians, patients or caregivers involved in these projects?
4. How would you describe making in the healthcare context?

i. How is it different from traditional/available methods to solve a health-related problem?

ii. Are there techniques you've seen makers use with specific audiences to tackle certain issues. For e.g., children and emotional distress

**Theme: Maker Space setup and motivation**

5. How did the idea for your makerspace come about?
    i. What were your key objectives?
    ii. Who are the investors in this makerspace? What are their goals?
    iii. Who was the makerspace set up for initially?
6. Describe setting up your makerspace.
    i. What are the resources did you need to setup this makerspace?
    ii. What did you refer to when setting up the makerspace for health purposes?
    iii. What were the machines you chose for the space?
7. At present, what resources do you need to run this space?
    i. Are any of these resources for training and support available online?
    ii. What kind of projects (time, scale) are typically made here?

    *Note: Understand if it is a hack or a crafted prototype*
8. Think of ____ (project mentioned) ___. I'd like to ask you some questions to understand your end-to-end experience.

    *Note: Check the examples of the artifacts made- who makes them*

    i. How did you decide on this project?
    ii. How did you put together a team, or did someone work alone?

iii. Did you need to provide training in the beginning or support at some point?

iv. What resources did you need to address […] challenge?

v. Did you turn to any online resources?

vi. In what ways did you document the project process?

vii. In what ways were you able to test the completed artifact?

viii. How did you measure success?

**Theme: Maker Community**

9. Who are the people you work with in the makerspace? Please describe your interaction.
    i. How often do you interact, is it the same group, do you meet online or offline?
    ii. What are the features of this community – where they meet, how they interact, what are its norms, how knowledge is collected, who becomes a member…
10. Reflecting on the projects you've witnessed and participated in, what do you think were the top 3 challenges of the community?

Just a few more questions about the usage and access to the makerspace.

11. Where is the makerspace located in your _____university/hospital?
12. Who comes to the makerspace now?
13. Are they involved in more than one project?
14. What is their motivation and reward for contributions?
15. Tell me more about the team in your maker space? Is it volunteer run?

### A.1.2 Study 3: Covid Makers (Intermediaries)

Thank you for taking the time to participate in our study.

Our research aims at understanding how people, particularly medical practitioners are responding to the PPE shortage during the COVID 19 pandemic in 2020. Your participation in this survey will help us understand your experience and views working with the community of makers in healthcare. The information we collect in this study will inform the design of technology to support your work in the future.

**Organizational Profile**

1. Organization's Name and location
2. Describe your role and responsibilities
3. Did your organization form in response to the Covid-19 shortage
    a. Yes > who initiated this effort and how
    b. No > what did your organization make before this?
4. Describe your community or organization's goal or mandate (add links if any)

**Organizational Resources**

5. What resources/equipment does your organization use
6. How did you mobilize the resources you needed to set up this organization?
7. Are you associated with a hospital or healthcare facility?
    a. Research lab/Hospital makerspace/University
8. Are there any medical professionals involved in your organization?
    a. Yes > doctors, nurses etc.

b. No > which of these describes some of the people in your org

9. How regular is your organizational interaction?
10. Where does it take place?
    a. Online presence > links to groups
    b. Offline presence > describe the space
11. What describes most of your organization's work (sliding scale)
    a. Online/offline
    b. Voluntary/enterprise
    c. Local/global impact
    d. Short-term/long-term goals

**COVID Related Activities**

12. What is your organization's role in responding to PPE supplies? Mark as applicable
    a. Manufacture parts
    b. Assemble devices
    c. Prototype designs
    d. Publish and document
    e. Test material quality
    f. Distribute
    g. Procure materials
    h. Advocate and mobilize
    i. Educate and train
    j. Other

13. Types of PPEs or medical devices made for Covid 19
    a. Surgical masks (sewn from fabric)
    b. Surgical masks (3D printed)
    c. Face shields
    d. N-95 or surgical masks (other materials)
    e. N-95 masks (3D printed)
    f. Surgical Gowns (made from fabric)
    g. Surgical Gowns (other materials)
    h. Ventilators
    i. Other
14. Where do you source the designs do you use for these devices (mention links if applicable)?
15. Do you follow any guidelines in producing your PPEs?
    a. Yes > mention sources > FDA vs their own
    b. No > how do you monitor feedback/quality
16. To what extent does your organization supply these PPEs to others
    a. Constant
    b. Intermittent
    c. On-demand

**Community Operations**

17. Describe the extent of activity for Covid 19 PPE production so far
    a. Approximate number of members till date
    b. Areas of reach and distribution (scale of operation)

c. Number of PPEs completed

d. How long you've been in operation

18. What have been the main challenges for your organization?

    a. Not enough skilled personnel

    b. Not enough time

    c. Not enough guidelines or testing

    d. Not enough support (Other)

    e. Too much demand

    f. Limited material resources (filament, machines, space, money)

    g. Other

19. Which of this best describes the response to your organizations' PPE supplies from your clients?

    a. Gratitude, more orders

    b. Feedback, higher expectations

    c. Overwhelming demand for more

20. Rate your level of satisfaction with the PPE manufacture from your organization or space.

Thank you for your participation. If you have any questions, please reach me.

### A.1.3 Study 4: Nurse Makers

First, we would like to thank you for taking the time to participate in our study.

This study is part of a larger research agenda to build an understanding of the medical community's need for design education (e.g., process, prototyping) typically available through makerspaces in engineering schools. Findings of this study will inform opportunities for HCI researchers and the community itself to build technology systems and processes.

Through this interview we hope to understand your experience and views about collaboration **as nurses**, project experiences, and specific needs for your goals through the **nurse community**. If I'm asking you something you don't really want to talk about right now, please let me know. You can just say, 'let's move on' or something like that and I'll move on right away. If you want to take a break, please let me know. If you would like to end the interview at any time, please let me know.

1. What is your occupation, specialization, and years of experience?
2. For this study problem-solving is focused on creating a physical artifact. Artifacts are any physical object, document, or device directly applicable in your role as a care provider. Given this definition, how would you define problem-solving in your experience.
3. What was you first experience with problem solving?
    a. Is it related to your role as a nurse?

*RQ: How do STEM courses introduce problem-solving with artifacts in med training?*

4. Describe your training for problem-solving as part of your professional education.
    a. What is the role or emphasis on problem-solving in your program?
5. What kind of technologies have you been trained to use in your role as a nurse?
    a. In what areas of your work do you apply these technologies?
    b. Do you prefer any specific technologies to solve problems?
    c. Could you explain why

*RQ: What is the role of design process in problem-solving as a nurse?*

6. How are nurse contexts different from other medical practitioners?
    a. Describe your workspace or daily routine.
    b. What do other nurses make?
    c. What technologies do they use?
    d. What type of problems do you encounter?
7. What kind of artifacts have you made in the past?

    *Note: Artifacts are any physical object, document, or device directly applicable in your role as a care provider.*

8. Describe the artifact you shared with us? [if shared!]
    a. What was your motivation?
    b. What technology did you use?
    c. How did you plan resources or gather support for your idea?

d. Where else do you look for support and resources?

e. Describe the time you spent planning, troubleshooting

f. Was this a onetime project or a continuing innovation? Explain.

g. What is the outcome, recognition, and exposure for this idea?

9. What are your key observations from this experience?

*RQ: What are the skills, processes, and barriers to integrate maker work in future roles?*

10. Reflecting on the maker projects you've witnessed,

    a. What are your top 3 challenges?

    b. What are the top 3 challenges for nurses to continue problem-solving?

11. In what ways can *or does* your current work scenario sustain your projects?

12. How do you pursue your interests as an individual?

13. Finally, do you identify as a maker? Describe what this means to you.

    a. Which of these words resonate with you: hack, make, create, solve?

14. Who are the key people you follow on DIY technology?

    a. Which organizations, makerspaces, labs, or people?

    b. Where did you look?

    c. How did you discover them?

    d. What was helpful? What was unhelpful?

    e. If not, why?

**Closing**

Thank you. We really appreciate your insights. If you think of something else you would like us to know or have questions about the research, please contact me.

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