Table 3: Considerations and Lessons Learned for Creating Registries

Exploratory registries generally enable broader and more comprehensive data capture than objective registries, but the trade-off is manageability and time required.
Initial data points should be extrapolated from existing knowledge on similar medical conditions to determine objective points, even if the overall nature of the registry is exploratory.
The registry needs agility to be able to manage evolving or changing parameters as the pandemic continues.
Manual data extraction requires at least 0.25-0.5 hours per chart for clinicians with health informatics familiarity, and 0.5-0.75 hours per chart for professional data extractors with limited clinical experience. For inexperienced user, it can take much longer.
For optimal sustainability, software compatible with the electronic medical record, automatic data extraction, and machine-based learning are needed.
Extracting information from subjective documentation may lead to measurement bias.
Data points with binary (yes/no) answers, or with numerical mapping (1=CHF, 2=DM, 3=CKD etc.) are more amenable statistical analysis; free text data entry should be reduced.
The number of parameters or data fields increases labor requirements and decreases manageability, but broadens the range and number of hypotheses that can be tested. Similarly, as the number of abstractors increases, so does inter-observer variability.
Serial or consecutive values of a data point will not be consistently obtained unless there a systematic or research protocol in place.
The platform on which the registry is created should provide data visualization tools in an interactive form.
Collaboration between multiple health systems with other patient populations increases generalizability of findings.
Clinicians need protected time to analyze data.
Robust registries from large EMR vendors take time to build and release, at times waiting for maturing knowledge making them unavailable to initial nodes of outbreak.
At such places, regional nodal registries are critical in early understanding and management of the pandemic The progress may be limited initially due to the manual process, but they critically guide development of robust semi-automated or automated solutions.
During the early part of a pandemic, focus changes to operational readiness and management, requiring lots of IT infrastructure bandwidth. At such times, having a manual process can be crucial to success of registry effort.