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Table 1: Systems of Leadership Domain

Components	1 - Not Started	2 - Beginning	3 - Intermediate	4 - Mature	5 - Idealized State	DK	Leader 1	Leader 2	Leader 3	Leader 4	Leader 5	Leader 6	Leader 7	Leader 8	Average	SD
Common Purpose*	The Network has no written statement of their purpose (e.g., Mission, Vision, value, Charter).	Some types of purpose statements exist, but not used in Network activities.	Mission and tenets/values are defined and visible (documents and website).	Mission and tenets/values are defined and visible; understood by participants and used in strategic planning.	The mission/vision statement is used to align and guide the Network, is fully integrated into the Network activities and structure.	Don't know										
Understanding of the Organization as a System*	The processes of the network are not documented.	Major processes, services and products of the network have been documented.	Relationships between network processes are documented and studied.	Systems diagrams exist to describe the network. System thinking is common in network activities.	Systems diagrams of the network are used in Network management systems.	Don't know										
Family of Measures	No regular measurement reports. Some data are shared periodically.	Network measures are reported. Some have operational definitions and are documented in standard format.	A clearly defined family of measures is assembled and reported at least quarterly.	A balanced set of measures including key network outcomes, are reported (at least quarterly) and graphically reviewed.	The family of measures, reported as a time series is integrated into Network management systems.	Don't know										
Information from Stakeholders*	No system in place - information is gathered on an ad hoc, reactive basis.	The network system is based on information collected passively.	The system is well-documented and includes active sources (feedback forms, surveys, focus groups).	Information is documented, analyzed and communicated to network leadership including from patients and families.	Information from stakeholders is organized in a knowledge management system.	Don't know										
Strategic Planning for Improvement of the Network*	No strategic planning is undertaken (e.g., the Network continues to evolve organically).	Network planning for improvement is done on an informal basis.	A formal, documented process exists for planning. Goals are set annually and reviewed regularly by the leadership team.	An integrated planning process identifies objectives, defines improvement activities, and assigns resources.	Strategic and business planning works as an integrated system and is improved each year.	Don't know										
Managing Improvement Efforts*	Improvement projects in the network are done on an ad hoc basis.	Improvements are recognized on an as-needed basis and resources are assigned.	Leaders provide formal guidance (e.g. charters) for individuals and teams on improvement activities.	Improvements are guided by the network planning processes. The impact of improvement on the network system is studied.	The improvement system is integrated in the work of the Network and regularly improved.	Don't know										
Development of Leaders	Network leaders are self-selected or volunteered.	A leadership development process is being tested. Opportunities exist for future leaders to participate in formal improvement initiatives.	A formal development process, including mentoring and rotation of assignments provides developmental opportunities for future leaders.	Leadership development opportunities are identified as part of strategic planning. A formal succession plan exists for all network leadership positions.	The leadership development processes and succession planning are reviewed as part of annual strategic planning.	Don't know										
Leadership System	The leaders of the network work relatively independently.	Leadership activities (decision making, planning, resource allocation, and communicating) are done on an ad hoc basis.	Some processes for leadership are documented in the network.	The activities of the leaders of the network are documented, standardized and integrated.	The leadership activities are improved on an annual basis as part of strategic planning.	Don't know										
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*Components from or based on "QBS: Progress on Integrating Improvement into the Business" in: Quality as a Business Strategy. Associates in Process Improvement-Austin. September, 1998. Austin, Texas.

Table 2: Components of the Governance and Management Domain

Components	1 - Not Started	2 - Beginning	3 - Intermediate	4 - Mature	5 - Idealized State	DK	Leader 1	Leader 2	Leader 3	Leader 4	Leader 5	Leader 6	Leader 7	Leader 8	Average	SD
Network Management	No management processes or operating procedures have been developed.	An operational needs assessment including issues of prioritization of work flows and opportunities has been completed.	A staffing model and operational procedures have been developed.	Network faculty and leadership have dedicated time for network management. Standard operating procedures are utilized.	The Network regularly evaluates and improves its management structure, processes and policies as part of routine operations.	Don't know										
Network Stakeholders Participation in Governance	No formally documented governance model for including all stakeholders is in place.	Key stakeholder groups have been identified. Governance model developed and implemented; includes some stakeholders only in advisory capacity.	Governance model developed and implemented; includes representation of most stakeholders with limited decision- making authority.	A governance model has been developed and implemented and includes all stakeholder groups (patients, families, clinicians, and researchers).	Stakeholders participate in all aspects of governance at both Network and local levels.	Don't know										
Membership Policy (guidelines, rights and obligations of members including patients, clinical care sites, health professionals)	A membership policy has not been developed.	A membership policy is being developed with expectations for members.	A membership policy has been developed, including procedures and training tools (e.g. how to respond to requests for data).	The network membership policy is regularly used in activities. Training and capacity building taking place.	The Network evaluates and improves membership policy as part of strategic planning.	Don't know										
Financial Sustainability - Business Plan	No business plan exists.	Business plan has been drafted and reviewed. The plan specifies funding streams, and financial goals.	Business plan includes financial plan tied to key products/processes and related initiatives.	An integrated business/financial plan including projections for activities and target levels for funding streams is used to coordinate actives.	Business plan integrated with strategic plan with long-term strategy. Financial scenario (sensitivity) analysis has been done Plan reviewed at regular intervals.	Don't know										

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Institutional Review Board policies and protocols	An institutional review board (IRB) policy has not been developed.	An IRB policy, including research considerations, informed consent and QI, and a Master Reliance Agreement (MRA) have been drafted.	An IRB protocol, including research considerations, informed consent and QI, has been developed and approved. 30% of centers have been engaged in the MRA.	An IRB protocol has been implemented across the Network. 80% of centers have approved the MRA.	The Network regularly evaluates human subjects' research policies, including the MRA as part of strategic planning.	Don't know										
Internal Network Policies and Procedures for intellectual property and data sharing	Network polices for data sharing and publication have not been developed. Capability for data sharing is not developed.	Policies for intellectual property, publication, data sharing and privacy, are in development. Data-sharing processes have been pilot tested.	Polices exist for intellectual property, publication and data sharing (ownership, access, privacy and security).	Network publication and data policies standard operating procedures are in use. Data sharing occurs with Network members and their collaborators.	The Network regularly evaluates attribution and data policies and procedures with intention for maximum transparency across the network.	Don't know										
Policies for working with entities external to the Network (e.g., sponsors, industry)	A collaboration policy has not been developed.	A collaboration policy is being developed.	A collaboration policy has been developed, including standard operating procedures.	A collaboration policy has been implemented.	The Network regularly evaluates collaboration policy as part of strategic planning for improvement.	Don't know										
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Table 3: Components of the Quality Improvement Domain

Components	1 - Not Started	2 - Beginning	3 - Intermediate	4 - Mature	5 - Idealized State	DK	Leader 1	Leader 2	Leader 3	Leader 4	Leader 5	Leader 6	Leader 7	Leader 8	Average	SD
Network framework for improvement	The Network has a project focus identified but does not have a systematic approach to improvement.	Network approaches projects with a theory for improvement, a Key Driver Diagram, Specific Aim and outcome measures.	A formal improvement approach exists and data is used to guide improvement efforts. 25-50% of participants have training on the use of the method and tools.	Standardized QI tools and methods are used reliably (>80%) across network teams to plan and carry out improvement work.	Standardized QI tools and methods are used reliably by ALL Network teams to plan and carry out improvement work.	Don't know										
System for Identifying and Prioritizing Quality Improvement Projects to Improve Network Efforts	The network does not use system methods for identifying and improving network efforts.	Improvement efforts for the network are developed on an ad hoc basis.	The network uses systematic methods on a regular basis (e.g. a data dashboard, maturity grid and/or milestone reviews) to identify opportunities for improvement.	QI projects are prioritized and developed as part of an annual strategic planning process using the Maturity Grid, incorporating information from the data dashboard and milestone reviews .	QI projects are strategically used to conduct and advance the mission of the Network.	Don't know										
QI learnings by Network participants shared with other members	There is no systematic process for sharing QI learnings among network participants.	QI learnings are shared ad hoc (e.g. comments on a call or in email).	Strategies are in place for active peer-to-peer learning using PDSAs, strategies, barriers (monthly calls, face-to-face meetings, newsletters).	Some Network participants share responsibility for planning and conducting sharing activities.	A majority of Network participants use a "Commons" to regularly share seamlessly and transparently.	Don't know										
Methods for dissemination and spread of key changes (best practices) across care centers doing the work	Methods for dissemination and spread of best practice are ad hoc. No formal plan for dissemination and spread have been developed.	Plans for dissemination and spread are drafted, however, not integrated into network efforts.	Initial alignment of the dissemination and spread goal is complete and strategic planning is underway.	Planning for dissemination and spread are integrated into the yearly strategic planning process.	Standard methods and five-year plans for dissemination and spread are in place.	Don't know										
Communication and publication of QI activities and results	Communication is ad hoc. No formal communication strategies are in place.	Communication plans developed to share information with Network teams (newsletters, website, social media, etc.).	A communication plan is in place for the Network teams and its effectiveness is assessed regularly.	Network progress and outcomes are shared publicly with manuscripts, presentations at conferences, manuscripts, etc.).	The network is considered the leading source for improvement in their topic area.	Don't know										
Quality Improvement Reports (of care site activities)	QI reporting (summarizing site QI activities) is ad hoc.	Network or care sites produce QI reports about QI activities at the care sites, and these reports are available for review by network or care sites.	Network produces QI reports that summarize testing activities at care sites and are distributed to care sites on a regular schedule.	Network produces QI reports that include documentation of testing, progress and graphical data display (e.g. run charts, SPC charts). These are available for sites on a regular schedule.	QI Reports documenting progress at care site are linked with other management reports. Network can share QI reports with others.	Don't know										
Quality Improvement Education and Training	QI training is not offered by the network.	Participants and teams receive basic QI training from the Network.	QI training and education at multiple levels (e.g. basic, advanced) are available. New participants receive QI training as part of orientation.	A mature QI training and education program is available with team assessments used to guide training plans.	QI training and education are integrated into the Network, assessment of team members' capability and evaluations of the training program are in place, feedback is used to continuously improve the program and track effectiveness.	Don't know										

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Innovation	Innovation is not considered as part of Network's QI work.	Teams share innovative strategies on an ad hoc basis.	Teams and/or Network identify key gaps and seek innovative solutions and strategies to fill these gaps.	Workgroups, formed to address and test innovative strategies, are supported by network infrastructure.	Innovation is a key part of Network QI strategy, and the network uses a systematic process to fully incorporate Innovation into QI practice (e.g., Innovation Rating Scale).	Don't know											
Data Transparency	Individual centers may track own data. Process and outcomes data are not shared among network participants.	Individual centers receive their own data. Aggregate Network outcomes data shared among Network care centers.	Key aggregate Network outcomes data shared publicly.	Aggregate and individual care center data shared among Network care centers teams.	Aggregate Network outcomes and care center-level outcomes data are transparent and public.	Don't know											
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Table 4: Components of the Engagement and Community Building Domain

Components	1 - Not Started	2 - Beginning	3 - Intermediate	4 - Mature	5 - Idealized State	DK	Leader 1	Leader 2	Leader 3	Leader 4	Leader 5	Leader 6	Leader 7	Leader 8	Average	SD
Parents, patients, clinicians and researchers are co-creators and co producers	No expectations of collaboration/ partnership; collaboration/partnership is ad hoc.	There is growing awareness of the need for and benefits of collaboration/partnership. Time and contributions of patient partners are valued and demonstrated.	Collaboration/ partnership is valued, some efforts are underway to spread this culture, and training in co-production exists.	There is a pervasive culture/expectation of collaboration/partnership. Parents/patients have defined leadership roles. Time and contributions of all partners are valued, demonstrated, celebrated, and acknowledged in fair financial compensation, as well as reasonable and thoughtful request for time commitment.	The Network regularly evaluates partnership/collaboration as part of strategic planning.	Don't know										
Communication to increase awareness of the Network, opportunities for and importance of engaging in it	Communications infrastructure and processes not developed.	Basic awareness-raising communications about importance of involvement have been developed on one or two channel (e.g., website, social media, newsletter).	Multiple media channels are used. Content is produced by a range of stakeholder groups. Campaigns to increase awareness, trust and cooperation exist.	Multi-channel communication is used to activate the community and engender trust and cooperation. Content is produced by all stakeholder groups. Regular campaigns to increase awareness are executed.	Network leaders know how many stakeholders are aware of Network and opportunities to engage, use this information to regularly increase awareness.	Don't know										
Competency in co-production and leadership	There is no awareness or investment in increasing competency.	There is ad-hoc training in co-production and leadership, mostly at the Network level.	Training materials exist, but are not widely disseminated, and there are some efforts to increase competency in local (care center) leadership.	Training for co-production and leadership is done regularly at Network and care-center levels.	There is a robust, distributed training system for co-production. There is systematic leadership development at the local and Network levels via progression along a well-described and documented ladder of engagement.	Don't know										
Coproduction in site level improvement teams	Site level improvement is performed by one type of stakeholders (.e.g. only clinicians)	Other stakeholders are part of the improvement team, participate occasionally in improvement work.	Diverse stakeholders participate in improvement work at the site level.	Diverse stakeholders take active ownership in site level improvement work.	Almost all site level improvement work involves high functioning multi-stakeholder teams with diverse leadership.	Don't know										
Growing local leadership through site level community organizing	No local organizing exists	A few sites have local leaders; some have recruited and organized volunteers to execute improvement work, with some success	Up to 50% of sites have robust local organizing efforts.	More than 50% or more of sites have robust local organizing efforts	Local organizing efforts are evaluated and integrated into annual strategic planning	Don't know										
Facilitating stakeholder collaboration	Stakeholder collaboration is ad hoc.	Some opportunities for collaboration (e.g., local meetings, online communities) exist, but only being piloted by a small proportion of target users.	25-50% of target users are able to find and collaborate with others who are working on similar problems; clear protocols exist for how to work together in self-organized teams.	50-75% of target users are able to self-organize into teams.	Processes exist for all network participants target users to self-organize into functional teams. More than 75% of participants have participated in such teams.	Don't know										
Production and sharing of information, knowledge, and knowhow	Sharing information, knowledge, and knowhow is ad hoc; no shared commons exists.	A commons for sharing resources exists; some stakeholders contribute resources; the type and amount of resources is limited.	Approximately 2-5% of stakeholders regularly contribute resources; the amount and type grows linearly.	Information, knowledge, and knowhow is shared seamlessly by >5% of stakeholders; the amount and type of resources are increasing non-linearly.	The network evaluates the amount and type of resources available and integrates this into strategic planning.	Don't know										

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Feedback from Patient Community	Feedback from patients and families is collected on an ad hoc basis.	A system exists to collect feedback from patients and families.	Feedback from patients and families is regularly analyzed and distributed to network leadership groups.	Patient and family feedback is used by Network QI improvement teams.	Feedback from community is an essential input to Network strategic planning.	Don't know											
Getting "What I need, when it's needed (WINWIN)"	The Network has general informational resources available for one or more groups of stakeholders.	Some stakeholders have access to a commons; use of the commons (e.g. views, downloads, conversations) is limited.	Less than 20% of stakeholders use the commons; the Network has a way of monitoring whether users get WINWIN.	20% or more of stakeholders use the commons regularly; satisfaction with getting WINWIN is high.	The Network has tools to anticipate stakeholder needs and pushes resources to stakeholders.	Don't know											
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Table 5: Components of the Data and Analytics Domain

Components	1 - Not Started	2 - Beginning	3 - Intermediate	4 - Mature	5 - Idealized State	DK	Leader 1	Leader 2	Leader 3	Leader 4	Leader 5	Leader 6	Leader 7	Leader 8	Average	SD
Data Collection	Data are not systematically available for improvement teams or other network stakeholders.	Data are available to evaluate baseline in outcome and process measures. Plans have been made for gathering and reporting care center and Network data.	Aggregate and individual data based on the Network's Key Driver Diagram are being collected by Network care centers on a regular and frequent basis.	Aggregate and individual data are available to Network care centers on a regular basis and used to guide improvement activities using SPC methods.	Network regularly assesses whether data is appropriately assessing target outcomes, and adapts data collection, measures and SPC methods as needed.	Don't know										
Data Quality and Validation	Network Data quality has not been measured.	Data quality is measured as required using manual processes.	Data quality reports are manually produced and distributed on a regular basis. Data quality improvement is beginning.	Data quality is measured automatically, reported in near real-time, and improved. There is evidence of improvement in data quality over time.	Data quality procedures achieve relevant standards when necessary. Source validation occurs on a regular schedule.	Don't know										
Completeness of Health Related Data*	I or fewer of the data sources.	2 of the data sources.	3 of the data sources.	4 of the data sources.	5 of the data sources.	Don't know										
Linked Data Sources (e.g., administrative health plan data, pharmacy claims, biorepository, PROs)	There is no capacity to link data sources.	Plan to link relevant data has been developed.	Up to 25% patients have relevant data linked to at least one source of administrative data.	25%-50% of patients have relevant data linked to at least one source of administrative data.	>75% patients have relevant data linked to multiple sources of administrative and biospecimen data.	Don't know										
Data capture and transfer from source (e.g. Electronic Health Record, schools)	There is no data capture or data transfer from the source.	Data are captured in the source but must be transformed to Network data standards. There is no data transfer.	Some data can be captured and transferred from the source according to Network data standards without transformation. Implementation at Network care centers has begun.	>50% of data elements can be captured and transferred from the source according to Network data standards without transformation. Implementation is complete in half of care centers.	100% of data elements can be captured and transferred from the source according to Network data standards without transformation. Implementation is complete across all Network care centers.	Don't know										
Data Standardization and Interoperability (with registry or data base)	Registry or data base lacks common standards, and is not interoperable with other data sources.	Registry or data base has defined a set of standards for a limited set of data elements (e.g., diagnoses, labs, meds) and transformed registry data into these standards.	All data elements including condition-specific data elements have been mapped to a standard terminology or other standard or the Network is working with the appropriate governing body to add them.	The Network has participated in over 25 multi-Network, short turnaround (<1 week) analytic queries.	The Network routinely participates in near real-time, multi-Network analytic queries.	Don't know										
Data accessibility for learning	Data cannot be explored using analytic tools.	Analysts can do data exploration on an ad hoc basis. Only a fixed list subset of variables are returned.	Analysts have the capacity to do near real-time on-demand data exploration.	Authorized users of the Network data are able to do real-time data exploration.	Authorized users regularly use the network data for complex data exploration and have the capacity to stratify data for learning.	Don't know										
Items below are most appropriate for LHS with Registries (Do not score if not appropriate)																
Consent Management	No consent management tools exist.	Consent status is managed manually and kept locally at each Network care center in disparate ways.	Consent status is managed manually and kept locally at each Network care center using a consistent process.	Consent status is managed manually using a consistent process and is sent to the central Network on a regular basis.	Consent status is managed through the Network's system. e-Consent tools are available.	Don't know										
Clinical decision support for either patients or clinicians (and chronic care management if appropriate for network)	Network Registry or data base does not provide clinical decision support (CDS).	Registry or data base provides basic clinician decision support (CDS) with latency > 1 day.	Registry or data base provides CDS including pre-visit planning (PVP), population-level analysis, and most recent patient data within 1 day.	Implementation of CDS across all Network care centers.	Registry provides CDS in real-time at the point of care with linkage to QI reports. Registry can transmit CDS criteria to external applications.	Don't know										

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Patient self-management and decision support (Personalized Learning)	No tools exist to facilitate patient self-management, personalized learning or decision support.	Patients are using tracking and self-management tools on their own.	Patients use the EHR for pre-visit planning (PVP) and tracking. Network data base or registry can receive data from other applications that enable PVP, patient activation, self-tracking, personalized experimentation.	Network data base can send and receive data from the EHR, registry and other applications that enable PVP, patient activation, self-tracking, personalized experimentation alone or with the clinician integrated with the EHR. Regulatory framework in place.	Patient-level predictive analytics are done in real-time and used for diagnostic and therapeutic decision-making. "Recommender" systems for personalized learning and decisions based on real-time subgroup analysis.	Don't know											
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*all information that accumulates about a person or population that may affect health outcomes, including: health data generated during clinical encounters; claims data; data gathered from research; genomic data; social environmental determinants of health; patient generated health data

Table 6: Components of the Research Domain

Components	1 - Not Started	2 - Beginning	3 - Intermediate	4 - Mature	5 - Idealized State	DK	Leader 1	Leader 2	Leader 3	Leader 4	Leader 5	Leader 6	Leader 7	Leader 8	Average	SD
Education and Training for Research using Learning Networks	The Network does not provide research training.	The Network provides ad hoc training in how to do research using its own resources.	The Network has developed training resources and programs for investigators on how to do research using its resources.	The Network has developed training resources and programs for multiple stakeholder groups on how to do research using its resources.	The Network regularly evaluates the impact of its research training program and the resources needed as part of its strategic planning for improvement.	Don't know										
Research Prioritization (a process by which stakeholders collaboratively define the research agenda for the LN)	No research prioritization activities have been undertaken.	A multi-stakeholder prioritization process has been designed and prototyped.	The multi-stakeholder informed research prioritization process has been implemented successfully, including feedback of priorities to stakeholders.	The Network has developed a methodology connected to strategic planning for ongoing research prioritization across a multitude of topics.	The Network uses quality improvement methods to regularly evaluate and enhance its research prioritization process.	Don't know										
Protocol Development and Review	Research proposals are reviewed on an ad hoc basis in the network.	Protocols are developed without any standardization and reviews are done on an ad hoc basis.	Network has developed guidance for protocol development and conducts formal review of protocols.	Network has a protocol development work group that assists research teams with concept and protocol development.	Network continuously monitors the costs and outcomes of its protocol development and review process and uses improvement methods to strengthen them.	Don't know										
Secondary Data Analyses	The Network has not conducted any secondary data analysis studies.	The Network has demonstrated that its data quality is adequate to support secondary data analyses.	At least one research study has been done using existing data.	The network has completed and published multiple secondary data analysis studies	Potential secondary data analysis is considered in network strategic planning.	Don't know										
Primary Data Collection	Primary data for research has not been collected from participants.	Primary data for research has been collected on an ad hoc basis.	Network has developed and implemented at least one tool (e.g. a survey platform) to assist researchers with primary data collection.	Network has tools and resources for primary data collection; these are used regularly by researchers or other stakeholders.	The Network regularly evaluates its primary data collection system as part of its strategic planning.	Don't know										
Interventional Studies	No interventional studies (e.g., clinical trial, effectiveness, step-wedge, multiple baseline, N-of-1, factorial design) have been conducted by the Network..	The Network is developing policies and processes to support elements of interventional studies. A small pilot has been conducted successfully.	The network has the capability to manage an interventional study including: recruitment, eligibility screening, enrollment, follow up, data management, dissemination of findings.	More than one Network interventional study has been conducted successfully.	All elements of interventional studies are managed with high reliability. Multiple (>5) large scale, multi-center CER studies have been undertaken.	Don't know										
Recruitment tools for Interventional Studies	The Network does not provide trial recruitment tools.	Network has designed and prototyped efficient trial recruitment tools.	Network has prototyped and pilot tested efficient trial recruitment tools for at least 3 studies.	Network uses recruitment tools regularly in research studies.	Network monitors patient recruitment and uses improvement methods to lower the time and costs involved.	Don't know										
Research contributing to the science of improvement	The network is not conducting research on QI methods.	Publication of improvement results by network participants.	Publication of Network-wide QI research.	Results of QI research are considered as part of Network's strategic planning.	Network participates in QI research in collaboration with other improvement Networks.	Don't know										
Logistical Support for Research	The Network does not provide any logistical support for research.	The Network provides ad hoc logistical support (e.g., the start-up, conduct or shutdown) for research.	The Network has provided logistical support for at least 3 studies.	The Network makes available a set of logistical resources for all research studies according to its standards.	The Network regularly evaluates its research infrastructure support, including its costs and effectiveness.	Don't know										
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