PRELIMINARY RECOMMENDATIONS – Thesis Goal

This Discussion module accomplishes the main thesis goal.

Built in the results, references and other information found along the process of developing our specific objectives and reviews - yet presented and discussed individually; this thesispart develops a set of future-oriented "preliminary recommendations" as a strategic roadmap towards a long-term envisioned US 'PAC Rehabilitation Quality System'. Such recommendations are built upon action yet being made or prepared in the field for, but focusing on developing and complementing the scope of system-level quality-initiatives and supportive research not yet started or adequately accomplished for the PAC Rehabilitation scope, taking the changing trends in healthcare quality-initiatives as referential.

Along time, the envisioned 'PAC Rehabilitation Quality System' should be self-maintained in progressively higher levels of equilibrium, stimulating/facilitating optimal qualityimprovement to happen at the multiple ecological levels. However, in this early stage of development, our recommendations direct mostly towards a set of strategic, system-level and infrastructural initiatives - setting the suitable infrastructural and external environment conditions for transformational quality-improvement could optimally occur at the macroand micro-system levels.

Within a two-level hierarchical structure, we begin to present a couple of overarching recommendations, followed by a sub-set of recommendations more at an operational level, yet the operational preliminary recommendations are them-selves to developed by the two entities and processes composing our overarching recommendations.

Important to recall, such set of "preliminary recommendations" are exactly what the name indicates: preliminary. They are literature-informed - supported by wide, integrative and complex-based review approaches - but also being subjective, interpretative and creative-based, which represent threefold dimensions that are author dependent. Such introductory

note outlines any of the following recommendations should be understood in the light of a perspective developed mostly of a single author (besides supported by literature and experts consultation). Thus, it is presented within the Discussion section.

Furthermore, the "preliminary recommendations" do not intent to represent 'the' solution to take, neither the 'exact' way it shall be accomplished. Indeed, even the most operational and detailed-described recommendations shall be better seen as a stimulus activating discussion around the topic. It would be a good outcome if these recommendations were able to raise stakeholders' awareness for the need and possibility to effectively develop and deploy strategic, infra-structural and systems-based PAC Rehabilitation quality-initiatives, facilitating transformational changes in PAC Rehabilitation quality of care.

In the page below we present a diagram (<u>fig. 6</u>), hierarchically exposed, over-viewing our major "preliminary recommendations" in a roadmap towards the development of the envisioned 'PAC Rehabilitation Quality System'.

A- OVERARCHING RECOMMENDATIONS

In a hierarchical disposition, we first present two overarching recommendations, interlinked with each other. The inter-linked process of these overarching recommendations shall represent the great underlying and infrastructural support for the development of further strategic directions and integrated solutions for the development of an envisioned 'PAC Rehabilitation Quality System', for instance including but not restricted to those we present after such overarching recommendations.

1- PAC Rehabilitation Consensus-Building Partnership for Quality

Engaging PAC Rehabilitation stakeholders in a consensus-building partnership for quality and quality-initiatives represent our first overarching recommendation. Such partnership structure or entity might become responsible by the strategic definitions for quality and



quality-initiatives within the PAC Rehabilitation scope, as well as actively engaged in overarching partnerships in terms of building definitions for the broader scope of quality and quality-initiatives as applied to acute 'episodes of care', and ultimately applied to overall health system in which PAC Rehabilitation is embedded.

The activity of such PAC Rehabilitation consensus-building partnership should be actively framed in a complementary mechanism with the second overarching recommendation, later outlined. Herein, we enter in the fundaments, function and overall description of the scope of such overarching recommendation.

1.1 The need for PAC Rehabilitation consensus-building about quality and qualityinitiatives

The major needs and perspectives of PAC Rehabilitation stakeholders must be equitably met by a 'system' of concerted/aligned PAC Rehabilitation quality-initiatives; otherwise these initiatives will fail in its ultimate intents of effectively and systemically improving PAC Rehabilitation quality. This is for instance denoted by the 'unintended consequences' of narrowly-defined quality-initiatives in general healthcare ^(1; 2; 3), and the "quality paradox" in PAC Rehabilitation field: in which the lack of specificity and lack of stakeholders involvement in definitions of quality-improvement initiatives have only created perceived discredit in its potential to effectively improve quality of PAC Rehabilitation services and care ⁽⁴⁾.

In order to PAC Rehabilitation quality-initiatives become effective on its broader scope and if we want to take the best achievable benefit from it - a system of quality-initiatives (quality-assessment, monitoring, reporting, and improvement initiatives - acting upon the political, external, macro, micro and consumer levels) must reflect a broad consensus among multiple stakeholders' perspectives: those stakeholders required for, and affected by, its development and deployment.

In synthesis, stakeholders must integrate their perspectives and unite their efforts - for instance in a partnership structure and consensus-building process - in order to create the structural long-term vision, roadmap and conditions for activating and sustaining a

transformational change for quality in PAC Rehabilitation services and care trough a effective, aligned and meaningful 'system' of quality-initiatives.

Therefore, a first, overarching, recommendation, we could outline is exactly the strong need to engage all type of stakeholders groups (for instance those providing structure for the 2^{nd} and 3^{rd} review results) to achieve enlarged consensus about an envisioned 'PAC Rehabilitation Quality System' – with consumers in a pivotal role, as outlined in the 1^{st} review.

1.2 The process of building consensus for PAC Rehabilitation quality and quality-initiatives

We outline a consensus-building process for PAC Rehabilitation quality and qualityinitiatives with four major functions. They are presented in sequence, yet in practice they might become partly overlapping: a quality concept/definition; a vision for an idealized system of quality-initiatives; priorities and a strategy to be followed; as well as a startingup/activation action-plan towards the envisioned or idealized scenario.

1.2.1 Consensus for quality concept/definition

To avoid unintended consequences of quality-initiatives that are based on non-specific, narrow or misconceptions of PAC Rehabilitation quality ⁽⁴⁾, a first task for stakeholders' consensus should be achieve a common understanding of what the specific PAC Rehabilitation quality conceptually and operationally means.

Consumers/users (patients and families) represent the stakeholders' group holding a pivotal role as source of definition and control for quality in general healthcare ^(5; 6), as well as in PAC Rehabilitation ^(7; 8; 9), ensuring consumers-centered quality-definitions. Indeed, stakeholders' consensus should be built first around patients' and families' perspectives - the primary source of quality-definition - as complemented by the perspectives of all other involved stakeholders allowing a feasible operationalization, and also ensuring alignment with overarching guiding policy for quality of general and PAC Rehabilitation services and care ^(10; 11).

In addition, consumers (as widely fostered and supported in Results, mostly in the 2nd review) have critical active roles in the prescribed transformational change for quality. But if we can enhance such critical active role, they must be early engaged in define the kind of quality they value and want to be reflected in quality-assessment, improvement and public-reporting initiatives, representing the kind of information they want to compare for quality-informed choices about health plans and providers. This is not yet accomplished in this field, and pointed a major reason for PAC Rehabilitation consumers' disengagement with quality-information in their decision-process for PAC Rehabilitation providers⁽⁸⁾.

Indeed, despite existing methods of engaging consumers in healthcare definitions and decisions applied all over the healthcare field ^(12; 13; 14); the stakeholders' participatory process were scarcely addressed in the PAC Rehabilitation field ⁽¹⁵⁾, with PAC consumers' perspectives being uncommonly called for such participatory process: This is a trend only beginning a changing process ^(9; 16), representing a requirement for overcoming quality misconceptions in the field ⁽⁴⁾.

The conceptual framework we presented in the 1st review (particularly after refinements as independently discussed before) could be a conceptual starting-point for engaging consumers and all other stakeholders in the consensus-building process that aims to shape the conceptual and operational meanings of PAC Rehabilitation quality.

1.2.2 Consensus on a vision for a 'PAC Rehabilitation Quality System'

After having an enlarged consensus and commitment around a specific concept/definition of PAC Rehabilitation quality, stakeholders should begin work towards reaching agreement about and envisioned 'PAC Rehabilitation Quality System', meaning achieving a common vision and idealized scenario for a medium/long-term 'system' of specific quality-initiatives facilitating PAC Rehabilitation quality of care could be improved (or constantly improved) across sites and sub-populations.

Such vision shall reflect the same generic foundations and vision of the US 'national quality strategy' ⁽¹⁰⁾, but going further in specification for the unique PAC Rehabilitation quality scope, needs of sub-populations attended, and process characteristics. In summary, the task is about envisioning the optimal system of PAC Rehabilitation quality-initiatives

and activities (including supportive research and development) that supports the optimal quality of PAC Rehabilitation services and care. Such vision should be able to drive a set of further priorities, strategies and a starting-up action-plan to take.

1.2.3 Consensus about priorities & strategy

Attached to a shared vision, there should be developed a consensus among PAC Rehabilitation stakeholders about priorities to be addressed, guiding the design of a strategy for quality and for a system of quality-initiatives applied to PAC Rehabilitation.

Priorities for the field should be reasoned, embedded and fitting with those in the National Quality Strategy for the US whole health/healthcare system ⁽¹⁰⁾. Indeed, we might recall that such priorities definition is it-self also a product of consensus-building, primarily coming from the National Priorities Partnership ⁽¹⁷⁾.

Despite aligned and embedded in a general healthcare National Quality Strategy, priorities for PAC Rehabilitation quality and quality-initiatives should be able to specify, refine or adding some new strategies that are tailored to the unique PAC Rehabilitation quality scope and profile. In synthesis, the PAC Rehabilitation strategy for quality shall gain needed specificity for its unique scope, but without losing congruency with national major strategies for quality-action in the general healthcare system - in which PAC Rehabilitation is embedded.

1.2.4 Consensus for a starting-up action-plan

A fourth task for PAC Rehabilitation stakeholders' consensus-building process would be developing a starting-up action-plan that activates the long-term (or never-ending) roadmap towards achieving the envisioned 'PAC Rehabilitation Quality System'. In summary, an action-plan that begins to put a consensus-based concept, vision, priorities and strategy into operational and action terms – a step for the PAC Rehabilitation scope equivalent to the recommendations for general healthcare of the seminal 'quality chasm' report (18), but in case with enlarged emphasis in stakeholders' consensus-building efforts.

A critical starting-up input would consist in creating the suitable structural and externallevel conditions and initiatives in which the macro- and micro-system quality-improvement efforts could optimally flourish. It means developing and aligning the conditions (activation input) that facilitates a spiral or chain of positive effects until an envisioned 'PAC Rehabilitation Quality System' becomes self-feed in a high-level of equilibrium and effectiveness for a PAC Rehabilitation quality transformational change.

1.2 Broadening PAC Rehabilitation consensus for quality and quality-initatives to the level of 'episodes of care':

In the quality movement there is a progressive and fundamental shift from a providersbased perspective of quality, to a more consumer-centered quality perspective which sees and analyzes quality in the continuum of services and care a single patient receives ⁽¹⁹⁾, and more recently population-centered view of quality concerning to care (sub-)populations receive ⁽²⁰⁾ - both in longitudinal view of health/healthcare quality.

In consequence, despite carrying out their specific duties of achieving consensus about a specific PAC Rehabilitation quality roadmap (a challenging task *per se* – as described so far); PAC Rehabilitation stakeholders consensus-building should also evolve - on a second stage - to actively contributing on the development of quality and quality-initiatives for acute 'episodes of care', in which PAC Rehabilitation is embedded. Indeed, even if PAC Rehabilitation quality and quality-initiatives become further integrated and in own-scope (actually still fragmented by providers-type), we might still to broaden the view of quality and quality-initiatives to the whole quality of care patients and sub-populations receive across the continuum of acute 'episodes of care'.

Such broader view of PAC Rehabilitation quality fits within the paradigm shift in the healthcare quality-movement, progressively more focused on improving the longitudinal value (quality of care, health and costs) of the whole services and care received by a patient and populations ^(20; 21). Therefore PAC Rehabilitation stakeholders' consensus must go beyond the aim of exclusively improving the quality of their own services, to be also more broadly able to be engaged in developing consensus and active collaborations for envisioning quality and quality-initiatives addressing extended 'service-lines' for acute 'episodes of care'.

A broad consensus on a roadmap for quality and quality-initiatives among stakeholders of different healthcare levels integrated into 'episodes of care' will be required, as it should also involve integration with policy, public health and other stakeholders at the community, macro and external environment. A consensus roadmap for quality-initiatives, with 'episodes of care' as unit of analyses, would foster aspects of quality that mostly relate with optimal coordination of care and with: ideal timing to transfer from an acute to a PAC Rehabilitation facility; the initiation of therapy yet in the acute place; enhancement of participation outcomes after PAC discharge, among other critical aspects for the quality and outcomes of acute 'episodes of care' – those that cannot be addressed by the PAC Rehabilitation quality alone.

1.3 A 'PAC Rehabilitation Quality Partnership': a consensus-building entity

The establishment of a formal structure or entity - we called 'PAC Rehabilitation Quality Partnership' – represents our recommended mean/instrument to facilitate the achievement of the needed consensus-building processes for the specific field of PAC Rehabilitation.

1.3.1 Facilitating consensus for the PAC Rehabilitation field

The 'PAC Rehabilitation Quality Partnership' shall not be understood as a substitution of the role of yet existing associations or providers' representatives, but rather an independent structure able to convene and facilitate a participatory process that engages a wide-scope of PAC Rehabilitation stakeholders, directed to the outlined matters.

With such regards, there is a model entity: the leading consensus-building organization for general healthcare, which represents a large body of stakeholders: the National Quality Forum (NQF – www.qualityforum.org). Among other levels of activity, such consensus-based activity convened the National Priorities Partnership (NPP) which guided the US National Quality Strategy ^(10; 17; 22). The 'PAC Rehabilitation Quality Partnership', at least in their initial set of outlined functions, could have a role and process equivalent to the NPP, but in case specifically applied to PAC Rehabilitation.

However, we recall PAC Rehabilitation quality-initiatives should also be framed and embedded in a broader health/healthcare system of quality-initiatives; thereby the activity of 'PAC Rehabilitation Quality Partnership' must be also framed accordingly.

1.3.2 'PAC Rehabilitation Quality Partnership' & general healthcare consensus

Considering PAC Rehabilitation quality and quality-initiatives cannot be exclusively framed in their own *silos*, but rather within an overarching healthcare system, the activity of the 'PAC Rehabilitation Quality Partnership' should be framed according to major national guides and priorities for a health/healthcare system as a whole.

At the same time, and in the opposite chain of influence, consensual perspectives among PAC Rehabilitation stakeholders – achieved and represented through the 'PAC Rehabilitation Quality Partnership' – could help to shape the constantly renewed scope of whole health/healthcare system priorities for quality and quality-initiatives within the – for instance through a NPP representativeness. Another activity can be actively collecting and submitting specific PAC Rehabilitation quality-standards to become NQF-endorsed: measures/indicators and evidence-based practices/guidelines in the scope of PAC Rehabilitation.

Finally, as an applied example, we believe that only with such type of enlarged strategic partnerships it could be possible to address the most complex healthcare quality problems, such the longitudinal quality of care for patients with disabilities: a great matter of concern for the quality-gap of disparities in the US healthcare system, building equity as a systems property ^(23; 24; 25; 26; 27).

1.3.3 'PAC Rehabilitation Partnership for Quality' and consensus for 'episodes of care'

As previously mentioned, the quality and quality-initiatives of acute 'episodes of care' represent a specific level of PAC Rehabilitation contribution. Therefore, a 'PAC Rehabilitation Partnership for Quality' should work to establish active partnerships with representatives of other healthcare areas embedded (ideally also consensus-based

representatives) in order to collaboratively establish an overarching quality and qualityinitiatives roadmap for acute 'episodes of care'.

However, a consensus among stakeholders across healthcare areas can only be wellestablished if there is yet at least some level of integration and consensus within each area it-self. As we outlined mostly in the 3rd review, there is yet a lot of fragmentation in the PAC Rehabilitation delivery system to overcome. Therefore, there is a need for integration and consensus-based work within the PAC Rehabilitation field it-self, before it could be able to establish consensus-bridges among other proxy healthcare areas for the quality of acute 'episodes of care'..

2- Interdisciplinary Center for Developing PAC Rehabilitation Quality-Solutions

We shall now present our second overarching recommendation, which has a great deal of inter-play and inter-dependency with the previous recommendation. After an overview of the recommendation, we outline its major specific features along complementary topics.

2.1 The scope of the recommendation

In the previous recommendation we highlighted the need for achieving stakeholders' consensus about quality and quality-initiatives: concept/definition; a vision; priorities & strategy; as well as for a starting-up action-plan, activating a roadmap towards 'PAC Rehabilitation Quality System'. We also highlighted the role of 'PAC Rehabilitation Partnership for Quality' entity facilitating consensus among stakeholders.

But consensus among PAC Rehabilitation stakeholders, by it-self, is not enough to optimally advance the quality of PAC Rehabilitation care and the effectiveness of its quality-initiatives. There is also a need for developing socio-technical, systems-based, solutions directed to PAC Rehabilitation quality-initiatives, including PAC Rehabilitation quality-improvement.

We mean the development of innovative solutions for PAC Rehabilitation qualityinitiatives - primarily infrastructural socio-technical solutions - based in a systems thinking approach to cross-disciplinary knowledge, and know-how integration – in case applied to facilitate the effectiveness, integration and meaningfulness of PAC Rehabilitation qualityinitiatives.

Such integrated innovative solutions would be primarily envisioned and developed at a permanent interdisciplinary center. Such centre, while science-based, should be highly applied in nature, working through a problem-focus and solution-oriented perspective. It means the center's process begins by clearly defining a complex and systems-based PAC Rehabilitation quality problems; then it works backwards to identify interdisciplinary and causal pathways - or the so-called 'causes of causes' - transforming the complex problem in a trans-disciplinary synthesis of smaller yet inter-linked system of casual problems or areas with great improvement-potential (a more positive perspective)⁽²⁸⁾.

These casual problems would constitute the targets for an inter-disciplinary scientific creativity and solution-oriented process ultimately leading to the development of innovative PAC Rehabilitation applied socio-technical and systems-based solutions: bringing together an inter- and trans-disciplinary technical know-how, balanced by social sensitivity. The need for inter-disciplinary input has its foundations in a growing awareness that complex/systems-based problems cannot be fixed by solutions that does not take into account all the system-wide casual problems; as well as all the system-wide effects (benefits and prejudices) caused at many health and societal levels. The innovative solutions need to be system-wide framed before its development ⁽²⁹⁾.

Therefore, the development of PAC Rehabilitation system-based solutions for quality needs to be early engaged in a 'requisite variety' principle: which means that a inter- or transdisciplinary research-team has the sufficiently diverse set of backgrounds, skills and interests in a way such: hidden assumptions are exposed; a broader repertoire of options, tactics and tools are made available; tacit knowledge made more explicit; and broader interpretations are expressed - enlarging what the team can both see and do ⁽³⁰⁾.

The interdisciplinary center should work not in a closed productive cycle for innovative and integrated solutions, but instead through an overarching and extended collaborative process (e.g. over-archly framed by what Shneiderman called as a 'collaboratories' ⁽³¹⁾) not only crossing disciplines knowledge, but also actively networking with other researchers *Tiago Jesus* 448

communities, politicians, patients, managers, practitioners, educators and other PAC Rehabilitation stakeholders (e.g. 'PAC Rehabilitation Quality Partnership').

2.2 Cross/Inter-disciplinary centers for healthcare quality-improvement

The idea of developing structured and permanent cross-disciplinary centers, providing innovative solutions for highly complex and urgent societal socio-technical problems is not in fact entirely new, but abstracted from other highly complex societal problems. A societal problem registering greater cross-disciplinary structured development, serving as a model, is the area of climate change.

Indeed, cross-disciplinary centers have been deliberately and carefully created and structured to combine a relevant range of disciplines and professions (e.g. scientists, economists, engineers, social scientists among others) in long-term collaboration for address the climate change problems and propose integrated solutions.

Moreover, these cross-disciplinary centers (taking the examples of the UK 'Tyndall Centre' or 'The Grantham Institute at the Imperial College London' accessible in their web-sites) embrace policy, business leaders, public engagement in their productive process, as they use education as essential components of their envisioned seminal influence for climate change action.

Finally, they regularly express their vision and work in periodic reports that are contextualized and including a sustained development perspective. For instance the reports outline implications for the elaborated translational research synthesis, supporting systems-based and systematic decision-making. This is made based in solid evidence, yet integrated into brief reports, using pragmatic and easy-digestible terms and suggestions.

The structure and activity of these centers were recently called as an example to be followed by other socio-technical systems-based problems, such as the healthcare quality and safety improvement. Indeed, Vincent and colleagues ⁽³²⁾ highlight the similarities of these problems and build upon the example of climate change centers to call for the deliberative and structured development, as well as long-term maintenance, of such type of applied inter/trans-disciplinary collaboration, applied to healthcare improvement. This is for

instance also happening in specific field of healthcare research, such cancer research, underpinned by a needed development of 'the science of team science' ^(33; 34; 35).

The model structure and function of climate changes centers have in healthcare quality and improvement close applied examples. For instance the 'Dartmouth Institute for Health Policy and Policy', the 'Institute for Healthcare Improvement' in the US or the 'Qulturum' in Sweden often produce solutions based on cross-disciplinary input, but not necessarily in the form of permanent well-established partnerships. The great challenges are to find effective and stable ways of supporting such cross-disciplinary partnerships institutionally ⁽³⁶⁾.

It could be expectable that foundations, universities, government agencies and others could permanently fund such institutional cross-disciplinary partnerships either through direct funding for the development of their activity, as indirectly by funding protected time, training, fellowships and academic career pathways for young clinicians and researchers willing to developing applied cross-disciplinary competence and working in the long-term on healthcare quality-improvement. In time, further funding for these centers would be secured by Master and PhD programs; as well as a variety of university-affiliated small education programs⁽³²⁾.

The aim will be creating a critical mass, tipping-point, where cross-discipline and systemsbased work and frameworks become the mainstream for quality-initiatives/improvement research and development ^(28; 32). However, it cannot be underestimated how difficult it would be to attract the brightest talents to an almost new born improvement and intrinsically cross-disciplinary specialty in the healthcare field. A great alignment of the array of incentives in the health and academic sectors will be needed to overcome such great challenge, but with enormous benefits for the quality and sustainability of the health/healthcare system⁽³⁷⁾.

Institutionally, the concomitant development of a network of permanently established cross-disciplinary centers can mount a sustained concerted 'attack' on the intractable quality and safety problems in healthcare. These centers would perform a set of inter-linked functions: interdisciplinary collaboration and societal exchange; provide infrastructural capacity for evaluation, improvement research, education, and training for quality-initiatives/improvement; as well as producing evidence-based policy-advising, such the climate change centers do.

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Vincent and colleagues proposes it might constitute a series of strategically located centers as geographically distributed for regions (e.g. a US state), thereby being able to effectively address the region needs for safety- and quality-improvement, exchanging and collaborating with regional stakeholders: policy-makers, practitioners, managers and citizens (32). The case of our recommended interdisciplinary center for developing PAC Rehabilitation quality-solutions remains a little bit different in the activity scope, as below outlined.

2.3 The specific roles of an interdisciplinary center for developing PAC Rehabilitation quality-solutions

The specific center we recommend would have an enlarged geographic scope of action (for instance the US as a country), but remaining focused in specifically developing PAC Rehabilitation quality-solutions.

2.3.1 Inter-linked roles with the 'PAC Rehabilitation Quality Partnership'

As a 'collaboratory', the activity of such interdisciplinary center - and their innovative system-based solutions - would benefit of being a result of an active network with other researchers' communities, politicians, patients, managers, practitioners, educators and other PAC Rehabilitation quality-related stakeholders. In this way, it goes in part similar to the consensus-based activity of the recommended 'PAC Rehabilitation Quality Partnership' entity.

Indeed, as initially framed, such two entities (our two overarching recommendations) would mutually benefit of intrinsic, iterative linkages and interchangeable inputs between each other. In practice, it means that consensus-generated definitions achieved by the quality 'partnership' would represent a guide for the activity of such interdisciplinary 'center'. In turn, the 'center' would be able to develop applied-solutions that meet the 'partnership' consensus-based demands. Additionally, the 'center' can a priori (actively/independently) propose solutions for PAC Rehabilitation qualityinitiatives/improvement, thereby driving/shaping the subjects and agenda for stakeholders' consensus discussion – with regards to priorities, strategies and action-plans to be taken. Tiago Jesus 451

Operationally, it could be benefic these two entities holding a common overarching leadership (above each independent entity leading macro-structures), facilitating integration among those distinct yet simultaneously inter-dependent and complementary structures for the advancement of PAC Rehabilitation systems-based quality and quality-initiatives.

2.3.2 Informing PAC Rehabilitation Policy

Similar to climate change and healthcare improvement centers, a role for this center would be releasing brief public-domain papers informing an evidence-based policy for the PAC Rehabilitation scope.

It would be made for instance by trans-disciplinary research synthesis applied to the PAC Rehabilitation policy-decision problems. Such synthesis should be followed by actionoriented recommendations that take into account the multi-dimensions of the policy action, including analysis of short and long-term societal costs, benefits and impacts of taking or non-taking pathways under analysis.

As told, these proposals should also embrace a collaborative participatory process, involving PAC Rehabilitation stakeholders (e.g. through the proposed inter-links with the 'Partnership'); as broadly being wide-open to the public, consumers, and stakeholders comments coming from other health/healthcare areas.

2.3.3 Developing external-level, infrastructural solutions, for an envisioned 'PAC Rehabilitation Quality System'

Beyond collecting, synthesizing, aggregating collaborative inputs, releasing and disseminating information that could be used to inform policy; the activity of the 'center' – as initially overviewed - would be also oriented towards actively develop socio-technical solutions for the systems-based PAC Rehabilitation quality and quality-initiatives problems.

External-level quality-initiatives in PAC Rehabilitation represent a field yet nascent, particularly notorious at the level of an external-system for quality measurement/reporting

and quality-aligned payments (3rd review). Therefore, at least initially, a major applied focus of the activity of such center would be on develop socio-technical solutions for a PAC Rehabilitation 'system' of external-level quality-initiatives: external assessment/monitoring, reporting and payment systems for quality. Along our supportive reviews, we outline multiple tips the literature highlights for the development of these systems. These are matters considered to be inter-disciplinary considered, studied, developed and tested by the activity of this 'center'.

Indeed, at least initially, it would be required a 'center' focusing on the study and development of infrastructural and external-based solutions – in inter-exchange with the 'partnership' consensus - developing the suitable conditions for a wave of organizational, meso- and micro-systems' quality-improvement initiatives at the PAC Rehabilitation level. For instance, the further four "preliminary recommendations", sub-titled as operational recommendations, represent illustrative examples of a strategic starting-up action-plan which the center could socio-technically develop in their initial set of activities.

2.3.4 Developing systems-based PAC Rehabilitation improvement approaches $(2^{nd}$ stage of activities)

Along time, and hypothesizing an effective and meaningful starting-up action plan is yet working on the field (1st stage of activities); the major attention of the 'center' could be directed towards the development of PAC Rehabilitation improvement approaches, mostly those with a systems-based action and impact (2nd stage of activities).

In practice, such stages would not come so quite distinctively (both could, and should, remain partly concomitant in time - these tasks are better seen as a never-ending process). However, the stages differentiation intends to outline the critical need to first build a well-aligned external system of incentives and support for quality and quality-initiatives (2nd review). This is a pre-requisite for a transformational and system-level change/improvement in general healthcare and specifically in PAC Rehabilitation.

As, told, in PAC Rehabilitation, an external system of quality-initiatives is something yet nascent, thereby holding a critical window of opportunity for establishing a fruitful path from the inception – an emphasis the 'center' might follow initially. Progressively, the

focus could slightly shift towards the development and facilitation of more specific systembased improvement approaches. In summary, first helping to set the suitable external conditions for PAC Rehabilitation quality and quality-initiatives to happen, thereafter specifically is supporting the development of quality-improvement initiatives.

The PAC Rehabilitation improvement approaches, developed by the center, could address the development, testing and facilitation of the implementation of specific improvement initiatives. However, its critical added-value would be mostly putted in developing transdisciplinary problem-focused diagnosis, followed by trans-disciplinary frameworks and improvement solutions across ecological and stakeholders' levels. These journeys can simultaneously act upon the multiple 'causes of causes' of sub-optimal quality in PAC Rehabilitation services and care, thereby enhancing its ultimate and system-wide impacts.

For instance, we cannot think about improving PAC Rehabilitation quality of care on a target aspect (e.g. patient-centered dimension of care) just by a single standard and focal implementation or quality-improvement-initiative directed to a single stakeholder's group (e.g. clinical practitioners). It requires a broader frame of targets and actions at different levels to obtain transformational quality-changes, with system-wide adoption and impacts – in the exemplified case a systems-based improvement approach to patient-centered care ⁽³⁸⁾.

Additionally, as supported in the final of the 3rd review (in turn supported in the definitions of the 2nd review); there is also a great room for developing multiple underlying competences in need for quality and quality-improvement (interpersonal/patient-centered, teamwork/coordination, and quality-improvement competencies) which could be developed under a same, integrated, practice-improvement and education-improvement projects. Such integrated initiatives might target competencies of multiple stakeholders taking part of it: not only clinical personal and clinical students, but also healthcare managers and other healthcare staff - since quality-improvement is everyone's job^(39; 40).

2.3.5 Education/training PAC Rehabilitation QI experts

In a way towards an optimal quality and quality-initiatives in PAC Rehabilitation, there is a need for having highly trained professionals leading and activating the field of PAC Rehabilitation quality-improvement (QI).

Nowadays, there is a critical mass of rehabilitation experts; as well as a growing body of quality/improvement experts (yet gaining critical mass). However, the existence of people mixing these two critical backgrounds for developing and implementing an envisioned 'PAC Rehabilitation Quality System' it is scarce.

The development of such critical mass, mixing these two backgrounds, could be promoted by the 'center' through educating new professionals who want to participate in such journey. The 'center' might provide the background they are not already experts: either educating 'improvers' for applied rehabilitation background, or educating rehabilitation experts about the improvement background.

The initial set of PAC Rehabilitation leaders/experts, despite contributing themselves for the activation of a 'PAC Rehabilitation Quality System', would then actively participate in education/training of further PAC Rehabilitation QI experts, as well serving as influential role models for young people to follow.

On a long-term journey, it will be needed PAC Rehabilitation QI experts not only to act at a collaborative research and development level, but also acting upon the level of higher and clinical education of new rehabilitation professionals (making quality-improvement an everyone's task from the educational level), as well as professionally acting at a macrosystem/organizational level across the nation, inclusively at a micro-system and further meso-system leadership levels of accountability for quality-improvement.

B- OPERATIONAL RECOMMENDATIONS:

Starting-up Action-Plan

Our overarching recommendations should over-determine all further major strategic and infrastructural action to be taken in a roadmap towards an envisioned 'PAC Rehabilitation Quality System', inclusively the following we propose. Either way, avoiding providing only overarching recommendations, we propose a possible starting-up action-plan to take, as outlined in the <u>figure 6</u>.

We should remind these "operational recommendations" represent the author's integrative, interpretative and creative solution-oriented perspective supported in the study's reviews, not 'the' one solution to be followed. Rather, those should be achieved by the complementary action of our overarching recommendations.

The following recommendations are presented by the order they could reach implementation: considering the complexity of development and implementation, the supportive research in need to be undertaken, as well as the windows of opportunity for its implementation, as defined other initiatives already being in place or prepared in the field. For instance the first outlined operational recommendation complements the scope of a US routine external quality/outcomes-monitoring initiative already being developed (3rd review).

Additionally, in figure 6 these operational recommendations appear divided into two pairs outlining complementary features, commonalities and synergic benefits of developing these recommendations together.

Finally, as the last feature illustrated in the figure 6, we denote that a comprehensive quality-assessment system (and subsequent public quality-reporting and quality-aligned payments) can be achieved by a further good match and complementary action between an external quality-monitoring system that includes the recommended assessment of consumers' experience, and the in-depth quality-assessment supported in a uniform clinical-registries data-system. The alignment of these complementary systems would represent the external-level component of an envisioned 'PAC Rehabilitation Quality System'.

1- External-Monitoring of Consumers' Experiences: Ensuring patient/familycenteredness through an external monitoring-system

Uniform external quality-monitoring is critical in a transformational change for quality. It shall assure a fair competition by informing stakeholders, as based on uniform, valid, reliable and meaningful quality-data driving to: consumers' quality-informed choice;

quality-aligned reimbursement, highlighting quality-improvement targets, and serving as quality-improvement stimulus^(19; 41; 42).

Continuous external quality/performance-monitoring needs to be sufficiently brief to be feasible in routine appliance, yet sufficiently comprehensive to cover the PAC Rehabilitation spectrum of aims, thus avoiding 'unintended consequences' on non-measured quality-aspects^(2; 43; 44; 45).

1.1 The need for a patient/family-centered external quality-monitoring system

In the PAC Rehabilitation scope, an external performance/quality monitoring system is being prepared to become nationally implemented as supported in the new CARE tool actually in demonstration process (www.rti.org)⁽⁴⁶⁾. The component of the CARE tool that is directed to outcomes/quality-monitoring shall be applied directly to patients/proxies, in a follow-up telephone-basis, made in three fixed intervals after discharge, independently of PAC settings type, and run by an external/independent entity to assure fairness of the results⁽⁴⁷⁾.

The recommended dimensions for such follow-up outcomes/quality-monitoring are related with: activity, participation, self-rated health status/HRQoL and place of discharge ⁽⁴⁸⁾. Advances in measurement methodologies applied to functional performance ^(49; 50), and (HR)QoL ^(51; 52; 53) can facilitate the task of routine external outcomes-monitoring. While the set of recommended constructs seems valid, it also seems incomplete. It is not able to assure patient- and family-centered quality of care.

Reminding, the patient- and family-centeredness is one of the six aims for quality ⁽⁵⁴⁾, being a critical dimension for it-self ⁽⁶⁾, and a major goal for the US PAC reform ⁽⁵⁵⁾.

Self-rated health status/ HRQoL ⁽⁴⁸⁾ (which can cover a part of subjective well-being and life satisfaction ^(56; 57)), and the outcomes being monitored by patient/proxy responses (reflecting outcomes from the patients' point of view); those two concepts might not fully or completely reflect the consumers-centered dimension of care. Namely, the responsiveness of services and care; as well as the care ability to reflect consumers' preferences, values, interests, and optimal experiences and satisfaction with care received – herein broadly aggregated in the operational concept of consumers' experience. Such a *Tiago Jesus* 457

measure should assure 'appropriateness' of PAC Rehabilitation care ^(58; 59); and consumercentered practices as a fundamental element of healthcare and particularly of the PAC Rehabilitation philosophy⁽⁷⁾.

An eventual non-use of a broader consumer-centered measure, in a set of external qualitymonitoring measures may lead to narrowly based quality-attached payments, it-self based on a narrow quality-monitoring. We remind that narrow-based quality-initiatives rather than stimulate comprehensive quality, are devaluing consumer-centered practices in favor of 'technical' measured aspects of care ^(1; 2; 4). In particular, it is been denoted that narrowly planned quality-initiatives can actually decrease the performance of the interpersonal and 'qualitative' dimensions of care – a quality dimension critically valuable by consumers⁽⁴⁵⁾.

Literature also denotes that consumer-centered quality-measures (e.g. consumers' experience) are those that better engage consumers in quality-informed choices by reflecting experiences of "persons like me" ^(60; 61; 62). This is a critical step in a fundamental change towards quality-driven choices for providers - thus the overall effectiveness of the quality-movement ^(18; 42).

Adding a consumer-centered measure in an external outcomes/quality monitoring data-set could be seen as an increased burden for routine appliance. However, there is a major example illustrating the feasibility of balanced set of quality-measures includins consumer-centered outcomes measures. Indeed, 2 out of 13 measures in a balanced set of whole system quality-measures exclusively targets consumers-centered dimension of care, namely the consumers' experience and the consumers' satisfaction ⁽⁶³⁾.

In a PAC Rehabilitation data-set for external outcomes/quality monitoring, perhaps just one of these measures (specific to PAC Rehabilitation) could be enough for ensuring consumers-centered quality of care (e.g. consumers' experience, as below explored), facilitating external outcomes-monitoring remains feasible for routine appliance.

<u>1.2 Developing a specific PAC Rehabilitation consumers experience tool (CAHPS) for</u> inclusion in the external-monitoring data-set

As part of internal quality-monitoring initiatives, each provider can use their own methods of measure, analyze and report experience/satisfaction data. Despite useful for internal *Tiago Jesus* 458

purposes, the external-system utility of such non-comparable quality-data is quite limited, giving no room for improvement or even being fallacious reported indicators of quality, since almost all providers report excellent levels of patients' experience/satisfaction with their services ^(59; 64).

The goal of external quality-monitoring and subsequent public-reporting initiatives is exactly to address this matter: serving as a trustful source of benchmark for payers, providers and mostly prospective consumers – basing their choice for providers on previous users' rating on a consumers-centered measure.

In general healthcare, there is yet routine the practice of external-monitoring of consumers' experience (CAHPS-tools family) in specific healthcare areas inclusively for setting in which PAC Rehabilitation care can be delivered. However, there is not yet existent or being prepared, to our knowledge, a CAHPS-tool that covers the PAC Rehabilitation as a whole integrated field (1st review).

Therefore, as an infrastructural initiative for developing consumers-centered dimension of quality for PAC Rehabilitation care, we recommend the development and implementation of a specific PAC Rehabilitation CAHPS tool, covering PAC Rehabilitation services independently of the settings in which it is provided (the same rationale underpinning the CARE tool development) for being included in a data-set for PAC Rehabilitation routine outcomes/quality-monitoring system.

1.2.1 The process of developing a PAC Rehabilitation CAHPS tool

We denote that more specific questioning (directed to the specific scope of PAC Rehabilitation care) can better distinguish different levels of satisfaction/experience, in contrast with general items ⁽⁶⁵⁾. Therefore, the items of the recommended tool should cover the specific scope and determinants of optimal PAC Rehabilitation consumers' experience, although it could have a similar structure of other CAHPS tools.

Therefore, it shall be constructed through an equivalent development and validation process used for other elements of the CAHPS family, but in this case tailored to PAC Rehabilitation consumers' perspectives. In concrete what consists an optimal consumers experience and patient-centered care for this specific healthcare area.

Such a task could be accomplished with the previous highlighted consumers' involvement in defining the operational concept/definition for what is quality of PAC Rehabilitation care: included in our first overarching recommendation.

Additionally, the process of developing a starting-up set of possible items for such specific CAHPS measure can be activated by collecting existing items of other CAHPS measures; as enhanced and complemented by specific wording and items abstracted from the array of PAC Rehabilitation experience/satisfaction measures. Indeed, there are a plenty of satisfaction measures emerging in PAC settings for specific providers' type ^(59; 66; 67; 68), as well as in outpatient rehabilitation ^(69; 70; 71; 72) to provide baseline and foundations for such task accomplishment.

Finally, the conceptual framework (1st review) highlights important constructs and some specific PAC Rehabilitation aspects of care that might be included in the content of such tool. The interpersonal dimension of care - the effectiveness of providers' communication and relationship with patients and families - are common elements in the CAHPS' family-tools. Therefore, we recommend the concomitant accomplishment of this and the following operational recommendation, as mentioned in the beginning of this sub-section.

1.3 Family-centered external outcomes/quality-monitoring

The term 'consumers' or 'users' also refer to family instead of just patients. Families are critical active elements and targets of care, particularly in a specialty better framed in a byopsychosocial model as it is PAC Rehabilitation - in which disability both affects and it is affected by a family system as a whole unit ⁽⁷³⁾.

Family own-reported experience and satisfaction - mostly with their own-directed care and outcomes - remains another dimension of users' experience, different in kind from what is the concept of proxy respondent for the patients' experience⁽⁵⁹⁾.

Family-experiences/satisfaction with care and families-HRQoL are two different concepts within the broader scope family-related outcomes. However, in order to facilitate feasibility for external outcomes/quality monitoring, those two different concepts could be integrated as two different dimensions of a same family-related macro-outcome - for the purposes of an external outcomes/quality-monitoring system.

Family-centered care would have different meaningfulness for different degrees and types of patients' impairments. Thus, a least for patients with higher levels of impairments, or impacting on family/caregivers' burden or quality of life (well-delimited criteria), family-directed care should constitute one of the most critical parts of PAC Rehabilitation care, thus it might be effectively reflected in external outcomes/quality-monitoring system.

1.4 An 'acute-episode-CAHPS' measure

So far, we were discussing the process of external quality-monitoring of consumers' experience as applied to a unified level of PAC Rehabilitation services, but only specifically to PAC Rehabilitation.

However, with on-going healthcare delivering reforms, the system advances towards a broader accountable unit for payments and quality: whole acute 'episode of care' rather than only PAC Rehabilitation ⁽⁴⁶⁾, as already discussed in our 1st overarching recommendation.

According to such scope enlargement, there will be needed specific ways to monitor quality-information for the whole 'episode of care', on aspects such transfer decisions and overall care coordination, beyond the quality of specific levels of care. Consumers' experience would be a critical aspect to measure the experience of such navigation across providers within the acute 'episode of care'.

Indeed, beyond measures of consumer experience for specific levels of care (acute care; PAC Rehabilitation; follow-up/outpatient care), an 'acute-episode-CAHPS' measure should reflect aspects of overall experience from the consumers' point of view: including coordination among providers, optimal transitions and preferences/values being respected at these levels.

It could have a critical role assuring appropriateness and consumers-centered decisions for the whole episode, preventing provider-driven decision with the underlying aim of maximizing profit already seen in previous reforms: for instance transfer according their own capacity available; discharging to subsequent providers for lower-price, etc⁽²¹⁾.

In a external outcomes/quality monitoring data-set, a 'acute-episode-CAHPS' measure could be applied just once per-episode, in a formative-evaluation format for the whole 'episode': for instance applied simultaneously with other consumers' reported assessments in the follow-up period after PAC Rehabilitation - causing no great additional burden.

Such 'acute-episode-CAHPS' measure shall not substitute but rather complement the more specific CAHPS measures for different levels of care (acute-hospital CAHPS yet existent; and CAHPS for whole PAC Rehabilitation settings we recommend to be developed). Thus, such broader measure shall focus on cover the domains related with: integration and coordination among settings and care levels; and the degree to which preferences were addressed along the episode management – reflecting the consumers experience and centeredness with the 'episode of care' as unit of analysis.

Indeed, the items of such 'acute-episode CAHPS' could for instance reflect how well preferences are reasonably considered in all major care decisions and transitions to different levels or subsequent providers. A further item shall reflect the need for consumers' active participation in care and placement decisions. Such active participation should be not only allowed, but actively fostered/facilitated by those responsible to manage the 'episode of care': for instance helping disclosing and interpreting existent public-reported information for the next-level of care: attending to consumers' specific conditions, preferences, needs and even convenience.

These items shall also assure patients do not stay necessarily 'locked in' to previous arrangements and contracts among providers for the continuum of care - a major threat to patient-centeredness of bundling payment for episodes of care ⁽⁷⁴⁾. Such feature is also one of the major gaps of the Continuing Care Hospital, as a solution proposed for integration of PAC and further levels care ⁽⁷⁵⁾ - as highlighted in the 3rd review.

In fact, a consumers' active role for a quality transformational change is mostly about choosing providers to their care also according to their quality-information, and not only imposed by previous arrangements made entities managing the bundled payments - criteria for allocation could be more on lower prices despite quality.

Finally, new consumers would be able to choose the entity that will begin to manage their acute episode of care, based on previous public-reported scores in the 'acute-episode-CAHPS' – peer benchmarking for the entities managing the 'episodes of care' made by

consumers, but also by payers. Such peer benchmarking would include other kind of quality-data for the whole 'episode of care' such as adjusted: survival rates, functional gains, re –hospitalizations, HRQoL in a balanced data-set ⁽⁶³⁾

This recommendation helps to accomplish the so-called redefined 'value-based competition' instead of a 'price-based competition' for healthcare systems ⁽²¹⁾. By choosing providers and entities managing 'episodes of care' on a quality-basis, consumers assume an ultimate source of control for the value of care they receive - a critical role within the quality-movement ^(5; 6) (2^{nd} and 3^{rd} review).

2- Developing the Interpersonal Dimension of Care: becoming a measurable and improvable quality dimension

As conceptualized in our conceptual framework (1st review), and later specifically complemented by the 1st review – part B; the quality of the PAC Rehabilitation process can be seen in three different yet complementary levels: the teamwork, a inner-process of rehabilitation; the technical dimension of care; and the interpersonal dimension of care with patients and families.

The PAC Rehabilitation technical dimension is a natural target for most quality-initiatives. The team-work process dimension has been leveraged in the latter 15 years by Strasser and colleagues' work: guided by a framework ^(76; 77), and having solutions for measurement and training, showing influence in the outcomes of PAC Rehabilitation care ^(78; 79; 80).

In contrast, in the interpersonal dimension of the care process, there is no systematic research agenda linking the features of this care dimension with health-related outcomes, something we begin to hypothesize with the conceptual pathways of the 1st review –part B, as mediated through a set of immediate and intermediate outcomes broadly labeled as 'psychosocial engagement outcomes'.

However, in order to develop studies empirically linking the interpersonal dimension of care (and mostly its improvement) with a broad range of PAC Rehabilitation outcomes, there is a need to first develop rehabilitation's specific interpersonal guidelines, yet to be

systematically made. Accordingly to such guidelines, there should be additionally promoted the systematic development of a specific measurement tool; as well the education/training and improvement/implementation initiatives.

2.1 Systematically developing guidelines for the specific PAC Rehabilitation interpersonal dimension of care

The development of guidelines for the specific PAC Rehabilitation specific interpersonal dimension might consist in a systematically-organized research agenda, involving a systematic interdisciplinary experts and enlarged stakeholders' consensus-building towards the definition of interpersonal process guidelines.

Such guidelines development might be team-based. It means developed by the the interdisciplinary PAC Rehabilitation team as major unit of analysis, as supported in 1st review - part B.

Interpersonal process guidelines might consist on core PAC Rehabilitation interdisciplinary functions, tasks and approaches; complemented by tasks addressing specific patterns of users' needs, preferences and circumstances ^(81; 82; 83), yet allowing room for further individualization – e.g. communication functions shifting alongside rehabilitative changing moments, goals and activities ^(84; 85).

Moreover, such guidelines need to fit and ideally facilitate workflow and other professional/improvement demands, otherwise later implementation would be easily mitigated by PAC Rehabilitation practitioners ⁽⁸⁶⁾. Finally, such interpersonal guidelines might be further refined by on-going empirical data, mostly concerning new empirical evidence linking its features with macro-outcomes of PAC Rehabilitation care.

2.2 Development of a specific assessment tool for the PAC Rehabilitation interpersonal dimension

The mentioned interpersonal guidelines might be used as background for the development of a specific interpersonal assessment tool - as uniformly applied to different PAC rehabilitation settings. The instrument should be developed to be valid, reliable, feasible, but also sensitive to performance differences in the specific PAC Rehabilitation interpersonal dimension of care. For instance, general items can enhance undesirable 'ceiling effects' which is characterized by a generalized over-rating of practitioners' performance ^(87; 88), making such assessment less useful. As much specific were the items, better differences or improvements in performance could be detected. For instance, in a specialty training study, higher improvements were detected on more specific items, than on those of more general scope ⁽⁸⁹⁾.

2.2.1 Concomitant development with a specific CAHPS measure

The interpersonal dimension of care is a greater determinant and dimension of consumers experience or satisfaction: as any of these consumers-centered outcomes measures reflect. Therefore, the development a specific PAC Rehabilitation CAHPS, and a broader 'acute-episode' CAPHS (previous recommendation) would benefit of being informed by the developments in the PAC Rehabilitation specific interpersonal dimension of care. We mean the construction, validation, and testing of interpersonal process guidelines, and a subsequent assessment tool.

Indeed, it could be mutually-benefic if the development and testing steps were taken concomitantly for both instruments: the specific CAHPS and the specific interpersonal process tool. Not only the research design will be more efficiently (less costs and burden due synergies in data collection and analyses process); as well as data from early development and testing stages of these tools could be used for mutual adjustments in development, and for later discriminative validity purposes.

2.3 Interpersonal dimension as an improvable dimension, able to improve outcomes

The development of specific PAC Rehabilitation interpersonal guidelines underpins and serves as content and background for the development of specific education, training, improvement and implementation interventions. For instance, as more specific guidelines are, better prospects exist for guidelines implementation ^(90; 91); as well as interpersonal training shall be enhanced, yet showed in a rehabilitation context ⁽⁹²⁾.

In an improvement-based perspective, the interest for testing interpersonal process improvement approaches is twofold.

First, improvement interventions might be tested if it produces an effective adoption of the interpersonal guidelines – assessing the efficacy and effectiveness of improvement, implementation, training, and educational models and approaches. Being a sub-explored training dimension, and with lower baseline practitioners' expertise ^(93; 94; 95), it is expectable improvements could be achieved at this level, as the few studies partly addressing the subject showed promising results ^(89; 96).

On a second level, there is interest to evaluate the impact of the effective adoption of guidelines on PAC Rehabilitation outcomes - the ultimate level of interest for improving this dimension. It might also represent a way (improvement-based) of empirically linking the interpersonal dimension of care with macro-outcomes of PAC Rehabilitation care, as discussed independently for the 1^{st} review – part B.

2.3.1 Improvement journeys integrating the PAC Rehabilitation interpersonal and team-work dimensions

Typically unaddressed by formal education/training from many years, improvements in the interpersonal dimension ^(95; 97; 98; 99), as well as in the team-work process ^(86; 79; 78), could potentially produce transformational, rather than just evolutionary or marginal quality-improvement gains. Both dimensions are supportive of optimal technical dimension implementation (e.g. individualization and coordination of care components); as well as the interpersonal dimension might also be able to facilitate psychosocial engagement outcomes, interfering though such a pathway with a broad range of rehabilitation health-related outcomes as addressed by 1st review - part B. Thus, despite yet to be developed and more strongly empirically tested, it is conceptually expectable a positive chain-of-effects towards optimal macro-outcomes, beginning with transformational improvements in these dimensions.

Additionally, interpersonal and team-work dimensions are seminally supported in same basis of communication and relationship competencies ^(100; 101), as 1st review exposes. Thus, a synergic (efficient) improvement could be achieved by framing and improving these two

dimensions together – then with specifications applied to the interactions with PAC Rehabilitation users $^{(102; 103)}$, and applied to team-work interactions $^{(104; 78)}$.

These improvements could be made by practice quality-improvement, interprofessional continuing education, and trainees education, or mostly these in combining each other in overarching projects ^(105; 106), for instance taking principles from the rehabilitation-suitable interprofessional education/training-wards, which integrates goals from different process-dimensions ^(104; 107; 108; 109; 110).

3- Developing a Uniform Clinical-Registries System: For practice, quality and research purposes

This is perhaps the more complex operational recommendation we propose. That is because it might serve as a common infrastructural basis for practice, quality and research purposes, and because it might implicate a minimum degree of uniformity in way clinical-registries are recorded across PAC Rehabilitation practices; thereby needing to be well-developed and calibrated as a socio-technical solution and among stakeholders' perspectives – a complex matter clearly benefiting of being addressed by our two overarching recommendations.

3.1 The need for uniform clinical-registries system and recommendation overview

In the first operational recommendation we complemented the features of external outcomes/quality-monitoring system. It operates in the follow-up period and mostly based on the macro/delayed-outcomes (a major conceptual feature employed the 1st review). Such follow-up outcomes-monitoring would represent one of the core-elements of an external quality-monitoring system, thus representing one important source of data for subsequent public quality-reporting and quality-aligned payment initiatives.

But the inherent limitations of an outcomes-monitoring system (described for instance in the 3rd review) requires another kind of information complementing its validity and further optimal application of the quality-aligned initiatives. Indeed, beyond such externally-

required outcomes and administrative data - yet uniformly collected for claims, regulatory or reimbursement purposes - there is a need to be based on complementary clinical and contextual data. This is information required for risk/severity-adjustments and for process-based quality-assessments.

Specifically in PAC Rehabilitation, policy is also demanding the use of process-information for complementing the scope of outcomes-based external quality-monitoring ^(11; 111). This is because it not only enhances the validity of quality-monitoring, but it also critically highlights process-targets for quality-improvement: as supported for instance in the 2nd and mostly the 3rd review.

In general healthcare, there is a recent growing recognition of the role of clinical-registries in complementing administrative-data for quality-purposes. The clinical-registries is where clinical-related information of greater detail is imprinted: not only information about patients (for risk-adjustment in outcomes-based quality-monitoring), but also about the clinical processes (for process-based quality-assessment) ^(112; 113). Both are of great relevance to complement outcomes-based external quality-monitoring.

As told, the clinical-registries can have imprinted information about the care process (caregoal, strategies and activities/interventions), as well as information about the immediate/intermediate outcomes tracking patients' clinical evolution over time. Thus, it can basically address the scope of continuum of process-outcomes, we broadly outlined in the 1st review.

But although clinical-registries are routinely recorded in clinical practice, those are not collected by a uniform recording system among professionals, settings, and delivering organizations; thereby it cannot be optimally used for quality-assessment purposes, neither for practice-based research purposes – two major applications of detailed clinical-registries data. Indeed, macro-outcomes data (e.g. follow-up outcomes-monitoring) and the continuum of process-outcomes (e.g. clinical-registries) are two complementary types of data which could be used for the mentioned quality purposes; but also and research purposes.

In a research perspective, if the continuum of process-outcomes data is uniformly and granularly collected in the clinical-registries, it holds the data for practice-based health-services and outcomes research - a suitable research approach for PAC Rehabilitation, as

outlined in the 3^{rd} review. Lately in this recommendation, we will specifically envision the role of such uniform clinical-registries system could have for PAC Rehabilitation research purposes - particular practice-based research – and mutual benefits of initiatives using the binomial quality and research.

But all these meaningful purposes could only be achieved if we had a PAC Rehabilitation uniform clinical-registries data-system – the integrative scope of this operational recommendation. Therefore, we first provide further description on such system, as suggesting some tips about how it could be operational into practice.

<u>3.2 Envisioning the scope of uniform clinical-registries system and how it could be made</u> <u>operational into practice</u>

A uniform clinical-registries system for both quality and research purposes would consist in two sub-systems to be accomplished.

- Uniform Recording-System: There is a need for developing a uniform datarecording system embracing the continuum of process-outcomes, consisting on recording the immediate/intermediate care goals and the subsequent careprocess/activities delivered. Such registries shall be made at the point-of-care (POC). Such recording-system shall necessarily fit and ideally facilitate the normal workflow; as well as ideally facilitate the evidence-based decisionmaking process.
- 2. Central processing: A uniform recording-system allows the further development of a central database for processing the uniform clinical-registries to be send, stored, as well as peer-, time-series and cross-analyzed with other data of the same provider (e.g. macro-outcomes externally-monitored), then compared with peer-providers.

Such information should finally come to providers in the format of a feedbackreport with comparative benchmark data, highlighting targets in the continuum of process-outcomes for quality-improvement. Possible ways to develop and operationalize such two complex set of tasks are outlined with suggested tips in the two different boxes bellow presented.

3.2.1 Possible Tips for a Uniform Recording-System

1) Overview of the tips for a Uniform Recording-System

There should be developed and implemented in field a uniform recording-system that providers need to comply at least with a minimum, mandatory or standard level, but without necessarily producing an extra-burden and even facilitating work-flow and decision-making. Such needed uniformization could be achieved through regulation, or alternatively through incentives already used such pay-for-reporting and further pay-for-performance (2nd review).

The tips will also include the use of electronic devices and software solutions that, if properly developed, could turn the uniform recording process quicker as compared to paper-based work; as additionally making the clinical-records timely available to every personnel, in every setting, facilitating care coordination and - only at a second level - serving as an optimal data-source for quality-initiatives and research-purposes.

Additionally, software solutions integrated in such uniform recording-system can simultaneously facilitate the clinical-reasoning and decision-process becomes more evidence-based. Let's now outline our proposed tips for the uniform recording-system on a step-wised and temporally-framed fashion.

2) Goal-setting and goal-planning stage

After baseline assessment at PAC-entry (primarily built in new uniform CARE tool); it should begin a consumers-centered teamwork process for meaningful goal-setting and planning for subsequent PAC Rehabilitation care.

When defined, the goals of care (macro and major immediate/intermediate goals, including the type but not necessarily the grade) would be electronically registered as uniformly framed by a respective classification (e.g. the ICF classification ^(114; 115)). All this goal-setting and underlying clinical and goal-reasoning process should follow

technical as well as interpersonal guidelines (previous recommendation), but possibly benefiting of being technically supported by a software - yet to be developed - with the aims of facilitating feasibility/quickness of the recording process, as well as the reasoning and evidence-based decision-making process at this early and critical stage.

For instance, the software could automatically display 'core sets' of possible goals in the screen, according the CARE tool evaluation and other data-entry. As an applied example, 'ICF core sets' have been recently developed and validated in Europe for different levels of care; different sub-populations; in 'comprehensive' and derived 'brief' ICF core sets^(116; 117; 118; 119; 120; 121; 122; 123; 124; 125).

The concept of 'ICF core sets', in its brief versions, can get a parallel with the minimum, mandatory, or standard level of the uniform recording-process we upfront outlined. The task of the team at this stage will be, to maintain/remove/add/specify the electronically automatically displayed definitions according to patient unique potential, values and preferences – individualization process.

Such electronically-supported process might be enlarged to interactively embrace the definition and registry of major care strategies and major care activities, supporting clinical-reasoning and outlining the case formulation and intervention rationale – feed-forward information for care coordination, further re-adjustments and later quality-purposes. Again, the team-task will be on maintain/remove/add/specify the automatically displayed standard strategic-care guidelines - previously developed by solid research - to the patient unique clinical status, context, values and preferences.

To our knowledge, there is only one project under development for using electronic registering and supporting systems to improve PAC Rehabilitation care. It relates with developing an innovative real-time clinical reporting and query system, derived from a research-based electronic point-of-care (POC) data collection system (http://www.post-acute.org/studies/atrc.php), fitting the rationale herein proposed.

Finally, we should denote that above a minimum, mandatory or standard level for the uniform-recording process herein described, providers could complement the process by using additional and more specific standardized measurement (www.reahbmeasures.org) for evaluating specific aspects of patients' conditions, reflecting those for instance in the immediate & intermediate goals/outcomes - then re-assessed along care. The suitable

additional measures could be automatically disposed by the supportive software, as an additional optional tool to be used according data-entry of potential goals selected.

3) Registering care-activities at the point-of-care (POC): developing an underlying uniform classification/taxonomy

On-going care-activities shall be registered it-self at the point-of-care (POC), constituting the granular-level of care-activities data. From such simple and necessarily easy-to-register on-going care-data it could be later abstracted what is actually done, when, by whom, and in what sequence beyond what was planned. Such information, as further consulted and analyzed, could be critical for coordination and later re-definitions on such patient care; as well as feeding later pro-active care planning and quality-improvement initiatives.

Being feasible, it might substitute all other kind of regulatory, administrative and billing data actually being required in the field, as using electronic portable devices ⁽¹²⁶⁾, with the software displaying care pathways. However, such uniform registering of care-activities requires a uniform classification/taxonomy of care-activities. But such classification does not exist.

Indeed, although taxonomies were recently developed in the PAC Rehabilitation field – applied to stroke $^{(127; 128; 129)}$ and spinal cord injury $^{(126; 130; 131)}$ – those are condition-specific and primarily designed for practice-based research purposes. It be useful (for adoption purposes) the development of an overarching classification/taxonomy that is not condition-specific describing the PAC Rehabilitation process and specific interventions, for instance hierarchically structured into different granular levels - such the ICF hierarchical structure and coding schema $^{(132; 133)}$

Due hierarchical organization of such classification, top-level codes could eventually consist in a common trunk of major interdisciplinary rehabilitation strategies and activities (rather than discipline-specific), while more granular classification levels could address specific activities or techniques or each different rehabilitation disciplines, which would also help – again using the ICF experience $^{(134)}$ - to clarify common and specific disciplines roles for the patients treatments.

A consensus (overarching recommendation) must be achieved among stakeholders - in

case practitioners having a pivotal role - in specifically designing and validating such rehabilitation process taxonomy, as well as specifically setting the minimum, mandatory or standard level of recording: before it could be tested by practitioners in the field also for feasibility into routine practice.

Finally, as an argument in favor of feasibility of this system, we could mention classifications/taxonomies of care-activities for practice-based research projects had a great breadth of specification for each of the multiple disciplines intervening in care - more demanding than what would be the minimum, mandatory, or standard level herein recommended. Even in such more demanding projects, practitioners did not considered it excessively burdensome when implemented into practice. It was mostly because they were pro-actively engaged to develop and refine the classification and recording system $^{(126)}$ – a major feature to be considered for these developments.

3.2.2 A central database processing the uniform clinical-registries and making a feed-back quality-report

The development of a central database storing and analyzing uniform clinical-registries can be developed envisioning multiple quality and research purposes.

1) A central database and processing system for the uniform clinical-registries

The clinical-registries, once uniformly collected, would be centrally reported (e.g. originally registered in an internet platform or uploaded) to be stored in wide PAC Rehabilitation database, centrally managed by an external/ independent entity.

The central storage on a 'clinical-registries database' would organize the great amount of uniformly collected clinical-registries, making it available for patient-focused outcomes/quality measurement ⁽¹¹²⁾, and secondarily used for research analyses.

The stored and organized content of this database should be cross-linked with externally collected data (macro-outcomes measurement), which can complement the scope of external quality-monitoring for a comprehensive quality-assessment, public-reporting, and quality-aligned payments (fig. 6); as well as being a valuable source for outlining

quality-improvement targets.

2) Feedback-report: a comprehensive, yet brief, 'quality profile'

After central analyses and mentioned cross-linkage of information, a periodic feedbackreport could be sent back to providers with a brief an easily interpretable 'quality synopsis' (charting cross-linked information) embedded in a broader 'quality profile' ⁽¹³⁵⁾. Indeed, such 'quality profile' feed-back report could be supported in an explicit datalinkage among externally-monitored information and the internally-collected clinicalregistries (e.g. explicit in structural-equation diagrams), providing granular information and quantified links among the continuum of process-outcomes and the macro-outcomes variables. Additionally, based on analyzed information, it could contemplate more explicitly guidance on quality-improvement targets, facilitating more effective organizational and micro-systems quality journeys, since feed-back is based on their own clinical practice-data of higher detail ^(112; 136).

3) Public-report of quality-information

From this comprehensive feedback-report, it will be abstracted information for being public-reported in easy-digestible formats, presenting meaningful quality-information for the consumers' choice process –e.g. matter for being developed by the inter-linked action of our overarching recommendations.

<u>3.3 Practice-based data-systems addressing research purposes: A spiral of synergic benefits</u> for quality and research

The uniform practice-based data-system we have been describing would primarily address practice and quality purposes. But such data systems can, and should, be additionally used as data-source (both external-outcomes and clinical-registries) for practice-based health-services and outcomes-research purposes. Therefore, the same uniform practice-based data systems could have the double role of supporting both quality and research purposes.

Additionally, since research would inform practice and new targets for qualityimprovement, ultimately the advances in research evidence - using or being triggered by practice-data systems - will be also reflected into enhanced quality of care, on a spiral of mutual benefits among quality and research initiatives. This is becoming advocated in the PAC Rehabilitation literature ⁽¹³⁷⁾. In this particular case we recommend it supported in a common practice-based data-system.

3.3.1 Practice-based data-system for outcomes-research: a way towards opening the rehabilitation 'black box'

The need for more comprehensive practice-data for quality-purposes - as the advances in the measurement and electronically-recording capability - opened a brand new world of opportunities for the research field. Indeed, it is nowadays possible to have available more detailed, accurate, easily-accessible, and timely clinically-related data - the critical source of research activity.

Additionally, such practice-based data-systems brings the bonuses of representing 'efficient' information yet collected, available and organized on central databases; as well as representing very large patients' samples that could be re-grouped into infinite number of ways, taking benefit - instead of potential prejudices that also exist – of data representing 'real' practice and 'real' patients, including inherent heterogeneity and co-morbidities. Indeed, 'real' patients/practice-data has the comparative advantage of reflecting 'real' practice challenges the practitioners routinely face; thereby enhancing the likelihood of research results become applied by them-selves into their further practices ^(138; 139; 140; 141).

However, the usefulness of such practice-based outcomes-research is highly dependent on how well-planned is the scope, content, organization and pragmatic features of the practice data-systems - we previously addressed with some possible operational tips – but that should be better developed by the inter-linked action of our two overarching recommendations.

Assuming the PAC Rehabilitation stakeholders and inter-disciplinary applied researchers could build and deploy and optimal practice-based data-system, the PAC Rehabilitation research community would have a very important data-infrastructure for the task of determining what processes, interventions, sequence and amount of those would be responsible for best outcomes achievement - namely, identifying the granular content inside

the rehabilitation 'black-box' – a feature outlined in 3^{rd} review, under the research community sub-section.

3.3.2 Practice-based data-system for health-services and outcomes research: informing macro-decision and policy

Practice-based data-systems represent the main data source for health-services research and its ability to determine the structural, service, macro, political and other contextual factors (varying across organizations, settings type, locals/regions/states) that could be also associated with lower and outstanding performance – being infrastructural barriers or facilitator for the most effective outcomes achievement, in turn the field of outcomes research more directed to uncover the clinical determinants of such optimal outcomes.

In a synthesis, while PAC Rehabilitation practice-based outcomes-research could be directed to inform frontline practitioners to achieve the best outcomes for their patients; the PAC Rehabilitation practice-based health-services research could inform health-services organization, macro-decisions and external-level policies that set the ideal context and external conditions facilitating optimal outcomes.

3.3.3 Practice-based Research Networks (PBRNs) as applied to PAC Rehabilitation & acute-episodes

In the PAC Rehabilitation scope, there are yet some promising examples of multi-site collaboration for practice-based research, in case with specific treated sub-populations as common aggregator ^(127; 131).

Such mentioned PBRNs - as well as providers and delivering systems - could use the structure of uniform clinical-registries data-system for their research purposes. Indeed, PBRNs could pro-actively plan to make use of deeper/granular levels (above the minimum, mandatory or standard level) of the registering system, according their specific research questions and purposes. It would represent a 'democratized' and facilitated PAC Rehabilitation's practice-based research methodology (outlined in the 2nd and 3rd review) as

baseline supported in the uniform clinical-registries system accessible to, and baseline applied by, all providers, however, varying in detailed levels of its appliance.

So far, we were focused on PBRNs restricted to PAC Rehabilitation as the scope of interest. But as outlined in previous recommendations, such scope should be also enlarged to embrace the features of general healthcare quality, particularly for the 'acute episodes of care', addressing the questions of best coordination, interfaces and pathways along continuum of practices. The entities outlined in overarching recommendations would be well-positioned to facilitate and actively foster the establishment of the PBRNs for the specific PAC Rehabilitation scope, as well as for the level of extended service-lines covering acute 'episodes of care'.

<u>3.4 The ingredients for business-case analysis about the uniform clinical-registries data-</u> system

The uniform clinical-registries data-system, if able to be implemented and maintained into practice, needs to have a positive business-case for its value or cost-effectiveness - meaning the system's development, infra-structural and operational costs should be compensated by the benefits (health value, efficient care and waste savings) it produces.

Indeed, there are inevitable upfront and operational costs associated with such system development. But if adequately developed and effectively deployed, the system's development and operational costs (not directly charging providers) can result in reduction of many other costs, bringing value for each dollar spent in the system.

For instance, it is estimated an amount of 30% of waste in general healthcare expenses for lack of quality and efficiency ⁽¹⁴²⁾. In PAC Rehabilitation the amount of waste/inefficiencies could be bigger due the actual 'black box' and uncertainties of what specific ingredients produce the value of PAC Rehabilitation care. Indeed, not knowing exactly what are the active ingredients of care is what greatly leads to a greater over-use, misuse and sub-use in healthcare ^(143; 144).

In addition, in a wider system perspective, there is actually a great amount of administrative and regulatory burden/expenses charging the healthcare system. The aim is to 'administratively' control quality, but it will be far less needed (as it is far less effective) if *Tiago Jesus* 477

we have an effective and well-aligned system of quality-initiatives (quality monitoring, reporting, payment and improvement) this system complements^(74; 75).

Regarding costs, in a closer inspection, the specific infrastructural costs would not be as high as it would seem in a first sight. The system is based in an electronic infrastructure which is yet a part of a national on-going effort yet being afforded ⁽¹⁴⁵⁾. Finally, since the system also furnishes data for research, not only the benefits but also the costs could be shared between the quality and research fields: common data-system infrastructure.

Indeed. It would be expectable a long-term spiral of mutual benefits for both quality and research, since the research knowledge advancements - triggered by practice-based data - would elevate the quality standards and feed quality-improvement (QI), thus feeding more effective/efficient ways of delivering care.

4- Improvement Data-System: Improving PAC Rehabilitation QI journeys/initiatives & QI research

This is our last operational recommendation about a starting-up action-plan we envision towards a 'PAC Rehabilitation Quality System'. Yet, as continuously mentioned, this operational recommendation would be better framed, shaped and developed in the context and inter-linked processes of our two overarching recommendations.

Among the set of operational recommendations, this might by the last that could achieve full implementation, since it is build in the scope of the previous recommendations; as well as it is based in the features of the yet emerging improvement and implementation sciences.

Taking the context-specific nature of improvement science ⁽¹⁴⁶⁾, and the repeated need for rehabilitation-specific quality-improvement (sustaining the need for this thesis development); we primarily refer to this recommendation as specifically applied to the PAC Rehabilitation context - although it could have a shared conceptual basis and operational platform with other healthcare levels, since interest in improvement-initiatives and underlying knowledge remain transversal across healthcare.

4.1 Improvement Data-System overview

Completing a starting-up action plan for PAC Rehabilitation quality-initiatives, mostly at external and infrastructural level, it would be helpful the development of an additional data-system. Such system does not embrace the quality-measurement/practice-based research field, as the previous recommendation; but rather embracing the improvement initiatives - namely an 'Improvement Data-System' for PAC Rehabilitation.

Briefly, the 'Improvement Data-System' envisions documenting, analyzing, and supporting systems, organizations and providers improving their own PAC Rehabilitation quality-improvement (QI) journeys/initiatives – a systems-based quality transformational change.

Such system could be operational under the following way: after registering a set of their own contextual variables, providers would be able document – for instance on a uniform web-based tool - the improvement action they plan/design, intent, and finally indeed implement in practice. Such acts could trigger two complementary mechanisms of the called PAC Rehabilitation 'Improvement Data-System':

1) Pro-actively, or on-time, supporting the design of QI initiatives;

2) Serve as data-source for retrospective feedback analyses of QI journeys, as complemented by tailored recommendations on providers' QI journeys.

Indeed, while the 1st mechanism envisions to improve the effectiveness of single QI initiatives; the 2nd mechanism envisions the effectiveness of organizations/providers' QI journeys as a whole, and framed along time. In two following sub-sections we describe each of these two complementary mechanisms. Then, such as in our previous recommendation, we address the benefits for research of such practice-based 'Improvement Data-System'. Finally, we over-look potential quality-benefits such system could trigger.

4.2 A tool facilitating on-time guidance for the design and implementation of PAC Rehabilitation QI-initiatives

Guidance on how well to design and implement PAC Rehabilitation QI initiatives can be made pro-actively or on the time QI initiatives are being designed or developed – thus able

to immediately produce changes and readjustments that facilitate its implementation and effectiveness. Perhaps the best way to achieve it would be through an interactive tool designed and developed specifically for this end, according the state-of-the-art of improvement and implementation sciences (highlighted in the 2nd review: research community), yet mixed with PAC Rehabilitation applied knowledge, state-of-the-art and quality-definitions. The tool might be periodically updated according research advances, but also accordingly formative evaluations after its implementation. All this process, as well as operational performance, could be run for instance by the PAC Rehabilitation interdisciplinary center (overarching recommendation) fitting with its scope of action and expertise.

The tool would have structure for the development of QI initiatives as the following: performance and context assessment; targets; portfolio of improvement initiatives, preparatory action; as finally strategies, approaches, improvement designs, methods, and techniques. Additionally, automatically and on a step-wised fashion, it might display easy-digestible improvement theory and supportive resources, as well as some practical guidance and tips on how to accomplish each step for QI design and implementation. Finally, the recommended tool could be linked to other improvement resources yet available, such the "Improvement Map" (app.ihi.org/imap/tool), guiding users to portfolios of improvement solutions.

The European in-development NorthStar tool ⁽¹⁴⁷⁾, and the more specific e-HIT toolkit for implementation of health information technologies ⁽¹⁴⁸⁾ are existing or in-development tools that can broadly illustrate what we recommend for being applied to support the design and implementation of PAC Rehabilitation quality-improvement initiatives. The great scope difference is that it would be designed specifically for unique PAC Rehabilitation quality-scope and quality-initiatives challenges.

Additionally, the recommended tool could include other important features mentioned tools do not cover. Indeed, data-entry in this recommended tool would be able to automatically furnish data to be stored, aggregated, organized and further analyzed in a PAC Rehabilitation improvement central database: suitable for the improvement feedback and research analyses (later outlined). Therefore, both the tool and the central database might be planned, designed and implemented together to fit with each other.

As similarly to the previous recommendations, such web-based tool should be based on a yet-to-be-developed classification/taxonomy for the elements of improvement interventions, their outcomes, and contexts. This is a matter for an infrastructural advance for the improvement science overall ⁽¹⁴⁹⁾; then with selected or re-arranged sub-sets of interventions as applied to the specific scope PAC Rehabilitation quality-improvement meanwhile ascertained.

4.2 Feedback-report and formative action-oriented guidance for PAC Rehabilitation QIjourneys

Beyond discretionary PAC Rehabilitation QI-initiatives, there are broader QI-journeys in which these initiatives are embedded on. Ultimately, is in the overall QI-journeys which it would consist the overall quality-improvement effectiveness in a systems-based and long-term organizational perspective.

As told, with information being documented in the web-based tool, the information might be stored and organized in a central database - improvement database - then able to be cross-linked with information contained in the two performance/quality-monitoring databases (macro-outcomes and clinical-registries data-systems); thereby it would be possible to retrospectively determine performance/quality gains - temporally delimitated associated with a set of deployed QI initiatives, or broadly seen, the providers or organizations' QI journeys or programs as a whole.

Retrospectively determining the performance/quality gains associated with QI journeys or programs is mostly as task for analytical methods, for instance Shewhart's graphics and multiple time-series analyses using repeated measures over time for the same provider; as well as tested under changed conditions; making multi-factorial designs, and mixing comparative data from improvements of peer-providers ^(150; 151; 152).

Besides graphics of cross-linked data, benchmarked and time-framed quantitative information; there should be made an expert's qualitative interpretation and over-analyses - yet structured - of the whole providers' QI journeys (e.g. strengths and weaknesses); as well as tailored action-oriented QI recommendations⁽¹⁵³⁾. These elements would complement the

scope of QI feedback and be the contents of periodic reports send back to providers regarding their improvement-action.

Both the expert's qualitative over-analyses and tailored action-oriented QI recommendations should be not only based in improvement graphics data, but also on: balanced data and information that also comprises analyses of the 'quality profile' of providers (previous recommendation); body of knowledge of the emerging improvement and implementation sciences; specificities PAC Rehabilitation quality-definitions and knowledge; and specific contextual factors (entered in the web-tool).

It is fairly recognized that making 'generalist' analyses and recommendations might be insufficient to drive improvement-action that is effective in its ultimate intents ⁽¹⁵⁴⁾. Therefore, the ability to make it tailored to providers' characteristics, 'quality profile', quality programs and specifically embracing PAC Rehabilitation quality challenges would determine much of the added-value of such system as an infra-structural facilitator of PAC Rehabilitation improvement journeys and initiatives.

4.3 Practice-based improvement/implementation science:

The development and deployment of QI interventions can be informed by the improvement and implementation sciences. The body of knowledge of such emerging science should continuously evolve and be updated (2nd review: research community section). Such kind of knowledge would be primarily of general healthcare scope, then applied to the specific challenges of PAC Rehabilitation quality-initiatives.

A privileged source of information (although not the unique) for such improvement and implementation sciences evolution will be the systematic analyses of general healthcare and context-specific, practice-based, improvement data. For instance, case-based analysis of the leading organizations is a major informing source for the advance of improvement science ⁽¹⁵⁵⁾. But although extremely valuable for highlighting successful tips other could start to follow, it is not representative of providers delivering care to the great proportion of population. A recommended 'Improvement Data-System' can furnish improvement practice-based information about a much wide sample of systems and provides - who could easily incorporate at least the basic principles of scientific quality-improvement ⁽¹⁵⁶⁾ - with

multiple possibilities for research to identify the best improvement patterns under specified organizational contexts. The practice-based findings can eventually be tested by directed replication, or eventually raising/triggering new questions/hypotheses for other advanced research methods to test ^(152; 157; 158).

An important function of improvement science is also highlighting the features or barriers that more often undermine the QI effectiveness ⁽¹⁴⁶⁾. With such regards, the web-based tool must allow sets of contextual information interfering with improvement initiatives might also be uploaded to the central database. Finally, if costs associated with QI initiatives become also documented in the web-based tool (highly recommend for efficiency-analyses), it would be also possible to determine what improvement initiatives, targets, journeys, designs, methods, techniques produce the more cost-effective improvements in the organizational 'quality profile'.

4.4 Improvement Data-System: an over-look of systems-based benefits for quality

Such kind of 'Improvement Data-Systems' would not be particularly helpful for those organizations or providers that already have yet a leading/top-edge QI journeys, as for instance elsewhere illustrated ⁽³⁹⁾. However, it could be particularly suitable and valuable for the other organizations that do not have or own top-edge quality-structures and process, and have no dimension to afford so great quality-expertise (there is no much experts available also). Such type small providers represent the great mainstream of US providers ^(159; 160).

Therefore, these mainstream providers (those providing care to most people) would be much suited to benefit with such type of 'Improvement Data System' they cannot afford as an infrastructure for themselves, yet reflecting tailored effects of their own QI efforts, linked to their own 'quality profiles'.

Within the mentioned scope, there is already in the field the action of the Quality Improvement Organizations (QIO: 2nd review at external/independent bodies sub-section) acting at a US state-level. However, such national-basis 'Improvement Data-System' (as applied to general healthcare and specifically to PAC Rehabilitation) shall not be a substitute or overlap of QIOs activity at a more proximal level, but rather can be seen as a

tailored data-based recommendation-system which is PAC Rehabilitation specific. Thus, it can activate improvement mechanisms, for instance putted on the field by on-site QIO action at the more proximal state-level of action.

In the specific case of PAC Rehabilitation, the national system (for instance managed by our overarching recommended interdisciplinary center) can additionally provide more specific PAC Rehabilitation improvement guidance for the generalized improvement supportive action of the QIOs.

All these external improvement mechanisms brought together could promote the equity in quality-improvement among organizations, thereby contributing for getting more homogeneous the quality of care patients receive in the different places they seek care: not raising the gap among the excellent providers and the others: an active concern that the quality-movement can, inadvertently, be stimulating ^(21; 161; 162; 163).



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