Co-funded by
the Health Programme
of the European Union

JARC
JOINT ACTION ON RARE CANCERS

"This Deliverable is a part of the joint action "724161/JARC" which has received funding from the European Union's Health Programme (2014-2020)".

Deliverable D5.2

Title: A framework of systems-based quality standards applicable to all networks and centres for rare cancers adding to ERN requirements

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1. Description

1.1 Joint Action on Rare Cancers

The Joint Action on Rare Cancers (JARC) is aimed to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers.

The public health challenges posed by rare cancers include the limited professional expertise in the community, the difficulties in clinical research, the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as an expert clinical decision provided by a multidisciplinary team. To this end, proper referral of patients and effective clinical networking are crucial in rare cancers. This is the main reason why JARC decided to shape its efforts around the new European Reference Networks (ERNs) with the following objectives:

1. Improving epidemiological surveillance of rare cancers in the EU
2. Identifying standards of care for all families of rare cancers to ensure sharing of best practices and equality of care for rare cancers across Europe, particularly through clinical networking
3. Improving the implementation at local level and within ERNs of clinical practice guidelines on rare cancers
4. Promoting integration of translational research innovations into rare cancer care
5. Improving education on rare cancers for medical and non-medical experts to ameliorate management of rare cancers and to improve rare cancer patients' empowerment in the EU
6. Identifying core strategies to incorporate in National cancer plans and Rare disease plans to address the specific needs of rare cancers across EU MSs

The JARC is structured in 10 work packages (WPs). Three cross cutting WPs (WP1 coordination, WP2 dissemination, WP3 evaluation) and 7 specific WPs based on the JARC objectives: WP4 epidemiology, WP5 quality of care, WP6 clinical practice guidelines, WP7 innovation and access to innovation, WP8 medical education, WP9 childhood cancers and, WP10 rare cancers policy. Patients work across all work packages, driving the JARC efforts along the needs of the only end users of all what we can do, in care and research as well.

1.2 WP5 Assuring Quality of Care

WP5 aims to design quality assurance systems and processes specific to the 11 major families of rare cancers. This is both as a recommendation to MSs for national initiatives to set up networks of rare cancers and also for the two adult cancer ERNs to add to the EU evaluation systems for ERNs. Childhood Cancers are already covered by WP9. The main deliverables of the WP5 are Quality Standards and Indicators for Cancer ERNs and recommended for Member States, together with a recommended evaluation programme. A further deliverable is a mapping of existing cancer networks in EU states.

1.3 Aim and Purpose of this Deliverable

The aim of this deliverable is to drive up the quality of care for rare cancer patients across Europe and in particular to achieve equity of access to high quality care across MSs. To achieve this aim the scope of the

deliverable has been stated at the outset of this JA as being: care, education and research. All three of these elements are key to driving up the quality of rare cancer care.

The purpose of the deliverable is to provide the ERN evaluation system and MSs with Quality Standards which Cancer Networks (both the Network Co-ordination and each Healthcare Provider (HCP) in the network) can apply within a Quality Assurance (QA) programme to self assess and be externally assessed for QA and Quality Improvement. The objective stated in the initial grant agreement was: "To propose consistent and Europe-wide systems-based standards for all families of rare cancers and the networks serving them. These standards will include provision for the holistic care of patients and their care providers from the beginning of the diagnostic process through to survivorship, rehabilitation or End of Life."

The purpose of the proposed Quality Indicators is also to measure improvements in Structures, Processes and Outcomes.

1.4 Target groups for the Deliverable

The target groups for the Deliverable are:

1) The 3 cancer ERNs and the ERN Monitoring Group of the EU
2) Policy makers for Cancer in MSs.
3) Leaders of existing rare cancer networks in MSs
4) Patient organisations for Rare Cancers

1.5 Summary of the main conclusions of the deliverable

The main conclusions of the deliverable are:

Internationally accepted findings are that Quality Standards fall into two categories: (a) Qualitative Standards which are SMART-forumulated descriptions of a structure or process and which can be scored; and (b) Quality Indicators which are normally either numercical or expressed by percentage compliance with a measure.

1.5.1 Quality Standards

This Deliverable recommends 36 Quality Standards for the three Cancer ERNs (Annex 1). These Quality Standards cover the similar domains of operation as the ERN Operational Criteria, as below. The Quality Standards have been carefully crafted to evaluate the quality of Cancer ERNs, taking into account that they are networks of already highly specialised Centres of Reference (CoRs) in MSs, and that only a minority of patients diagnosed and treated by network HCPs become Network Patients through the CPMS system. The scope therefore is that the ERN cannot be *responsible* for the quality of treatments by CoRs for non-Network patients, but can be *influential* in raising quality through various instruments.

- Governance and Co-ordination
- Patient-centredness and care
- Multidisciplinary approach
- Quality Assurance
- Research
- Education, Training and Development

- Networking and collaboration
- Infrastructure and Data

This Deliverable also recommends 51 Quality Standards for use or adoption by MSs when setting up a QA systems for Rare Cancer Networks, or alternatively from the bottom up by Rare Cancer Networks (RCNs) themselves (Annex 2). This set of Quality Standards is more detailed than the Cancer ERN set around the area of Multidisciplinary Approach because they assume that at a national level RCNs are likely to be sharing responsibility for the majority of rare cancer patients through Multi-Disciplinary Teams (MDTs), and therefore Quality Standards can be set for the protocols and Standard Operating Procedures of MDTs. This set of Standards follows the same domains as for Cancer ERNs, but are focussed at a national level.

1.5.2 Quality Indicators (QIs)

For Cancer ERNs, 18 generic Quality Indicators have already been proposed by the ERN monitoring group (reproduced at Annex 3) . Thus this Deliverable is only called upon to recommend any QIs which are **supplemental** and **specific to cancer** ERNs. After extensive discussions with EURACAN and the ERN Monitoring Group, this Deliverable recommends only 4 cancer-specific QIs at Annex 4.

For National Networks of Rare Cancers (RCNs), which do not have the 18 generic QIs from the ERN group to follow, WP5 has had more scope to craft specific QIs according to Structure, Processes and Outcomes according to the Donabedian model. Those 19 recommended QIs are reproduced at Annex 5.

2. Introduction, including the Purpose of the Deliverable

The EU in 2014 set up the instruments to create European Reference Networks (ERNs) in the belief that establishing high level networks of CoR in rare diseases will raise the level of research, education and care in rare diseases in Europe. Furthermore, a minority of patients with expectionally rare or complex disease could benefit from a shared diagnostic system within the ERN which could convene some of the top experts in that disease across Europe (the Clinical Patient Management System (CPMS)). The 3 cancer ERNs, EURACAN, Eurobloodnet and PaedCan, were created after an EU call in 2016.

At a national level, as evidenced by Deliverable 5.1 of WP5, many MSs have or are taking steps to establish Rare Cancer Networks for the care of patients with rare cancers. In most cases these act according to patient pathways to provide care between different providers to provide continuity for patients and all necessary expertise convened in extended Tumour Boards.

However, how does anyone know whether these networks, at EU, or at National level, are being effective for improving care for rare cancer patients?

Are the networks effective?
Are they constantly improving?
Are they improving outcomes for patients?
What best practices do they disseminate?

The most effective way of answering the questions above it to set Quality Standards and QIs for both *self assessment* and *external assessment and peer review.* This was also the conclusion of the CanCon Joint Action which concluded in the European Guide on Quality Improvement in Comprehensive Cancer Control, page 90, "Among the RARECAREnet-proposed indicators there is the establishment of a quality assurance system to monitor the services provided. This will be essential to assess the CCCNs also on the basis of cancer-specfic quality indicators."

No set of Quality Standards begins in a vacuum, and in Section 3 Materials and Method, we outline which other sets of Quality Standards were used as starting points for the development of the Quality Standards in this Deliverable. We also set out how those standards were honed and developed by Expert Panels.

When the ERN framework was established in 2014, a set of Eligibility Criteria [insert reference] and Operational Criteria were set for both Co-ordinators and HCPs. This was to set minimum requirements for eligibility. The Operational Criteria were independently assessed by an Independent Audit Provider under an OJEU tender. In 2016 the call for cancer ERNs was announced and concluded. The JARC was not party to this process and has not seen any detailed results of the applications concerned.

The EU had not yet set Continuous Monitoring Criteria for ERN (including Cancer ERNs), However in 2019 the EU is in the process of developing an AMEQUIS system (Assessment, Measurement and Evaluation of Quality System). The Quality Standards and QIs in this Deliverable are offered as a contribution to this development.

At a national level the JARC has not been able to discover that any QA system exists in any MS specifically for Rare Cancer Networks.

From our researches (Section 3) the only specific existing set of standards for Rare Cancer Networks has been set up for Neuro-Endocrine Tumours under the organisation European Neuro-Endocrine Tumor Society (ENETS - https://www.enets.org/coe_procedures.html). It is instructive to read the reason for establishing a network of Centres of Reference for NETs.
"A network of centers, they reasoned, would allow NET patients to seek specialists who could best treat them, and would also unify the care and research being conducted in the NET field across Europe".

The purpose of this Deliverable is to provide the ERN evaluation system and MSs with Quality Standards which Cancer Networks (both the Network Co-ordination and each Healthcare Provider (HCP) in the network) can apply within a Quality Assurance (QA) programme to self assess and be externally assessed for QA and Quality Improvement. The purpose of the proposed Quality Indicators is also to measure improvements in Structures, Processes and Outcomes.

Deliverable 5.3 of the JARC will propose Programmes which can implement the Quality Standards and Indicators in this Deliverable. They have initial value for *self assessment* by any Rare Cancer Network in any MS, or even inform the process of creation of Rare Cancer networks within a quality system.

The Quality Standards and QIs can also be used as a basis for the proposed AMEQUIS system within the EU Monitoring Task Force for ERNs, with a specific focus on cancer and the way that cancer multidisciplinary teams have developed according to best practice.

The Quality Standards could also be used for *external assessment* of the quality of national Rare Cancer Networks. This might be at the initiative of Ministries of Health, or on a voluntary basis by the Rare Cancer Networks themselves to achieve an independent recognition of quality which could be recognised by patients.

Finally, the ultimate purpose of Quality Standards and QIs is to identify opportunities for Rare Cancer Networks or individual HCPs to improve quality for cancer patients. The Quality Standards are set at a level which is necessarily aspirational, and achievable in the vast majority of cases. However, *every* Network or HCP should find that it does *not* meet a handful of the Standards in the set, and therefore needs to put in place Actions for Improvement.

3. Materials and Methods

3.1 **Phase 1 Survey of existing Quality Assurannce (QA) systems worldwide relating to cancer.** Task 5.2 was to "Perform a survey of existing quality assurance programmes for assuring quality of care for rare cancers, and systems-based criteria for centres of excellence and for networks of care."

The first step toward the identification of existing QA systems related to cancer networks was a **literature search**, which included both research literature and gray literature

The research literature search was structured according to two different domains: "health network efficacy" and "quality assurance systems", using the most sophisticated medical search engines (see Annex 7).

The grey literature search was meant to identify the most relevant standards and models for the assessment of rare cancer networks. The target of the analysis were mainly European Models – given the scope of the project – but the partnership expanded the exercise also to other international models.

Finally, to assure completeness, a survey among relevant partners was also performed, with the objective of collecting additional inputs on key-sources of information.

The **data** were **collected** in a single database, ccording to the following main characteristics:

Mandatory/Voluntary
Cancer Specific (Y/N)
National system/International? (Y/N)
Hospital-wide system (Y/N)
Network system (Y/N)
Does the QA system cover cancer research?
Does the QA system cover rare diseases? (Y/N)
Process(es) covered by the QA system

After an in-depth analysis of the materials available, partners and their experts identified a **shortlist** of the most relevant cancer care QA models, which included thos from the Organisation of European Cancer Institutes (OECI), The European Society for Neuro Endocrine Tumours (ENETS), French National Cancer Institute (INCa), the German Cancer Society (DKG) and ERN Requirements.

3.2 **Phase 2 Analysis of shortlisted QA systems.** Task 5.2 included: "The survey will then be analysed for the quality and effectiveness of those programmes. This will draw on the outputs of the RARECAREnet project; the experience of the OECI Quality Assurance Framework and those of Member States; and the newly established operational quality criteria for the assessment of ERNs.

A qualitative **comparison** of standards/criteria of the abovementioned models against the OECI qualitative standards was performed, with the main objective of identifying communalities (in terms of contents and domains of expertise), possible integration of the models as well as best practices.

A second level of analysis was then performed, which enabled to **select** and pull-out the best (most complete, transparent and evidence-based) standards, which constituted the theoretical and methodological base for the development of the JARC standards.

3.3 **Phase 3 Establishing the scope and format of the new Standards by reference to Expert Groups.** It was important to establish the scope of the Quality Standards and Indicators. First, the WP5 aimed to maintain the scope set out in the Grant Agreement that the Standards should encompass "provision for the holistic care of patients and their care providers from the beginning of the diagnostic process through to survivorship, rehabilitation or End of Life". Given the timing of the call for cancer ERNs in 2016, it was germane that the Operational Criteria for Co-ordination and Healthcare Providers should be given due weight in guiding the scope of the Quality Standards for Rare Cancer Networks. The domains of those eligibility criteria are:

- Highly Specialised Healthcare
- Governance and Co-ordination
- Patient centredness and care
- Multi-discplinary approach
- Good practice, outcome measures and quality control
- Research
- Education, training and development
- Networking and collaboration
- Infrastructure and Data

The scope and format of the new Standards was referred to the JARC meetings in November 2016 in Luxembourg, in October 2017 in Milan, and re-affirmed in June 2018 in Poznan, and with EURACAN in Oxford in April 2018.

In those meetings, whilst it was acknowledged that there could be a future need for a detailed set of standards and indicators relating to *specific families* of rare cancers, this was really a matter for EURACAN and Eurobloodnet expertise, and was not appropriate to the scope of Quality Standards and Indicators for WP5 of the JARC. The WP5 Standards should be framed as applicable to all rare cancers.

In the Poznan and Milan meetings it was also determined that, from the point that the call was made by the EU for Cancer ERNs, there was a need for two related sets of Quality Standards:

- Quality Standards and Indicators for Cancer ERNs which can be incorporated into, adapted for, or are supplemental to the AMEQUIS system for ERNs outlined at paragraph 2

- Quality Standards and Indicators which can be recommended in the JARC to Members States for the monitoring of National Rare Cancer Networks whether existing or for future formation.

3.4 **Phase 4 Formation of the first draft set of Quality Standards by the W5 working group.** Following on from the first 3 phases of the work, the WP5 working group used as principal sources of material the Quality Standards of the following organisations:

- OECI Quality Standards in the Qualitative Questionnaire Manual 2.0[1]
- ENETS Standards[2]
- German Cancer Society Catalogue of Requirements for Oncology Centres[3]
- ERN Operational Criteria[4]

With reference to these principal sources, **but constituting original work**, a first draft of Quality Standards was drawn up under the headings outlined in paragraph 3.3 above, with a first set for Cancer ERNs, and a second set for National Rare Cancer Networks. This first draft set of Standards was designed to fulfil the scope set out in the Grant Agreement that the Standards should encompass "provision for the holistic care of patients and their care providers from the beginning of the diagnostic process through to survivorship, rehabilitation or End of Life." This work was completed in January 2018.

3.5 Phase 5 Consultation and Refinement of the Quality Standards. A process of consultation was initiated in February 2018, which involved the draft Quality Standards being sent to all Associated Parners of WP5, and the three Cancer ERNs, EURACAN, Eurobloodnet and PaedCan. Input and suggestions were received from several parties, and in specific detail from ECPC and Eurordis. More detailed consultations were held with the Quality Transversal Task Force (TTF) of EURACAN – including discussions at the EURACAN conference in Oxford on 5 April 2018, leading to the support of this group. Triangulating with Childhood Rare Cancers (WP9), input was received from SIOP-Europe.

As a result of these consultations a second draft of the Quality Standards was issued in May 2018 and circulated to all partners of WP5, all WP leaders of JARC, and the 3 Cancer ERNs for further consultation.

The second revised draft was also brought for consultation to the Plenary Meeting of WP5 held in Poznan in June 2018. The input from that meeting was to direct the working group to: reduce the number of Quality Standards where possible; to recognise the fact that the existence of networks does not detract from the responsibility of HCPs for the treatment and care of each rare cancer patient; to create two sets of Quality Standards, one for Cancer ERNs and a slightly more detailed set for National Rare Cancer Networks; and to place the emphasis on the Cancer ERNs' set on evaluating quality (including Quality Indicators) for "Network Patients" – being defined as those patients who become part of the shared decision-making process of the ERN through the CPMS process.

[1] https://www.oeci.eu/Accreditation/Page.aspx?name=OECI_STANDARDS
[2] https://www.enets.org/coe_procedures.html
[3] http://www.ecc-cert.org/certification-system/catalogue-of-requirements/
[4] https://ec.europa.eu/health/sites/health/files/ern/docs/ev_20160407_co02_en.pdf

Draft 3 of the Quality Standards in these two sets was created in August 2018, including a first draft of Quality Indicators. After refinement within the internal working group Draft 4 was presented to the Milan JARC General Assembly in October 2018 without disagreement of the Quality Standards but with further instructions for the development of Quality Indicators for ERNs in conjunction with the ERN Monitoring Group (see 3.6 below).

Further minor improvements were made to the Quality Standards between October 2018 and March 2019 resulting in two Draft 7s presented to the Plenary Meeting in Catania on 26-27 March 2019 (see 3.8 below).

3.6 Phase 6 Development of Quality Indicators. WP5 was made aware of the work of the ERN Monitoring Group in June 2018 and closely followed the development of Quality Indicators for ERNs, from a long list of 43 to a shortlist of 18 – with some indicators such as for Patient Experience still requiring further definition.

It was recognized that National Rare Cancer Networks would require a recommended set of Quality Indicators irrespective of ERNs, an a first draft of these quantitative indicators (generic for all rare cancers within the network) was developed in Drafts 3 onwards of the Quality Standards from August 2018 onwards. The categories of these QIs was decided to be according to the Donabedian Model of Structure; Process; and Outcomes. The sources for these Quality Indicators was diverse, but on Structure and some Processes largely from ERN Monitoring Group consensus outputs, from OECI and German Cancer Society evidence-based quantitative models, and for Outcomes the same sources and in addition the Indicators referred by the experts in Table 5.1 of the European Guide on Quality Improvement in Comprehensive Cancer Control[5].

The first draft of QIs was informed by specific consultation with the EURACAN Quality TTF both on 5 April 2018 at Oxford and on subsequent occasions, both considering the already proposed "Short Scorecard" or Indicators (most of which were Process QIs) and the "Extended Scorecard". Most of these measures were not specific to cancer, and covered domains such as: Network Structure, Communication, Best practice, Research, Training and Funding.

Initial drafts of the QIs were refined between August and October 2018 and presented to the JARC General Assembly in Milan in October 2018. The list of recommended QIs for National Rare Cancer networks was generally felt to be too long and requiring further precise definitions in some cases, and the list of QIs for ERNs needed to be (a) Cancer Specific (acknowledging the work of the ERN Monitoring Group) and (b) predominantely related to Network Patints as defined (especially for Outcomes).

Refinements and deletions were made in the period October 2018 to March 2019 and cross referenced to the Quality Standards, resulting in two drafts presented to the Plenary Meeting in Catania on 26-27 March 2019 (see 3.8 below).

3.7 Phase 7 Consultation of Quality Indicators with ERN Monitoring Group. Triangulation with the work of the ERN Monitoring Group on QIs for Rare Diseases began in June 2018 and had a particular focus at the 4th Annual ERNs Conference in Brussels in November 2018 when the JARC WP5 and ERN Monitoring Group presented and compared work and results. The result of this consultation renewed the focus on QIs for Network Patients (those becoming so as a result of the CPMS process) whilst not excluding the need for a very limited number of QIs on processes that were specific to cancer patients. Subsequent work

[5] https://cancercontrol.eu/archived/uploads/images/Guide/pdf/CanCon_Guide_FINAL_Web.pdf, page 87

demonstrated that the generic rare disease QIs developed by the ERN Monitoring Group covered almost all the ERN monitoring requirements for Cancer ERNs.

3.8 Phase 8 Consensus agreement of the Quality Standards for ERNs and RCNs

In a 1-day meeting plenary involving most of the partners and associated partners of the WP5, including patient organisations and the Co-ordinator of the iPAAC Joint Action, consensus was reached on the definition of 36 Quality Standards to be recommended to the EU for the use of Cancer ERNs (Annex 1). Consensus was also reached on 51 Quality Standards recommended for National RCNs (Annex 2). This set of Quality Standards is more detailed than the Cancer ERN set around the area of Multidisciplinary Approach because they assume that at a national level RCNs are likely to be sharing responsibility for the majority of rare cancer patients through Multi-Disciplinary Teams (MDTs), and therefore Quality Standards can be set for the protocols and Standard Operating Procedures of MDTs. This set of Standards follows the same domains as for Cancer ERNs, but are focussed at a national level.

Where a final consensus on precise wording or definition was not achieved by 27 March 2019, the Standards in Annexes 1 and 2 are reproduced in italics.

3.7 Phase 9 Recommendation for the Quality Indicators for ERNs and RCNs

In a ½ Day meeting following on from the meeting in 3.8, involving most of the partners and associated partners of the WP5, including patient organisations and the Co-ordinator of the iPAAC Joint Action, consensus was reached on 4 Quality Indicators specific to Cancer ERNs to be recommended to the EU for use as supplemental to the 18 already agreed Quality Indicators for ERNs (Annex 4). Consensus was also reached on 19 Quality Indicators for RCNs. RCNs do not have the 18 generic QIs from the ERN group to follow, so agreement was reached on specific QIs according to Structure, Processes and Outcomes according to the Donabedian model. Those 19 recommended QIs for RCNs are reproduced at Annex 5.

Where a final consensus on precise wording or definition was not achieved by 27 March 2019, the Quality Indicators in Annexes 4 and 5 are reproduced in italics.

4. Results

4.1 **Quality Standards for the 3 Cancer ERNs.** As a result of the methods and materials outlined in section 3 above, WP5 recommends 36 Quality Standards for the three Cancer ERNs (Annex 1). These Quality Standards cover the same domains of operation as the ERN Operational Criteria. The Quality Standards have been carefully crafted to evaluate the quality of Cancer ERNs, taking into account that they are networks of already highly specialised Centres of Reference (CoRs) in MSs, and that only a minority of patients diagnosed and treated by network HCPs become Network Patients through the CPMS system. The scope therefore is that the ERN are not *responsible* for the quality of treatments by CoRs for non-Network patients, but can be influential in raising quality through various instruments, such as recommending or writing clinical guidelines, sponsoring conferences or raising awareness for research and clinical trials.

4.2 **Quality Standards for recommendation for National Rare Cancer Networks.** As a result of the methods and materials outlined in section 3 above, WP5 also recommends 51 Quality Standards for use or adoption by MS when setting up a QA systems for Rare Cancer Networks, or alternatively from the bottom up by Rare Cancer Networks themselves (Annex 2). This set of Quality Standards are more detailed than the Cancer ERN set around the area of Multidisciplinary Approach because they assume that at a national level Rare Cancer Networks are likely to be sharing responsibility for the majority of rare cancer patients through extended Tumour Boards, and therefore Quality Standards can be set for the protocols and Standard Operating Procedures (SOPs) of MDTs, which are much more amenable to being organised according to consistent SOPs at a national or regional level. This set of Standards follows the same domains as for Cancer ERNs, but are focussed at a national level.

4.3 **Quality Indicators for the 3 Cancer ERNs.** For Cancer ERNs, 18 generic QIs have already been proposed by the ERN monitoring group reproduced at Annex 3) . Thus this Deliverable is only called upon to recommend any QIs which are specific to cancer ERNs. After extensive discussions with EURACAN and the ERN Monitoring Group, this Deliverable recommends only an additional 4 cancer-specific QIs at Annex 4.

4.4 **Quality Indicators for National RCNs.** For National Networks of Rare Cancers, which do not have the 18 generic QIs from the ERN group to follow, WP5 has had more scope to craft specific QIs according to Structure, Processes and Outcomes according to the Donabedian model. As a result of the methods and materials outlined in section 3 above, WP5 recommends 19 QIs which are reproduced at Annex 5.

5. Conclusions and Recommendations

5.1 The purpose of the deliverable is to provide the ERN evaluation system and MSs with Quality Standards which Cancer Networks (both the Network Co-ordination and each Healthcare Provider (HCP) in the network) can apply within a Quality Assurance (QA) programme to self assess and be externally assessed for QA and Quality Improvement. The objective stated in the initial grant agreement was: “To propose consistent and Europe-wide systems-based standards for all families of rare cancers and the networks serving them. These standards will include provision for the holistic care of patients and their care providers from the beginning of the diagnostic process through to survivorship, rehabilitation or End of Life.”

The 36 Quality Standards proposed for the 3 Cancer ERNs and the 51 Quality Standards proposed for recommendation for National Networks conform to the scope above and are considered by expert groups to be realistic, valid and measurable Standards of Quality of diagnosis, treatment and care fror rare cancer patients, as well as covering education and research in rare cancer networks.

The 19 Quantitative Indicators proposed for recommendation to National RCNs are validated, evidence-based and measurable. Many of them have been used for a period of more than 10 years in the context of cancer centres by either OECI or the German Cancer Society, and are extended for Rare Cancer Network application. They are claussified according to the Donabedian model under Structure, Process, and Outcomes.

The 4 QIs chosen for recommendation to the ERN Monitoring Group as supplemental to the 18 generic QIs already chosen by experts reflect cancer specific requirements and are limited in number because the generic indicators already covered the main monitoring requirements of the ERNs.

5.2 Recommendations

Recommendation 1: that the set of 36 Quality Standards and the 4 supplemental QI for the 3 Cancer ERNs be recommended for consideration by the ERN Monitoring Group as part of the emergent AMEQUIS system being developed for ERNs, to monitor and evaluate quality of cancer care for network patients in the Cancer ERNs.

Recommendation 2: that the set of 51 Quality Standards and the 19 QIs proposed for RCNs either existing or for future formation by recommended to National policy-makers, to patient organisations and to RCNs themselves as means of driving continuous quality improvement for rare cancer patients treated in networks.

Annex 1 - Recommended Quality Standards for application to Cancer ERNs

Considerations specific to the ERN PaedCan and the paediatric cancer community are provided in a dedicated section of the tables in this annex.

1. Governance and Co-ordination
1.1 The ERN has a Board of Directors which provides the ultimate Governance of the strategy, policy and activities of the Network.
1.2 The Board of the ERN contains representatives from each HCP Member of the Network, or else representatives by election, including patient representatives. * * Not directly applicable to ERN PaedCan – please refer to ERN PaedCan section note 1
1.3 The role and terms of reference of the Board are clearly defined and documented in a set of governance policies, rules and procedures.
1.4 There is one Member within the ERN designated as the Coordinating Member. Guidance: One individual is appointed by the Coordinating Member to act as "Coordinator" of the Network and normally also the Chair of the Board.
1.5 The ERN monitors the activity, outcomes and initiatives of the Network and its members in regard to their specific, predefined roles.
1.6 The ERN defines minimum volumes of patients per rare cancer family which define the eligibility to be an HCP within the Network. Guidance: The Network should determine whether these minimum volumes are defined by Hub or HCP or by treatment modality, where possible, to ensure quality * * Not applicable to ERN PaedCan – please refer to the ERN PaedCan section note 2
1.7 The ERN has a Strategic Plan covering a 3-5 year period. Guidance: The Strategic Plan may include: 1) Assurance of the sustainability of the network (e.g. financing, education) 2) Research Strategy. 3) Risk management. 4) Improvement of patients' care pathways. 5) Policy making. 6) Integration of new members * * Please refer to the ERN PaedCan section note 3
1.8 The Board agrees an Annual Budget and resource allocation. Guideline: Resources could be people, conferences, websites etc * * Please refer to the ERN PaedCan section note 3

1.9 The Board has established mechanisms to incorporate the voice and opinions of patients and families through nominated ePAGs' representatives in each level of the ERN.
1.10 The Board delegates to expert groups in the ERN the development of new or revised clinical guidelines to be used for network patients *. * Please refer to the ERN PaedCan section note 4

2. Patient-centeredness *
2.1 Patients and patients' representatives are actively involved in planning and monitoring of the strategic activities of the ERN. Examples are: involvement in the Board to define policies, strategies and improvement plans (e.g. reviewing research outputs), reviewing pathways, improving referral procedures, communication.
2.2 The ERN promotes the regular collection and analysis of patients' experiences and satisfaction by HCPs; the information is used by the network to take strategic decisions.
2.3 The ERN promotes the use of written patient pathways to ensure that at all times it is clear which physician and which HCP has the responsibility for the care of the patient.
2.4 The ERN encourages its HCP members to have policies and procedures for ensuring the holistic care of patients (including paediatric patients) and their care providers from the beginning of the diagnostic process throughout the whole survivorship span, including transition of care, rehabilitation or end of life. Guidance: Policies and Procedures for holistic care include psychological support for patients and their caregivers, financial and employment advice, rehabilitation support, end of life care and bereavement support for families.
***** ERN PaedCan - Please refer to the ERN PaedCan section note 5

3. Multi-disciplinary Approach *
3.1 The ERN promotes the practice that HCP Multi-disciplinary Team (MDT) meetings should follow defined criteria about documentation and communication for care delivery.
3.2 The ERN defines mandatory and case specific representation of medical and clinical disciplines in each MDT to ensure optimal patient management.
3.3 There is a clear definition of the point at which a patient becomes a Network Patient (as defined in the glossary: Level 1 a "CPMS patient"; Level 2 any rare cancer patient of an HCP in the network).
3.4 In compliance with the EU General Data Protection Regulation, appropriate data from the Electronic Patient Record (EPR) can be shared with the ERN registries. (This standard is conditional on a common EPR format being in place across Europe).

3.5 The ERN promotes the practice that each HCP MDT should review best practice evidence in a Learning Event periodically (Ideally annually). Guidance: • Where appropriate, reviews of best practice evidence, and updating protocols are made in conjunction with ePAGs • The Agenda for Learning Events should include outcome measurements and regular departure from clinical guidelines
***** ERN PaedCan - Please refer to the ERN PaedCan section note 6

4. Quality Assurance *
4.1 The ERN promotes the practice that each HCP has a system in place to regularly monitor and report performance and risk indicators and to construct an improvement plan based on the reports. Guidance: These Performance Indicators should include: volume of patients seen (by HCP); waiting times from first referral to diagnosis and first treatment; specific surgical interventions and follow ups; length of inpatient Stay; outcomes in terms of survival; quality of Life measures.
4.2 The ERN promotes the practice that each HCP has a procedure in place to report, document and learn from adverse events and complications. The HCP uses this information to make ongoing improvements.
4.3 The ERN has minimum volume requirements for key procedures, where this is appropriate in context.
***** ERN PaedCan - Please refer to the ERN PaedCan section note 7

5. Research *
5.1 The ERN has a Research Board to promote basic, translational and clinical research into all fields of rare cancers within the scope of the ERN. Guidance: • The scope of research could include prevention, detection, treatment, rehabilitation, economic and social studies, outcomes and epidemiology • "Research" includes also innovation • The Research Board should report annually to the ERN Board
5.2 The ERN specifically promotes the creation of new investigator-initiated and commercial clinical trials and observational studies for Rare Cancers.
5.3 Publications by the ERN with HCP members collaborating together (using the name of the ERN) are regularly achieved in peer reviewed journals.
5.4 The results of ERN-based research are made available in accessible language(s) for patients and the public.
5.5 The ERN makes publicly available comprehensive and accessible information about open clinical trials.
5.6 The ERN has access to a virtual database of biosamples in rare cancers.

Guidance: The virtual database should provide anonymised linking with clinical data of the patient.
5.7 The ERN has an independent Scientific Advisory Board composed of internationally renowned scientists in rare cancers to advise on the progress of the ERN in research. Guidance: The Scientific Advisory Board meets the ERN at least every 2 years to critique the strategy and progress of network research.
***** ERN PaedCan - Please refer to the ERN PaedCan section note 8

6. Training, Development and Education *
6.1 The ERN promotes oncology training and education in rare cancers (including conferences and educational events) for physicians, nurses, researchers, supportive disciplines, other relevant disciplines and patients.
6.2 Patient Education programmes and tools (including online tools) are available across the ERN to patients and their families Guidance: The ERN has educational activities to inform and empower patients and to improve patients' health behaviours and/or health status.
***** ERN PaedCan - Please refer to the ERN PaedCan section note 9

7. Networking and collaboration *
7.1 The ERN gathers, exchanges, and disseminates knowledge, data, best practice evidence, and clinical expertise within and outside of the network.
7.2 The ERN has a communication plan and communication tools taking into account the different languages spoken at EU level. Guidance: The tools should *1)* support collaborations with other organisations *2)* promote the patient access to the ERN
7.3 The ERN provides clear information on its website about how patients can be referred to the ERN for expert advice
7.4 The ERN uses instruments to promote collaboration with other related ERNs.
***** ERN PaedCan - Please refer to the ERN PaedCan section note 10

8. Infrastructure and Data
8.1 The ERN provides information about where highly specialized diagnostic techniques and treatment can be accessed within the HCP members of the ERN.
8.2 The ERN supports the establishment of disease-based shared registries and databases, gathering information on diagnoses and outcomes
8.3 The ERN maintains a shared system that allow real time confidential submission and review of clinical information, including histopathology, radiology, and medical imaging by all network members e.g. CPMS (Clinical Patient Management System).

Considerations specific to ERN PaedCan – notes

1. With specific reference to the ERN PaedCan, the governance structures have aligned with the existing organisational structures of the paediatric cancer sector including SIOP Europe as follows. The function of the Board of Directors for ERN PaedCan is fulfilled by an independently chaired Oversight Committee (OC). The OC is chaired by the President of SIOP Europe and includes the elected representatives for the relevant stakeholders, including the two chairs of the SIOP Europe Clinical Research Council representing the disease-oriented European Clinical Trial Groups and National Paediatric Haematology Oncology Societies, the two chairs of Childhood Cancer International – Europe representing parents, patients and survivors, and the ERN PaedCan Coordinating Member. The OC has Terms of Reference to define its governance policies, rules and procedures.

2. Minimum patient numbers for a rare childhood and adolescents cancer entity is not an appropriate criterion for HCP membership to the ERN PaedCan. Relevant criteria are developed with consideration for specific tumour communities as opposed to individual HCP members. The emphasis is on knowledge and expertise transfer through tumour boards.

3. The ERN PaedCan strategy development is aligned with the SIOP Europe Strategic Plan. The research and policy agenda is driven through the OC together with SIOP Europe stakeholder community.

4. The ERN PaedCan OC supported by the SIOP Europe Clinical Research Council may delegate activities such as the development of new or revised clinical guidelines to experts in the European Clinical Trial Groups.

5. The focus on ensuring patient-centeredness may apply at the level of specific tumour communities as opposed to individual HCP members. The paediatric haematology oncology community has a voice of parents and patients represented by Childhood Cancer International – Europe, working collaboratively on patient and survivor needs, assuring thus improvements in patient-centred approaches as needed and in view of varying contexts in respective Member States.

6. ERN PaedCan may provide information to consult functioning MDT and tumour boards via the CPMS whenever needed by individual HCP for individual complex cases, particularly for countries with limited health care budgets where children with cancer still face a less favourable outcome prediction.

The culture within SIOP Europe's European Clinical Trial Groups is to include every young patient into a prospective trial whenever possible or to capture treatment data based on guidelines within cancer type-specific registries. There are still areas in Europe, particularly in countries with low health expenditure rates, lacking such structures and practices. Here, ERN PaedCan offers an important opportunity to catch up and to improve individual HCPs in Europe towards high quality childhood cancer care. The CPMS is an ideal structure to exchange clinical knowledge and to give advice to HCPs on the individual patient level.

ERN PaedCan promotes the MDT functionalities at the network level in particular through the CPMS function Virtual Tumour Boards whenever HCPs outside the ERN PaedCan network are still lacking such functionality.

RN PaedCan establishes the SIOP Europe Clinical Trial Groups clinical diagnosis and treatment roadmaps and clinical guidelines at the level of specific tumour communities.

7. The Quality Report will include metrics relevant at the level of specific tumour communities rather than at an individual HCP level.

8. Research structures are embedded and aligned within the existing organisational structures of the paediatric cancer sector driven through the European Clinical Trial Groups. The ERN PaedCan will support relevant research initiatives arising in cooperation with SIOP Europe, the SIOP Europe Clinical Research Council and associated basic and translational research. This activity will be reviewed within the ERN PaedCan Oversight Committee meetings.

9. Educational activities take place in coordination and cooperation with SIOP Europe and the SIOP Europe Clinical Research Council. In addition, ERN PaedCan specifically fosters twinning activities between HCPs thus supporting in particular widening countries. ERN PaedCan further develops webinars with state-of-the-art teaching on specific childhood cancer entities with support of the experts in the respective European Clinical Trial Group community. These activities need to be enhanced to reach their full potential and impact. ERN PaedCan is calling for enhanced support from Member States and the European Commission to foster teaching and learning through non-competitive funding streams.

10. Within ERN PaedCan this activity will be undertaken in partnership with SIOP Europe through relevant large and medium scale meetings and events dedicated to sharing, exchanges and dissemination of knowledge, data, best practice evidence, and clinical expertise within and outside of the network.

Annex 2 – Recommended Quality Standards for application to National Rare Cancer Networks (RCN) for adult rare cancers (see note 1 for paediatric cancers which have a more limited application in these recommendations).

1. Governance and Co-ordination
1.1 The RCN has a Board of Directors which provides the ultimate Governance of the strategy, policy and activities of the Network.
1.2 The Board of the RCN contains representatives from each HCP Member of the Network, or else representatives by election, including patient representatives.
1.3 The role and terms of reference of the Board are clearly defined and documented in a set of governance policies, rules and procedures.
1.4 The criteria to become a Member of the RCN are clearly defined; new Members are able to be admitted to the Network.
1.5 There is a RCN secretariat with the resources to co-ordinate the activities of the Network Guidance: activities could be conferences, board meetings etc.
1.6 The RCN Board monitors the activity, outcomes and initiatives of the Network and its HCP members in regard to their specific, predefined roles.
1.7 The RCN defines minimum clear criteria per rare cancer family which define the eligibility to be an HCP Hub or Centre of Reference within the Network according to national/international regulations or best practice. Guidance: • Criteria may relate to volume • The Network should determine whether these minimum criteria are defined by HCP or by treatment modality to ensure quality • Minimum patient numbers for a rare childhood and adolescents cancer entity is not an appropriate criterion for HCP eligibility.
1.8 The RCN has a Strategic Plan covering a 3-5 year period. Guidance: The Strategic Plan may include: 1) Assurance of the sustainability of the network (e.g. financing, education) 2) Research Strategy. 3) Risk management. 4) Improvement of patients' care pathways. 5) Policy making. 6) Integration of new members
1.9 The RCN Board agrees an Annual Budget and resource allocation. Guidance: Resources could be people, conferences, websites etc
1.10 The RCN Board has established mechanisms to incorporate the voice and opinions of patients and families through nominated patient representatives at each level of the RCN.
1.11 The RCN Board delegates to expert groups in the network adoption of clinical guidelines to be used for patients in all phases of patient management. Guidance: It is recommended that there should be a mechanism to harmonize national guidelines by reference to the relevant ERN.
1.12 The scope and coverage of the RCN is defined in terms of the geographical area covered, the rare cancers included, and the HCP Members of the Network.
1.13 The RCN is authorised by the relevant national Ministry of Health or its HCP members are otherwise commissioned to provide rare cancer services.
1.14 The RCN is formally linked to the appropriate Cancer European Reference Networks (ERNs) so that patients can be referred into the ERN systems, and that the vision and purpose of the ERN can be fostered in the RCN.

2. Patient-centeredness
2.1 Patients and patients' representatives are actively involved in planning and monitoring of the strategic activities of the RCN. Examples are: involvement in the Board to define policies, strategies and improvement plans (e.g. reviewing research outputs), reviewing pathways, improving referral procedures, communication.
2.2 The RCN promotes the practice of written patient pathways based on the needs of patients, clinical evidence, and best use of resources. Guidance: • Patient pathways should be regularly reviewed and updated (ideally every 3 years) • Definition of Patient pathway: A patient pathway is a plan for decision-making and organisation of diagnostic and care processes for a well-defined group of patients in well-defined stages, beginning with first suspicion of cancer to survivorship/follow-up or end of life. This is distinct from a "care plan" which is personal to an individual patient.
2.3 The RCN promotes the practice that patients' experiences and satisfaction are regularly collected by HCPs; the information is used by the network to take strategic decisions.
2.4 The RCN promotes the practice that HCPs have processes to ensure that at all times in the pathway it is clear which physician and which HCP has the responsibility for the care of the patient, and contact details are provided to patients.
2.5 The RCN HCP members actively involve patients in shared decision-making concerning their own treatment plans.
2.6 The RCN promotes the practice that its HCP members have policies and procedures for ensuring the holistic care of patients (including paediatric patients) and their care providers from the beginning of the diagnostic process throughout the whole survivorship span, including rehabilitation or end of life.
2.7 Information about the members of the Network and all relevant patient pathways is sufficient to enable patient access to the Network.

3. Multi-disciplinary Approach
3.1 The RCN ensures that Multi-disciplinary Teams (MDTs) covering each family of rare cancers covered by the RCN are operational in the relevant HCPs.
3.2 The RCN obtains confirmation from all its HCP members that **every** rare cancer patient is discussed in the appropriate MDT.
3.3 The RCN ensures that HCP MDT meetings follow defined criteria about documentation and communication for care delivery Operational Guidelines: • All relevant data are available to members of the MDT in a timely manner • The MDT has digital access to an expert pathological and radiological analysis based on the rare cancer specific criteria • The conclusions and recommendation resulting from the MDT meeting are documented in the medical record of the patient • The inclusion of patients in clinical trials is a structural formal aspect of each MDT meeting • According to a defined procedure, the conclusions and recommendations resulting from the MDT are communicated to the patient • According to a defined procedure, the implementation of the MDT decision recorded in the patient's file is designated to a named responsible person • Patient care decisions in the MDT comply with clinical guidelines unless a deviation is deliberately chosen.

• Deviations from agreed guidelines, and treatment decisions where no guidelines are available for very rare cancers, are clearly documented and re-evaluated.
3.4 The RCN defines mandatory and case specific representation of medical and clinical disciplines in each MDT to ensure optimal patient management.
3.5 Each HCP has electronic patient records (EPRs) which record all the data of diagnosis, treatments, side effects, appointments, communications and follow-up.
3.6 In compliance with the national General Data Protection Regulation, appropriate data from the Electronic Patient Record can be shared with RCN databases.
3.7 The number of rare cancer patients discussed in MDT meetings are reported annually to the RCN.
3.8 The RCN promotes the practice that each HCP MDT reviews best practice evidence in a Learning Event periodically (Ideally annually). Guidance: • Where appropriate, reviews of best practice evidence, and updating protocols are made in conjunction with Patient Representatives • The Agenda for Learning Events should include outcome measurements and regular departure from clinical guidelines.

4. Quality Assurance
4.1 The RCN uses an agreed set of performance and risk indicators.
4.2 The RCN promotes the practice that each HCP has a system in place to regularly monitor and report performance and risk indicators and to construct an improvement plan based on the reports.
4.3 The RCN promotes the practice that each HCP has a procedure in place to report, document and learn from adverse events and complications. The HCP uses this information to make ongoing improvements.
4.4 The RCN has minimum volume requirements for key procedures, where appropriate in context.
4.5 The RCN ensures implementation of agreed clinical guidelines among its HCPs for every type of rare cancer.

5. Research
5.1 The RCN has a Research Board to promote basic, translational and clinical research into all fields of rare cancers within the scope of the RCN. Guidance: • The scope of research could include prevention, detection, treatment, rehabilitation, economic and social studies, outcomes and epidemiology • "Research" includes also innovation • The Research Board should report annually to the RCN Board
5.2 The RCN specifically promotes the creation of new investigator-initiated and commercial clinical trials and observational studies for Rare Cancers.
5.3 Publications by the RCN with HCP members collaborating together are regularly achieved in peer reviewed journals.
5.4 The results of RCN-based research are made available in accessible language(s) for patients and the public
5.5 The RCN makes publicly available comprehensive and accessible information about open clinical trials
5.6 The RCN has access to a virtual database of biosamples in rare cancers Guidance: The virtual database should provide anonymised linking with the clinical data of the patient.
5.7 The RCN has an independent Scientific Advisory Board composed of internationally renowned scientists in rare cancers to advise on the progress of the RCN in research. Guidance: • The Scientific Advisory Board meets the RCN at least every 2 years to critique the strategy and progress of network research. • In some cases the relevant ERN may have a role in scientific advice.

6. Training, Development and Education
6.1 The RCN promotes oncology training and education in rare cancers (including conferences and educational events) for physicians, nurses, researchers, supportive disciplines, other relevant disciplines and patients.
6.2 Patient Education programmes and tools (including online tools) are available across the RCN to patients and their families Guidance: The RCN has educational activities to inform and empower patients and to improve patients' health behaviours and/or health status
6.3 The RCN has a policy on ensuring provision of general and disease specific patient education resources either at HCP level or RCN level. Guidance: These resources should be in all languages commonly spoken by patients in the RCN.

7. Networking and collaboration
7.1 The RCN gathers, exchanges, and disseminates knowledge, data, best practice evidence, and clinical expertise within and outside of the network.

7.2 The RCN has a policy of transparency to its members, patients and the public. Guidance: The Network should provide a report on a regular basis that is accessible and understandable for citizens which may include the following topics: the results of the quality and risk report of the network; Network goals and achievements; results of patient surveys; summarised patient outcomes; research developments and results.
7.3 The RCN has a communication plan and uses communication tools, taking into account the different languages spoken at national level. Guidance: The tools should *1)* support collaborations with other organisations *2)* promote the patient access to the RCN.
7.4 The RCN website enables access to clinicians, and to patients to be referred to the Network, and contains all relevant information about the Network HCP Members.
7.5 The RCN uses instruments to promote collaboration with other related RCNs.

8. Infrastructure and Data
8.1 The RCN provides information about where highly specialized diagnostic techniques and treatment can be accessed within the HCP Members of the RCN.
8.2 The RCN supports the establishment of disease-based shared registries and databases, including for diagnoses and outcomes.
8.3 The RCN maintains a shared system that allows real time confidential submission and review of clinical information, including histopathology, radiology, and medical imaging by all Network Members.

Note 1 – Paediatric Cancers. National and European networks for childhood cancers are in place and are complemented by the activities of the ERN PaedCan, as childhood cancer activities are based on cross-border collaborations through clinical trials. Within Members States, co-ordinating hubs on the HCP level are in place and interact collaboratively on the European scale and beyond. For the majority of childhood cancer entities, innovation and research activities require a reach beyond national borders to achieve relevant numbers, and many of the structures outlined below as RCN are ongoing on a European collaborative level rather than being limited to national activities.

Annex 3 – 18 Quality Indicators agreed by the ERN Monitoring Group for ERNs (as at March 2019)

ERN basic set of 18 Indicators		
Nº	**Indicator**	**Definition**
Obj 1	**To ensure that ERNs are operational**	
1.1	Within an ERN, the number & percentage of Member States with full Health Care Providers as members	*Within a particular ERN, the total number of Member States with at least one full Health Care Provider member within that ERN, also shown as a percentage of the total number of Member States with the EEA covered by Directive 24/201 (currently 29)..*
1.2	Number of Health Care Providers represented in the ERN	*The total number of full Health Care Providers within the ERN.*
1.3	Number of affiliated partners (AP) represented in the ERN	*The total number of affiliated partners (APs) within the ERN.*
1.4	Number of patient organisations represented in the ERN meetings	*The total number of recognised patient organisations [1]represented within ERN meetings as agreed by the ERN Board.*
Obj 2	**To improve access to clinical advice, diagnosis, treatment and follow-up of patients within the ERNs**	
2.1	Total number of new patients referred to Health Care Providers with diseases / conditions that fall within the scope of the ERN	*The total number of new patients referred to the ERNs' Health Care Providers within the specified timeframe whose disease/condition falls within the codes listed[2].*
2.2	Number of patients entered into CPMS (total volume)	*The total number of unique patients entered into CPMS within the specified timeframe for that ERN.*
Objective 3	**To optimise patient outcomes by combining healthcare professionals' skills & resources used**	
3.1	Number of patients entered into CPMS and reviewed by the ERN (a panel case review)	*The total number of patients who have been entered into CPMS within the specified timeframe and whose case is subsequently reviewed by a panel that consists of at least three experts or for bilateral consultation between two experts.*
3.2	Time taken to provide multidisciplinary clinical advice - non-urgent cases: days (median) between referral to ERN and multidisciplinary clinical advice	*The days (expressed by the median) for the time period specified between the date of enrolment of a new patient to CPMS[3] and the date of issue of multidisciplinary clinical advice [4](i.e. panel closure) from the created panel for that same patient, where at least three experts have participated or for bilateral consultation between two experts.*
Objective 4	**To increase capacity of professionals to recognize and manage cases of rare and complex conditions and diseases within the scope of the ERN**	
4.1	Number of educational webinars aimed at healthcare professionals delivered by the ERN	*The total number of educational webinars[5] aimed at healthcare professionals created and delivered on an*

[1] Patient organisations are defined as not-for profit organisations which are patient focused, and whereby patients and/or carers represent a majority of members in governing bodies. Each ERN Board will define the type of and the number of meetings where Patients Representatives are expected to participate.

[2] The disease should be preferably confirmed at the moment of the data inclusion by using, in principle, the same codes as those specified in the ERNs disease-area breakdowns. Depending on the particularities of some diseases, patients still under diagnosis process could be included as referred patients.

[3] Creation of a patient record in CPMS and invitation of experts to a panel to review this case

[4] CPMS outcome report created and sent to the treating clinician ie the clinician who is responsible for treating the patient in the Member State where the patient lives.

[5] Webinar is a seminar conducted over the internet

		appropriate platform by the ERN within the specified time period.
4.2	Number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN	*The total number of formal educational activities (i.e. those accruing higher educational credits) aimed at healthcare professionals organised by the ERN within the specified time period.*
Objective 5	**To reinforce clinical research in the field of rare and complex conditions and diseases by collecting data and carrying out research activities**	
5.1	Number of Clinical Trials or Observational prospective studies (with > 1 Member State and Health Care Provider within the ERN)	*The total number of Clinical Trials or Observational Prospective Studies within the specified time period that involve at least two Health Care Providers of two different Member States within the ERN.*
5.2	Number of accepted peer-reviewed publications in scientific journals regarding disease-groups within the ERN and which name the ERN	*The total number of accepted peer-review publications in scientific journals regarding disease-groups within the ERN and within the specified time period. Publications should be PubMed accredited scientific journals and involve as major contributors at least two Health Care Providers of two different Member States within the ERN, and which specifically name the ERN.*
Objective 6	**To ensure that patients referred to ERNs have equal access to high and quality healthcare services**	
6.1	Number of Clinical Practice Guidelines adopted for diseases within the scope of the ERN	*The total number of Clinical Practice Guidelines (CPG)[7] adopted for diseases within the scope of the ERN, according to evidence based recognised methodology.*
6.2	Number of new Clinical Practice Guidelines written by the ERN	*The total number of new Clinical Practice Guidelines (CPG)[6] developed by the ERN for diseases within the scope of the ERN where no guidelines existed previously, according to evidence based recognised methodology.*
Objective 7	**To guarantee that knowledge is spread outside the ERN so that more people can benefit from the ERN activities**	
7.1	Number of congresses/ conferences/ meetings at which the ERN activities and results were presented	*Within the specified time period, the total number of congresses/ conferences/ meetings at which the ERN activities and results were presented via a dedicated slot in the programme/agenda.*
7.2	Number of individual ERN website hits	*The total number of page views including both the homepage of the website and the "child" pages.*
Objective 8	**Complex and long-term indicators which need further development**	
8.1	Level of patient satisfaction	*To be developed*
8.3	Health Care Provider Compliance to Clinical Guidelines	*To be developed*

Annex 4 – Recommended supplemental cancer-specific Quality Indicators for adult Cancer ERNs

Outcome Indicators*

Not directly applicable to ERN PaedCan, please see footnote

1 year survival of network patients in each rare cancer family and in sub-types according to RareCare groupings.	*Answer is a percentage*
5 year survival of network patients in each rare cancer family and in sub-types according to RareCare groupings.	*Answer is a percentage*
30-day mortality after primary surgery of network patients for each rare cancer family	*Answer is a percentage. The ERN may limit these data to particular rare cancers*
30/90-day unexpected re-admission of network patients after therapy for each rare cancer family	*Answer is a percentage. The ERN may limit these data to particular rare cancers*
***ERN PaedCan:** In paediatric haemato-oncology, outcome parameters are rather considered on 5- and 10-year time scale. Primary surgery is not a common approach in solid tumors in the paediatric population. Unexpected readmission is not directly applicable as an outcome indicator in childhood cancer.	

Annex 5 – Recommended Quality Indicators for application to National Rare Cancer Networks for adult rare cancers (see note 1 for paediatric cancers which are not specifically covered in these recommendations)

The overall recommendation would be for annual collection of

these data <u>Structural Indicators</u>

S1: Number of HCPs in the RCN, and the geographical population covered	*It is left to the RCN to define its Members between specialist Centres of Reference and others*
S2: The number of patients newly treated in each disease area by the RCN in the year (A)*	*It is necessary to de-duplicate for patients who are treated in several HCPs*
S3: Number and topic of ongoing shared research projects in rare cancers in the RCN	*RCN level*
S4: Amount of new research grant funding in rare cancers (each HCP and the RCN) in the year	*At HCP and RCN levels*

<u>Process Indicators</u>

P1: The percentage of patients with a specific rare cancer type who are fully discussed in an MDT within the RCN (related to the total number of patients with this cancer).	*The denominator would have to be established be reference to calculated epidemiology for the geographical area, and compared to the numbers of new treatments in the RCN.*
P2: Number of **new** consensus clinical guidelines written by the RCN in the year.	
P3: Number of consensus clinical guidelines agreed for adoption by the RCN in the year.	
P4: Number of formal educational activities (i.e. those accruing higher educational credits) aimed at professionals organised by and within the scope of RCN in the year	
P5: Number of new trials and studies opened in the year (analysed as: observational, interventional, prospective, retrospective, all).	*At HCP and RCN levels*

P6: Number of patients recruited to rare cancer trials in the year in the RCN (all, observational, interventional) (B)*	*At HCP and RCN levels*
P7: Percentage of all new rare cancer patients newly- treated in the Network recruited to RC trials in the year (B/A)*	*At HCP and RCN levels*
P8: Average waiting time from first referral to an HCP to the point of being discussed at the MDT.	*The starting point of this measurement would need to be defined by the RCN: When the patient first enters the network by referral? Date of biopsy/radiology? First histological diagnosis? At HCP and RCN levels.*
P9: Average waiting times from MDT discussion to the point of primary treatment.	*At HCP and RCN levels*
P10: Number of accepted peer-reviewed publications in scientific journals in the year regarding disease- groups within the RCN and which name the RCN.	*Explanation: Publications should be: PubMed accredited scientific journals, list in the affiliations at least two Health Care Providers belonging to the RCN, and which specifically name the RCN in the front page (e.g. title, authors, abstract, affiliations). RCN level.*
P11: Number of educational activities for patients, families, patient representatives and patient organisations organised by the RCN.	*RCN level.*

Note 1. The paediatric haemato-oncology sector organisation in Europe is rarely restricted to the national level. Rather, a national structure is consistently part of a European concept/activity embedded within the European Clinical Trial Groups.

Outcome Indicators

O1: 1 year survival of network patients in each rare cancer family and in sub-types according to RareCare groupings.	*Answer is a percentage. RCN level.*
O2: 5 year survival of network patients in each rare cancer family and in sub-types according to RareCare groupings.	*Answer is a percentage. RCN level.*
O3: 30-day mortality after primary surgery of network patients for each rare cancer family.	*Answer is a percentage. The RCN may limit these data to particular rare cancers.*
O4: 30/90-day unexpected re-admission of network patients after therapy for each rare cancer family.	*Answer is a percentage. The RCN may limit these data to particular rare cancers.*

PROJECT PLAN WP 5.2

Task 5.2 – Survey of existing QA best practice

Rev 3 – 08/03/2017

1 DESCRIPTION-SUMMARY

"Task 5.2. Perform **a survey of existing quality assurance programs** on **quality of care for rare cancers**, and **systems based criteria for centres of excellence** and for **networks of care**.

The survey will then **be analysed for the quality and effectiveness** of those programmes.

This will draw on the outputs of the RARECAREnet project; the experience of the OECI Quality Assurance Framework and those of Member States, and the newly established operational quality criteria for the assessment of ERNs, implementing the EU Directive on Patients' Right to Cross- Border Healthcare.

Lead Partner: OECI (and its affiliated organisations: the Cambridge Cancer Centre, IKNL, CRO Aviano), working with Institut National du Cancer, EURORDIS, ECPC, SIOPE and OOI. Institut National du Cancer and OOI will provide support on French and Hungarian systems of quality assurance and draw on WP5 (Benchmark tools piloting, external review) in the Bench-Can project in which OOI is leading the piloting exercise.

EURORDIS with SIOPE will share their experiences on ERN quality systems."

D5.2 A framework of systems-based quality standards applicable to all networks and centres for rare cancers adding to ERN requirements (M30).

M5.2 Review completed (M12, Task 5.2)

What are we looking for

The survey should be focused specifically on:

- QA programs with specific focus on rare cancers
- Criteria for centers/networks of care specializing in rare cancers.

To achieve this task, we should filter/organize the information available, focusing on the following criteria:

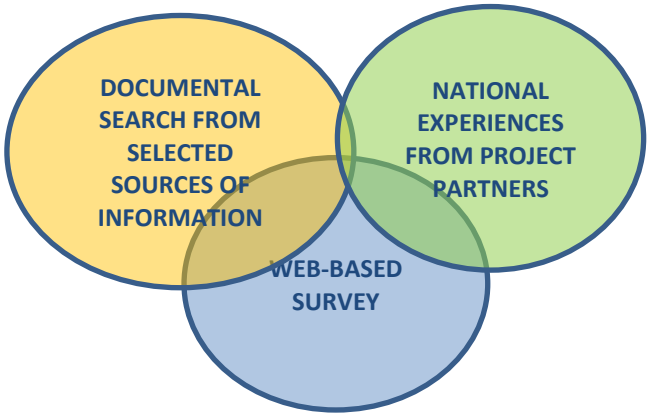
		
QA programs/models	Clinical practice Guidelines	Scientific Literature
National and international Accreditation systems/models	Clinical Protocols	Guidelines/Recommendations (eg article)
Standards manuals		

Networks criteria and standards		

The third column contains sources of information which will be considered in an explorative phase, but that shouldn't preferably be included if validated standards or models are available.

Survey – Data sources

The sources of information that will be used are the followings:



a) Documental search from selected sources of information: a review of the literature and a market research of the most relevant QA programs will be performed;
b) National experiences from project partners: this information will be collected via email. We will ask to recommend existing 'best practice' QA systems in cancer; Key partners, namely EURORDIS and SIOPE will also be contacted separately for an interview;
c) Web-based survey: in order to obtain a complete mapping, we might consider to set up a web-based survey that could be accessible from the institutional website or sent via e-mail to relevant contacts.

Contacts list

A database of contacts will be created. This list should include at least the followings:

CONTACTS	**Who can help with contact list?**
Project partners	JARC TL (INT)
OECI members	OECI secretariat
ERN members	INKL
Leaders of other existing networks	
International Accreditation/Standards bodies with active projects on rare cancers	

Mapping

The survey will cover as many countries as possible, according to the following priorities:

HIGH PRIORITY	national/EU experiences
HIGH/MEDIUM PRIORITY	USA/CANADA*
MEDIUM PRIORITY	Rest of the world

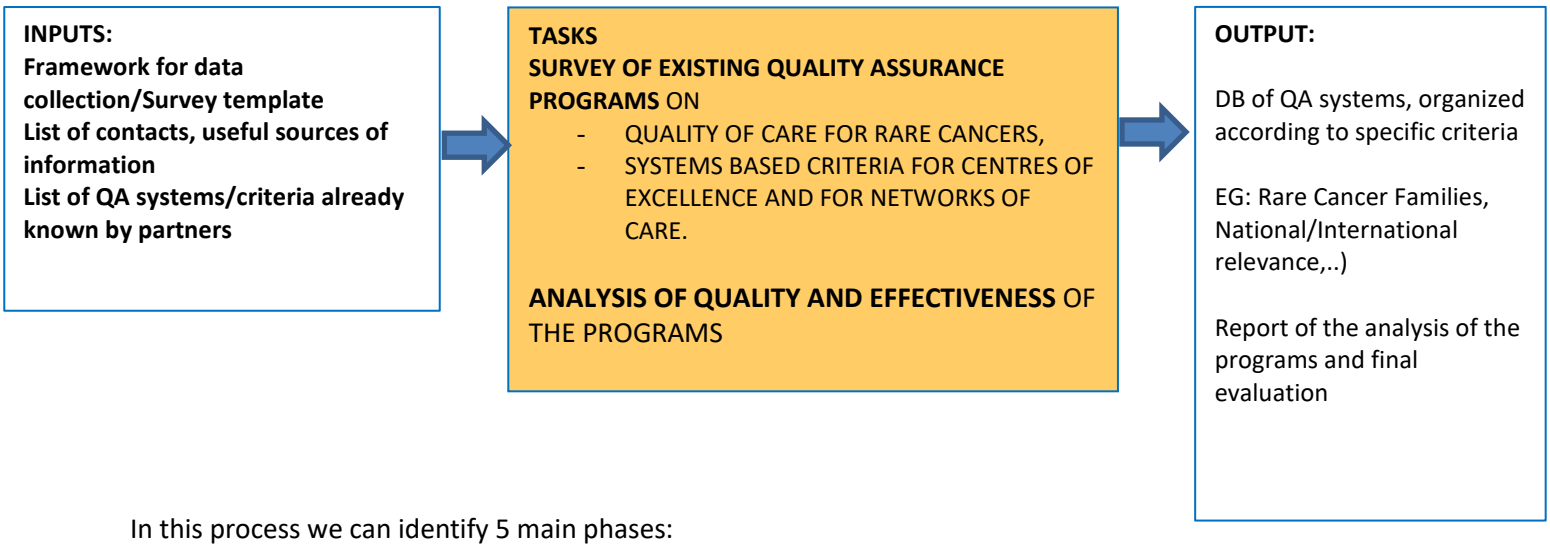
Nota bene: Accreditation Canada International was involved in the ERN project and contributed to the definition of the Network criteria.

Evaluation

The evaluation of the quality and effectiveness of the programs will be performed according to specific **indicators** and **criteria**, which will be defined according to the literature.

2 ORGANIZATION OF THE ACTIVITIES

The Task 5.2 will be developed according to the following process:



In this process we can identify 5 main phases:

1. Preliminary activities and planning
   - Identification of resources and know how
   - Definition of the project plan
   - Validation of the project plan with the WG

2. Definition of contacts/sources of information:
   - Mapping of main sources of information and prioritization according to specific criteria
   - Creation of a DB of contacts
   - Definition of the strategy to contact/reach the different targets

3. Definition of key items for DB:
   - Identification of the best tool to be used for the DB (this should integrate information which will automatically feed the DB through the web-based survey and should allow at the same time a manual data entry)
   - Define data and criteria required for the analysis
   - Set up of the DO

4. Survey:
   - Perform documental search
   - Create web-based survey
   - Perform survey according to phase 2
   - Data collection
   - Data translation in English as and if appropriate
   - Integrate the information collected through the different data survey

5. Analysis of the quality of the programs:
   - Analysis of the quality of the programs
   - Choice of best practice
   - Reporting

3 PLANNING

Phase	1	2	3	4	5	6	7	8	9	10	11	12
Preliminary activities and planning												
Definition of contacts/sources of information												
Definition of key items for DB												
Survey												
Analysis of the quality of the programs												

Annex 7 – Literature search on the Effectiveness of Health Networks

EFFECTIVENESS SYSTEMS – LITERATURE SEARCH

Networks, Organisational Learning and Knowledge management – NHS cancer networks. Public Money and Management 2006, 87-94.

Abstract

There has been increased interest in the UK in network-based modes of organizing in the public services, as opposed to markets or hierarchies. One supposed advantage of the network form is a greater capacity for the transfer of evidence-based or 'best' practices across the network and accelerated organizational learning. Such networks may have a knowledge management role and stimulate the formation of 'communities of practice'. This article tests these arguments using data from a study of managed NHS cancer networks in London. The general pattern was for networks to concentrate on structural reconfiguration, while their knowledge management role remained marginal. Some alternative implications for future policy development are considered.

PubMed Results

Items 1 - 97 of 97 (Display the 97 citations in PubMed)

1. BMC Health Serv Res. 2016 Aug 8;16:360. doi: 10.1186/s12913-016-1615-z.

The effectiveness of clinical networks in improving quality of care and patient outcomes: a systematic review of quantitative and qualitative studies.

Brown BB[1,2], Patel C[3], McInnes E[4], Mays N[2], Young J[2], Haines M[3,2].

Author information:

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4 Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, 15-17 Tavistock Place, London, WC1H 9SH, UK. liz.mcinnes@acu.edu.au.

Abstract

BACKGROUND:

Reorganisation of healthcare services into networks of clinical experts is increasing as a strategy to promote the uptake of evidence based practice and to improve patient care. This is reflected in significant financial investment in clinical networks. However, there is still some question as to whether clinical networks are effective vehicles for quality improvement. The aim of this systematic review was to ascertain the effectiveness of clinical networks and identify how successful networks improve quality of care and patient outcomes.

METHODS:

A systematic search was undertaken in accordance with the PRISMA approach in Medline, Embase, CINAHL and PubMed for relevant papers between 1 January 1996 and 30 September 2014. Established protocols were used separately to examine and assess the evidence from quantitative and qualitative primary studies and then integrate findings.

RESULTS:

A total of 22 eligible studies (9 quantitative; 13 qualitative) were included. Of the quantitative studies, seven focused on improving quality of care and two focused on improving patient outcomes. Quantitative studies were limited by a lack of rigorous experimental design. The evidence indicates that clinical networks can be effective vehicles for quality improvement in service delivery and patient outcomes across a range of clinical disciplines. However, there was variability in the networks' ability to make meaningful network- or system-wide change in more complex processes such as those requiring intensive professional education or more comprehensive redesign of care pathways. Findings from qualitative studies indicated networks that had a positive impact on quality of care and patients outcomes were those that had adequate resources, credible leadership and efficient management coupled with effective communication strategies and collaborative trusting relationships.

CONCLUSIONS:

There is evidence that clinical networks can improve the delivery of healthcare though there are few high quality quantitative studies of their effectiveness. Our findings can provide policymakers with some insight into how to successfully plan and implement clinical networks by ensuring strong clinical leadership, an inclusive organisational culture, adequate resourcing and localised decision-making authority.

PMCID: PMC5018194 **Free PMC Article**
PMID: 27613378
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6. JAMA Pediatr. 2015 Aug;169(8):709-10. doi: 10.1001/jamapediatrics.2015.0324.

Using Collaborative Improvement and Innovation Networks to Tackle Complex Population Health Problems.

McPherson ME[1], Gloor PA[2], Smith LA[1].
Author information:
1
National Institute for Children's Health Quality, Boston, Massachusetts.
2
MIT Center for Collective Intelligence, Cambridge, Massachusetts.
PMID: 26075524 [Indexed for MEDLINE]
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Did hospital engagement networks actually improve care?

Pronovost P[1], Jha AK.
Author information:
1
From the Armstrong Institute for Patient Safety and Quality, Johns Hopkins Medicine, and the Department of Anesthesiology and Critical Care Medicine, the Department of Surgery, and the Department of Health Policy and Management, Johns Hopkins University - both in Baltimore (P.P.): and the Department of Health Policy and Management, Harvard School of Public Health, the Department of Medicine, Division of General Internal Medicine, Brigham and Women's Hospital, and the Veterans Affairs Boston Healthcare System - all in Boston (A.K.J.).

Comment in

- Did hospital engagement networks actually improve care? [N Engl J Med. 2014]
- Did hospital engagement networks actually improve care? [N Engl J Med. 2014]

Free Article
PMID: 25140953 [Indexed for MEDLINE]
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26. BMC Health Serv Res. 2014 Jan 20;14:24. doi: 10.1186/1472-6963-14-24.

Improving accountability through alignment: the role of academic health science centres and networks in England.

Ovseiko PV, Heitmueller A, Allen P, Davies SM, Wells G, Ford GA, Darzi A, Buchan AM[1].
Author information:
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Medical Sciences Division, University of Oxford, John Radcliffe Hospital, Oxford OX3 9DU, UK. alastair.buchan@medsci.ox.ac.uk.

Abstract

BACKGROUND:

As in many countries around the world, there are high expectations on academic health science centres and networks in England to provide high-quality care, innovative research, and world-class education, while also supporting wealth creation and economic growth. Meeting these expectations increasingly depends on partnership working between university medical schools and teaching hospitals, as well as other healthcare providers. However, academic-clinical relationships in England are still characterised by the "unlinked partners" model, whereby universities and their partner teaching hospitals are neither fiscally nor structurally linked, creating bifurcating accountabilities to various government and public agencies.

DISCUSSION:

This article focuses on accountability relationships in universities and teaching hospitals, as well as other healthcare providers that form core constituent parts of academic health science centres and networks. The authors analyse accountability for the tripartite mission of patient care, research, and education, using a four-fold typology of accountability relationships, which distinguishes between hierarchical (bureaucratic) accountability, legal accountability, professional accountability, and political accountability. Examples from North West London suggest that a number of mechanisms can be used to improve accountability for the tripartite mission through alignment, but that the simple creation of academic health science centres and networks is probably not sufficient.

SUMMARY:

At the heart of the challenge for academic health science centres and networks is the separation of accountabilities for patient care, research, and education in different government departments. Given that a fundamental top-down system redesign is now extremely unlikely, local academic and clinical leaders face the challenge of aligning their institutions as a matter of priority in order to improve accountability for the tripartite mission from the bottom up. It remains to be seen which alignment mechanisms are most effective, and whether they are strong enough to counter the separation of accountabilities for the tripartite mission at the national level, the on-going structural fragmentation of the health system in England, and the unprecedented financial challenges that it faces. Future research should focus on determining the comparative effectiveness of different alignment mechanisms, developing standardised metrics and key performance indicators, evaluating and assessing academic health science centres and networks, and empirically addressing leadership issues.
PMCID: PMC3909383 **Free PMC Article**
PMID: 24438592 [Indexed for MEDLINE]
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29. Acad Pediatr. 2013 Nov-Dec;13(6 Suppl):S69-74. doi: 10.1016/j.acap.2013.07.004.

Pediatric collaborative networks for quality improvement and research.

Lannon CM[1], Peterson LE.
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Abstract

Despite efforts of individual clinicians, pediatric practices, and institutions to remedy continuing deficiencies in pediatric safety and health care quality, multiple gaps and disparities exist. Most pediatric diseases are rare; thus, few practices or centers care for sufficient numbers of children, particularly in subspecialties, to achieve large and representative sample sizes, and substantial between-site variation in care and outcomes persists. Pediatric collaborative improvement networks are multi-site clinical networks that allow practice-based teams to learn from one another, test changes to improve quality, and use their collective experience and data to understand, implement, and spread what works in practice. The model was initially developed in 2002 by an American Board of Pediatrics Workgroup to accelerate the translation of evidence into practice, improve care and outcomes for children, and to serve as the gold standard for the performance in practice component of Maintenance of Certification requirements. Many features of an improvement network derive from the Institute for Healthcare Improvement's collaborative improvement model Breakthrough Series, including focus on a high-impact condition or topic; providing support from clinical content and quality improvement experts; using the Model for Improvement to set aims, use data for feedback, and test changes iteratively; providing infrastructure support for data collection, analysis and reporting, and quality improvement coaching; activities to enhance collaboration; and participation of multidisciplinary teams from multiple sites. In addition, they typically include a population registry of the children receiving care for the improvement topic of interest. These registries provide large and representative study samples with high-quality data that can be used to generate information and evidence, as well as to inform clinical decision making. In addition to quality improvement, networks serve as large-scale health system laboratories, providing the social, scientific, and technical infrastructure and data for multiple types of research. Statewide, regional, and national pediatric collaborative networks have demonstrated improvements in primary care practice as well as care for chronic pediatric diseases (eg, asthma, cystic fibrosis, inflammatory bowel disease, congenital heart disease), perinatal care, and patient safety (eg, central line-associated blood stream infections, adverse medication events, surgical site infections); many have documented improved outcomes. Challenges to spreading the improvement network model exist, including the need for the identification of stable funding sources. However, these barriers can be overcome, allowing the benefits of improved care and outcomes to spread to additional clinical and safety topics and care processes for the nation's children.

PMID: 24268088 [Indexed for MEDLINE]
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Net benefits: assessing the effectiveness of clinical networks in Australia through qualitative methods.

Cunningham FC[1], Ranmuthugala G, Westbrook JI, Braithwaite J.
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Centre for Clinical Governance Research, Australian Institute of Health Innovation, Level 1, AGSM Building, University of New South Wales, Sydney, NSW 2052, Australia. f.cunningham@unsw.edu.au

Abstract

BACKGROUND:

In the 21st century, government and industry are supplementing hierarchical, bureaucratic forms of organization with network forms, compatible with principles of devolved governance and decentralization of services. Clinical networks are employed as a key health policy approach to engage clinicians in improving patient care in Australia. With significant investment in such networks in Australia and internationally, it is important to assess their effectiveness and sustainability as implementation mechanisms.

METHODS:

In two purposively selected, musculoskeletal clinical networks, members and stakeholders were interviewed to ascertain their perceptions regarding key factors relating to network effectiveness and sustainability. We adopted a three-level approach to evaluating network effectiveness: at the community, network, and member levels, across the network lifecycle.

RESULTS:

Both networks studied are advisory networks displaying characteristics of the 'enclave' type of non-hierarchical network. They are hybrids of the mandated and natural network forms. In the short term, at member level, both networks were striving to create connectivity and collaboration of members. Over the short to medium term, at network level, both networks applied multi-disciplinary engagement in successfully developing models of care as key outputs, and disseminating information to stakeholders. In the long term, at both community and network levels, stakeholders would measure effectiveness by the broader statewide influence of the network in changing and improving practice. At community

level, in the long term, stakeholders acknowledged both networks had raised the profile, and provided a 'voice' for musculoskeletal conditions, evidencing some progress with implementation of the network mission while pursuing additional implementation strategies.

CONCLUSIONS:

This research sheds light on stakeholders' perceptions of assessing clinical network effectiveness at community, network, and member levels during the network's timeline, and on the role of networks and their contribution. Overall, stakeholders reported positive momentum and useful progress in network growth and development, and saw their networks as providing valuable mechanisms for meeting instrumental goals and pursuing collaborative interests. Network forms can prove their utility in addressing 'wicked problems,' and these Australian clinical networks present a practical approach to the difficult issue of clinician engagement in state-level implementation of best practice for improving patient care and outcomes.

PMCID: PMC3541150 **Free PMC Article**
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Improving patient access to specialized health care: the Telehealth Network of Minas Gerais, Brazil.

Alkmim MB[1], Figueira RM, Marcolino MS, Cardoso CS, Pena de Abreu M, Cunha LR, da Cunha DF, Antunes AP, Resende AG, Resende ES, Ribeiro AL.
Author information:
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Telehealth Center, University Hospital, Universidade Federal de Minas Gerais, Belo Horizonte, Brazil.

Abstract

PROBLEM:

The Brazilian population lacks equitable access to specialized health care and diagnostic tests, especially in remote municipalities, where health professionals often feel isolated and staff turnover is high. Telehealth has the potential to improve patients' access to specialized health care, but little is known about it in terms of cost-effectiveness, access to services or user satisfaction.

APPROACH:

In 2005, the State Government of Minas Gerais, Brazil, funded the establishment of the Telehealth Network, intended to connect university hospitals with the state's remote municipal health departments; support professionals in providing tele-assistance; and perform tele-electrocardiography and teleconsultations. The network uses low-cost equipment and has employed various strategies to overcome the barriers to telehealth use.

LOCAL SETTING:

The Telehealth Network connects specialists in state university hospitals with primary health-care professionals in 608 municipalities of the large state of Minas Gerais, many of them in remote areas.

RELEVANT CHANGES:

From June 2006 to October 2011, 782,773 electrocardiograms and 30 883 teleconsultations were performed through the network, and 6000 health professionals were trained in its use. Most of these professionals (97%) were satisfied with the system, which was cost-effective, economically viable and averted 81% of potential case referrals to distant centres.

LESSONS LEARNT:

To succeed, a telehealth service must be part of a collaborative network, meet the real needs of local health professionals, use simple technology and have at least some face-to-face components. If applied to health problems for which care is in high demand, this type of service can be economically viable and can help to improve patient access to specialized health care.

PMCID: PMC3341691 **Free PMC Article**
PMID: 22589571 [Indexed for MEDLINE]
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52. BMJ Qual Saf. 2012 Mar;21(3):239-49. doi: 10.1136/bmjqs-2011-000187. Epub 2011 Nov 30.

Health professional networks as a vector for improving healthcare quality and safety: a systematic review.

Cunningham FC[1], Ranmuthugala G, Plumb J, Georgiou A, Westbrook JI, Braithwaite J.
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Abstract

BACKGROUND:

While there is a considerable corpus of theoretical and empirical literature on networks within and outside of the health sector, multiple research questions are yet to be answered.

OBJECTIVE:

To conduct a systematic review of studies of professionals' network structures, identifying factors associated with network effectiveness and sustainability, particularly in relation to quality of care and patient safety.

METHODS:

The authors searched MEDLINE, CINAHL, EMBASE, Web of Science and Business Source Premier from January 1995 to December 2009.

RESULTS:

A majority of the 26 unique studies identified used social network analysis to examine structural relationships in networks: structural relationships within and between networks, health professionals and their social context, health collaboratives and partnerships, and knowledge sharing networks. Key aspects of networks explored were administrative and clinical exchanges, network performance, integration, stability and influences on the quality of healthcare. More recent studies show that cohesive and collaborative health professional networks can facilitate the coordination of care and contribute to improving quality and safety of care. Structural network vulnerabilities include cliques, professional and gender homophily, and over-reliance on central agencies or individuals.

CONCLUSIONS:

Effective professional networks employ natural structural network features (eg, bridges, brokers, density, centrality, degrees of separation, social capital, trust) in producing collaboratively oriented healthcare. This requires efficient transmission of information and social and professional interaction within and across networks. For those using networks to improve care, recurring success factors are understanding your network's characteristics, attending to its functioning and investing time in facilitating its improvement. Despite this, there is no guarantee that time spent on networks will necessarily improve patient care.
PMCID: PMC3285140 **Free PMC Article**
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Development and implementation of a performance measure tool in an academic pediatric research network.

Stanley R[1], Lillis KA, Zuspan SJ, Lichenstein R, Ruddy RM, Gerardi MJ, Dean JM; Pediatric Emergency Care Applied Research Network (PECARN).
Collaborators: (77)
Kuppermann N, Alpern E, Borgialli D, Callahan J, Chamberlain J, Dayan P, Dean JM, Gerardi M, Gorelick M, Hoyle J, Jacobs E, Jaffe D, Lichenstein R, Lillis K, Mahajan P, Maio R, Moler F, Monroe D, Ruddy R, Stanley R, Tunik M, Walker A, Kavanaugh D, Park H, DeaN M, Holubkov R, Knight S, Donaldson A, Zuspan S, Singh T, Drongowski A, Fukushima L, Kim E, Monroe D, O'Gara G, Rincon H, Tunik M, Zuspan S, Gorelick M, Alpern E, Borgialli D, Brown K, Cimpello L, Donaldson A, Foltin G, Moler F, Teach S, Jaffe D, Chamberlain J, Cooper A, Dayan P, Dean JM, Holubkov R, Mahajan P, Maio R, Mann NC, Shaw K, Walker A, Stanley R, Ehrlich P, Enriquez R, Gerardi M, Holubkov R, Jacobs E, Lichenstein R, Lillis K, Ruddy R, Shults M, Schalick W, Callahan J, Atabaki S, Burr J, Call K, Hoyle J, Ruddy R, Suhajda J, Schamban N.
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Abstract

BACKGROUND:

The Pediatric Emergency Care Applied Research Network (PECARN) is a federally funded multi-center research network. To promote high quality research within the network, it is important to establish evaluation tools to measure performance of the research sites.

PURPOSE:

To describe the collaborative development of a site performance measure tool "report card" in an academic pediatric research network. To display report card template information and discuss the successes and challenges of the report cards. DEVELOPMENT AND IMPLEMENTATION OF THE NETWORK PERFORMANCE MEASURE TOOL: The PECARN Quality Assurance Subcommittee and the PECARN data center were responsible for the development and implementation of the report cards. Using a Balanced Scorecard format, four key metrics were identified to align with PECARN's research goals. Performance indicators were defined for each of these metrics. After two years of development, the final report cards have been implemented annually since 2005. Protocol submission time to the Institutional Review Board (IRB) improved between 2005 and 2007. Mean overall report card scores for site report cards increased during this period with less variance between highest and lowest performing sites indicating overall improvement.

CONCLUSIONS:

Report cards have helped PECARN sites and investigators focus on performance improvement and may have contributed to improved operations and efficiencies within the network.

PMID: 20478406 [Indexed for MEDLINE]
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75. J Natl Compr Canc Netw. 2007 Oct;5(9):875-82.

Development and implementation of a medical oncology quality improvement tool for a regional community oncology network: the Fox Chase Cancer Center Partners initiative.

O'Grady MA[1], Gitelson E, Swaby RF, Goldstein LJ, Sein E, Keeley P, Miller B, Li T, Weinstein A, Cohen SJ.
Author information:
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Abstract

Fox Chase Cancer Center Partners (FCCCP) is a community hospital/academic partnership consisting of 25 hospitals in the Delaware Valley. Originally created in 1986, FCCCP promotes quality community cancer care through education, quality assurance, and access to clinical trial research. An important aspect of quality assurance is a yearly medical oncology audit that benchmarks quality indicators and guidelines and

provides a roadmap for quality improvement initiatives in the community oncology clinical office setting. Each year, the FCCCP team and the Partner Medical Oncologists build disease site- and stage-specific indicators based on National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology. Concordance with multiple indicators is assessed on 20 charts from each community practice. A report for each FCCCP medical oncology practice summarizes documentation, screening recommendations, new drug use, and research trends in a particular disease site. Descriptive statistics reflect indicators met, number of new cases seen per year, number of disease site cases from tumor registry information, and clinical trial accrual total. Education and documentation tools are provided to physicians and oncology office nursing staff. The FCCCP Clinical Operations Team, consisting of medical oncologists and oncology-certified nurses, has conducted quality audits in medical oncology offices for 7 years using NCCN-derived indicators. Successful audits comprising gastric, colorectal, and breast cancer have been the focus of recent evaluations. For the 2005 stage II/III breast cancer evaluation, mean compliance per parameter was 88%, with 15 of 16 practices achieving mean compliance greater than 80%. A large-scale quality assurance audit in a community cancer partner network is feasible. Recent evaluation of localized breast cancer shows high compliance with guidelines and identifies areas for focused education. Partnership between academic and community oncologists produces a quality review process that is broadly applicable and adaptable to changing medical knowledge.

PMID: 17977500 [Indexed for MEDLINE]

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A controlled "before-after" study: impact of a clinical guidelines programme and regional cancer network organization on medical practice.

Ray-Coquard I[1], Philip T, de Laroche G, Froger X, Suchaud JP, Voloch A, Mathieu-Daudé H, Fervers B, Farsi F, Browman GP, Chauvin F.
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Abstract

A regional cancer network has been set up in the Rhône-Alpes region in France. The aim of the project is to improve the quality of care and to rationalize prescriptions in the network. In this network, we assessed the impact of the implementation of a clinical practice guidelines project by assessing the conformity of practice with the guidelines and comparing this with the conformity in an external matched control group from another French region without a regional cancer network. Four hospitals (private and public) accepted to assess the impact of the clinical practice guidelines on the management of breast and colon cancer in the experimental group and three hospitals (private and public) in the control group. In 1994 and 1996, women with non-metastatic breast cancer (282 and 346 patients in the experimental group, 194 and 172 patients in the control group, respectively) and all new patients with colon cancer (95 and 94 patients in the experimental group, and 89 and 118 patients in the control group, respectively) were selected. A controlled "before-after" study, using institutional medical records of patients with breast and colon cancer. The medical decisions concerning the patients were analyzed to assess their compliance with the clinical practice guidelines. When medical decisions were judged to be non-compliant, we verified if they were based on scientific evidence in a published article, if they were not, the medical decision was classified as having "no convincing supporting scientific evidence". The compliance rates were significantly higher in 1996 than in 1994 in the experimental group; 36% (126 out of 346) vs 12% (34 out of 282) and 46% (56 out of 123) vs 14% (14 out of 103) (P<0.001) for breast and colon cancer, respectively. Whereas, in the control group the compliance rates were the same for the two periods; 7% (12 out of 173) vs 6% (12 out of 194) (P=0.46) and 39% (49 out of 126) vs 32% (31 out of 96), P=0.19. In the experimental group, in 1994, 101 of the 282 medical decisions (36%) and 27 of the 103 (26%) for breast and colon cancer, respectively, were classified as having "no convincing supporting scientific evidence" compare with 72 out of 346 in 1996 (21%) for breast cancer, and 21 of the 123 (17%) for colon cancer P<0.05. Whereas in the control group these results were 106 out of 194 in 1994 (55%) and 90 out of 172 in 1996 (52%), P=0.65 for breast cancer and 28 out of 96 in 1994 (29%) and 30 out of 126 in 1996 (24%), P=0.36 for colon cancer. The development and implementation strategy of the clinical practice guidelines programme for cancer management results in significant changes in medical practice in our cancer network. These results would suggest that introducing guidelines with specific implementation strategy might also increase the compliance rate with the guideline and "evidence-based medicine".

PMCID: PMC2375218 **Free PMC Article**
PMID: 11875690 [Indexed for MEDLINE]

Similar articles

SCOPUS

1) Chubak, J.[a] , Ziebell, R.[a] , Greenlee, R.T.[b] , Honda, S.[c] , Hornbrook, M.C.[d] , Epstein, M.[e] , Nekhlyudov, L.[f] , Pawloski, P.A.[g] , Ritzwoller, D.P.[h] , Ghai, N.R.[i] , Feigelson, H.S.[h] , Clancy, H.A.[j] , Doria-Rose, V.P.[k] , Kushi, L.H.[j]
The Cancer Research Network: a platform for epidemiologic and health services research on cancer prevention, care, and outcomes in large, stable populations
(2016) *Cancer Causes and Control*, 27 (11), pp. 1315-1323.

DOI: 10.1007/s10552-016-0808-4

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Abstract
Purpose: The ability to collect data on patients for long periods prior to, during, and after a cancer diagnosis is critical for studies of cancer etiology, prevention, treatment, outcomes, and costs. We describe such data capacities within the Cancer Research Network (CRN), a cooperative agreement between the National Cancer Institute (NCI) and organized health care systems across the United States. Methods: Data were extracted from each CRN site's virtual data warehouse using a centrally written and locally executed program. We computed the percent of patients continuously enrolled ≥1, ≥5, and ≥10 years before cancer diagnosis in 2012–2015 (year varied by CRN site). To describe retention after diagnosis, we computed the cumulative percentages enrolled, deceased, and disenrolled each year after the diagnosis for patients diagnosed in 2000. Results: Approximately 8 million people were enrolled in ten CRN health plans on December 31, 2014 or 2015 (year varied by CRN site). Among more than 30,000 recent cancer diagnoses, 70 % were enrolled for ≥5 years and 56 % for ≥10 years before diagnosis. Among 25,274 cancers diagnosed in 2000, 28 % were still enrolled in 2010, 45 % had died, and 27 % had disenrolled from CRN health systems. Conclusions: Health plan enrollment before cancer diagnosis was generally long in the CRN, and the proportion of patients lost to follow-up after diagnosis was low. With long enrollment histories among cancer patients pre-diagnosis and low post-diagnosis disenrollment, the CRN provides an excellent platform for epidemiologic and health services research on cancer incidence, outcomes, and costs. © 2016, Springer International Publishing Switzerland.

Author Keywords
Cancer; Epidemiology; Health services; Integrated health care delivery systems

Document Type: Article
Source: Scopus

2) Archer, S.W.[a i] , Carlo, W.A.[b] , Truog, W.E.[c] , Stevenson, D.K.[d] , Van Meurs, K.P.[d] , Sánchez, P.J.[e f] , Das, A.[g] , Devaskar, U.[h] , Nelin, L.D.[f] , Petrie Huitema, C.M.[g] , Crawford, M.M.[g] , Higgins, R.D.[a]
Improving publication rates in a collaborative clinical trials research network
(2016) *Seminars in Perinatology*, 40 (6), pp. 410-417.

DOI: 10.1053/j.semperi.2016.05.003

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Abstract
Unpublished results can bias biomedical literature, favoring positive over negative findings, primary over secondary analyses, and can lead to duplicate studies that unnecessarily endanger subjects and waste resources. The Neonatal Research Network's (NRN) publication policies for approving, reviewing, and tracking abstracts and papers work to combat these problems. In 2003, the NRN restricted investigators with unfinished manuscripts from proposing new ones and in 2010, urged authors to complete long-outstanding manuscripts. Data from 1991 to 2015 were analyzed to determine effectiveness of these policy changes. The NRN has achieved an overall publication rate of 78% for abstracts. For 1990–2002, of 137 abstracts presented, 43 (31%) were published within 2 years; for 2003–2009, after the manuscript completion policy was instituted, of 140 abstracts presented, 68 (49%) were published within 2 years. Following the effort in 2010, the rate increased to 64%. The NRN surpassed reported rates by developing a comprehensive process, holding investigators accountable and tracking abstracts from presentation to publication. © 2016

Author Keywords
Authorship policies; Network collaboration; Publication rates

Document Type: Article
Source: Scopus

3) Brown, B.B.[a d] , Patel, C.[b] , McInnes, E.[c] , Mays, N.[d] , Young, J.[d] , Haines, M.[b d d]
The effectiveness of clinical networks in improving quality of care and patient outcomes: A systematic review of quantitative and qualitative studies
(2016) *BMC Health Services Research*, 16 (1), art. no. 360, . Cited 1 time.

DOI: 10.1186/s12913-016-1615-z

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Abstract
Background: Reorganisation of healthcare services into networks of clinical experts is increasing as a strategy to promote the uptake of evidence based practice and to improve patient care. This is reflected in significant financial investment in clinical networks. However, there is still some question as to whether clinical networks are effective vehicles for quality improvement. The aim of this systematic review was to ascertain the effectiveness of clinical networks and identify how successful networks improve quality of care and patient outcomes. Methods: A systematic search was undertaken in accordance with the PRISMA approach in Medline, Embase, CINAHL and PubMed for relevant papers between 1 January 1996 and 30 September 2014. Established protocols were used separately to examine and assess the evidence from quantitative and qualitative primary studies and then integrate findings. Results: A total of 22 eligible studies (9 quantitative; 13 qualitative) were included. Of the quantitative studies, seven focused on improving quality of care and two focused on improving patient outcomes. Quantitative studies were limited by a lack of rigorous experimental design. The evidence indicates that clinical networks can be effective vehicles for quality improvement in service delivery and patient outcomes across a range of clinical disciplines. However, there was variability in the networks' ability to make meaningful network- or system-wide change in more complex processes such as those requiring intensive professional education or more comprehensive redesign of care pathways. Findings from qualitative studies indicated networks that had a positive impact on quality of care and patients outcomes were those that had adequate resources, credible leadership and efficient management coupled with effective communication strategies and collaborative trusting relationships. Conclusions: There is evidence that clinical networks can improve the delivery of healthcare though there are few high quality quantitative studies of their effectiveness. Our findings can provide policymakers with some insight into how to successfully plan and implement clinical networks by ensuring strong clinical leadership, an inclusive organisational culture, adequate resourcing and localised decision-making authority. © 2016 The Author(s).

Author Keywords
Clinical networks; Delivery of healthcare; Health services; Health system planning; Implementation science; Organisation of healthcare; Quality improvement

Document Type: Review
Source: Scopus

6) Tremblay, D.[a b] , Touati, N.[c] , Roberge, D.[a b] , Breton, M.[a b] , Roch, G.[d e] , Denis, J.-L.[c] , Candas, B.[f] , Francoeur, D.[g]
Understanding cancer networks better to implement them more effectively: A mixed methods multi-case study
(2016) *Implementation Science*, 11 (1), art. no. 39, .

DOI: 10.1186/S13012-016-0404-8

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Abstract
Background: Managed cancer networks are widely promoted in national cancer control programs as an organizational form that enables integrated care as well as enhanced patient outcomes. While national programs are set by policy-makers, the detailed implementation of networks is delegated at the service delivery and institutional levels. It is likely that the capacity to ensure more integrated cancer services requires multi-level governance processes responsive to the strengths and limitations of the contexts and capable of supporting network-based working. Based on an empirical case, this study aims to analyze the implementation of a mandated cancer network, focusing on governance and health services integration as core concepts in the study. Methods/design: This nested multi-case study uses mixed methods to explore the implementation of a mandated cancer network in Quebec, a province of Canada. The case is the National Cancer Network (NCN) subdivided into three micro-cases, each defined by the geographic territory of a health and social services region. For each region, two local health services centers (LHSCs) are selected based on their differences with respect to determining characteristics. Qualitative data will be collected from various sources using three strategies: review of documents, focus groups, and semi-directed interviews with stakeholders. The qualitative data will be supplemented with a survey that will measure the degree of integration as a proxy for implementation of the NCN. A score will be constructed, and then triangulated with the qualitative data, which will have been subjected to content analysis. Qualitative, quantitative, and mixed methods data will be interpreted within and across cases in order to identify governance patterns similarities and differences and degree of integration in contexts. Discussion: This study is designed to inform decision-making to develop more effective network implementation strategies by thoroughly describing multi-level governance processes of a sample of settings that provide cancer services. Although the study focuses on the implementation of a cancer network in Quebec, the rich descriptions of multiple nested cases will generate data with a degree of generalizability for health-care systems in developed countries. © 2016 Tremblay et al.

Author Keywords
Cancer; Case study; Governance; Health-care integration; Implementation; Mixed methods; Network

Document Type: Article
Source: Scopus

22) Cassiman, J.-J.
Improving quality and harmonization of standards in clinical genetic services in Europe: The EuroGentest network of excellence
(2010) *Quality Issues in Clinical Genetic Services*, pp. 1-10.

DOI: 10.1007/978-90-481-3919-4_1

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Abstract
The most important contributions of the EuroGentest NoE can be summarized as follows: • European diagnostic labs are moving towards accreditation under ISO 15189, hereby helped by training workshops in quality management and accreditation; integration and harmonization of the three EQA schemes in Europe and new Best practice guidelines for the labs. The Orphanet database has been overhauled and expanded. It now also provides information on the degree of quality assurance of many registered labs • Gene cards containing information on the clinical validity and utility of 32 different molecular tests are available. Different aspects of the clinical utility of genetic tests have been critically analyzed • A technology platform for the validation of emerging technologies is in place and generic SOPs for the validation of these technologies have been drafted • A context-dependent definition of genetic testing, important for any official or legal document, is being finalized and a review of the legislation pertaining to patient's rights in each Member State is already available for 15 countries and minimal criteria for quality genetic counseling have been defined and tools to evaluate performance are available • Core competences for health professionals have been defined and leaflets explaining to families different aspects of a visit to a genetic clinic are freely available in 27 languages © Springer Science+Business Media B.V. 2010.

Author Keywords
EuroGentest; Genetic testing; Quality issues

Document Type: Book Chapter
Source: Scopus

NETWORKING LITERATURE ABOUT DETERMINANTS OF NETWORK EFFECTIVENESS

Authors

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- **First published:** 18 December 2009Full publication history
- **DOI:** 10.1111/j.1467-9299.2009.01791.xView/save citation
- **Cited by:** 75 articles

Citation tools

Abstract

Since the early 1990s, public networks have been implemented in many countries to solve 'wicked' public problems, addressing such issues as health, social care, local development and education. While considerable research has been carried out into public networks, both managers and scholars are left with some doubts about network effectiveness. In fact literature on this topic has been highly fragmented, comprising a plurality of definitions, multiple theories, multiple methods and multiple explanations. This paper aims to review and classify previous theoretical and evidence-based studies on network effectiveness and its determinants. Our aim is to rearrange existing literature into a unitary framework in order to shed light on both hitherto unfilled gaps and established theoretical cornerstones.