



# **Facilitating Networks of Expertise with Patient Support Groups**

## **Annual Report 2008/09**

## **Executive Summary**

The Facilitating Networks of Expertise (FNE) with Patient Support Groups Project has had a very successful first year. Of the numerous accomplishments this period has seen, the most noteworthy has been the project's ability to stimulate an open and continuous dialogue with each of the nine participant patient groups.

The versatility in this project's approach is indicative of the inherent complexities met when engaging voluntary groups in work of this nature. Four of the nine project groups are run by individuals who are directly affected by the rare genetic conditions of concern, and 'work' for the voluntary organisation in their 'spare' time. This situation often places restrictions on the amount of time and energy that can be dedicated to time-bound initiatives (such as FNE), and fairly insists that the project facilitators learn to juggle the work patterns of various groups whilst adhering to project objectives. Towards the other end of this spectrum, the remaining five (of the nine) groups do have paid staff and could therefore more readily manage the project's requirements in a linear fashion.

A comprehensive list of the FNE patient support group includes the following;

- The Ectodermal Dysplasia Society; supporting patients and families affected by Ectodermal Dysplasia
- HITS; supporting patients and families affected by Hypomelanosis of Ito
- FAP; supporting patients and families affected by Familial Adenomatous Polyposis
- Costello Kids; supporting patients and families affected by Costello Syndrome
- Neurofibromatosis Association; supporting patients and families affected by Neurofibromatosis (type 1 only)
- Rett Syndrome Association; supporting patients and families affected by Rett Syndrome
- Ataxia UK: patients and families affected by Inherited Ataxias
- Cavernoma Alliance; supporting patients and families affected by Cerebral Cavernous malformations
- Tuberous Sclerosis Association; supporting patients and families affected by Tuberous Sclerosis.

We would like the reader to note that since the original proposal was confirmed there have been changes made to the support groups GIG had intended to work with. Due to the time lapse between applying for funding and having it approved, the groups we first enlisted had each progressed to various degrees. One such group, The XP Support group, had come along quite some way in playing an active role within the commissioning of specialist services for patients with XP. It was decided that the project would consider other patient support groups that would benefit from participating in a project of this kind, and as a result The Ectodermal Dysplasia Society and HITS support group were invited to partake.

The project's main activities over the course of this year can be categorised within the four central themes seen below:

*Working across all stakeholder groups; acknowledging that if care is to be truly integrated then all key organisations need to be involved right from the start with the designing and delivering of effective pathways, this was made a main priority. This focused on determining the various stages at which each stakeholder group would*

need to be consulted and the most effective way in which to facilitate this. By attuning the FNE's objectives within this stakeholder framework, the project's work stream was able to move from the conceptual rationale (outlined in the original proposal) towards operationalised and viable tasks for each stakeholder to address.

*Engaging patients;* through the use of questionnaires, focus groups and interviews, the FNE project has created opportunities for patients and families to share their experiences of healthcare services they currently receive. These activities have also helped to raise the awareness of projects work permitting patients to express their opinions and influence the way in which objectives were implemented.

*Consulting clinicians;* utilising the database of clinicians already affiliated with the condition groups enabled the project team to commence meetings with 'expert clinicians' identifying individuals who could potentially champion the forthcoming networks.

*Documenting activity;* The information gathered from each of these undertakings has been collated and will be used to inform the development of the forthcoming networks.

The points listed above have assured a firm foundation upon which to build the networks in the following year. This report presents a systematic review of the work undertaken this project year, whilst assessing the extent to which each of the objectives has been achieved and methods employed to do so.

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## Establishing Networks: Learning From Existing Models

Coordinating a project of this scope requires a diligent project team adept in acknowledging the utility of information and guidance provided by organisations with experience of undertaking similar work. In line with this 'do once and share' ethos, FNE sought to learn from GIG members who already had established Networks of Expertise.

The project identified five of our member groups we deemed suitable for such *mentoring*; namely The Cystic Fibrosis Trust; Primary Ciliary Dyskinesia; Sense UK; Alstrom UK; and Niemann Pick Disease Support group. Meetings with these groups were staggered over the project's first four to five months. This allowed information to be collected at a steady pace and ensured the data could be meaningfully applied to the FNE endeavours.

In an effort to offer a consistent and structured approach to the information gathered, a semi-structured interview schedule was developed and used to guide all discussions. Please refer to Appendix A to review an example of the interview format.

Our initial research enabled the project to observe the practical application of the network theory. From these observations, the project team were able to begin constructing a skeletal framework highlighting the fundamental issues the FNE networks may need to address. These are outlined below;

- *Network initiation*; each of the networks began with some form of initiation- albeit formal or informal. The common practice, evidenced within each of the groups was the identification and invitation of all key stakeholders to contribute to this initial formation.
- *Agreeing the overall purpose of the network*; recognising what areas of work/clinical practice to focus on whilst acknowledging the limitations imposed by a lack of resources- as was often seen to be the case. A mission statement clearly outlining the terms of reference between constituent groups is usually agreed upon.
- *Network evolution*; Within the groups we consulted there were three distinct ways in which the networks developed; these can be classified as (1) Patient led (2) Clinician driven (3) Research inspired
- *Identifying areas of collaboration*; this consideration is inherently derived from consideration of the previous two points made. Two of the networks studied focused on one particular area of collaboration (i.e. diagnostics and standards of care). Identifying synergies across constituent groups seemed to provide an impetus for a concerted approach that would benefit all stakeholders.
- *Network coordinators*; this denotes the individual/s that act as the intermediaries at the interface of different agencies involved. Crucially, these named individuals will manage the inter-organisational, inter-professional relations. In the case the five networks we observed, this key enabler took the form of a lead clinician, specialist nurse or a representative from the patient support group. It is important to note this role was deemed essential to the ongoing effectiveness of the networks as this individual often served to harnesses the efforts of all parties concerned.

The list above is not comprehensive as a seasoned observer of other clinical networks might recognise. Its value lies in its ability to provide a 'checklist' for the FNE groups to contemplate in the nascent stages of their network development.

## **Current levels of Patient involvement in existing Networks of Expertise**

In order to gauge the current level of patient representation within the formation of clinical networks, the project employed a bilateral approach when implementing the survey for GIG members. With the intention of generating both quantitative and qualitative data, the project separated the GIG members who were selected to participate in the project from those who were not (denoted as our 'general members'). General members received a broader questionnaire which was designed to produce an overview detailing the number of patient support groups working with networks of excellence and their views on their potential benefits and disadvantages (please see Appendix B).

Within this faction, it is important to note that the representatives of the patient support groups responded to the questions on the behalf of their members. The focus of this enquiry was based on the organisations' experiences of using networks, where they existed. They were given a description of a network being 'linked groups of health professionals from across all sectors of health care who work in a coordinated manner to ensure equitable provision of high quality and clinically effective services', and asked whether they were currently working with clinicians in this way.

Although only 52% of the groups reported having practical experience of working within a network, a unanimous 100% expressed an emphatic support for this working model. Some of the benefits, as expressed by these representatives have been captured below;

"A network of Specialist Clinicians is absolutely ESSENTIAL given the wide range of complex, specialist & unpredictable aspects of Neurofibromatosis"

"Consistent care plans and genetic counselling irrespective of where patient lives or which centre they attend"

"Sharing of expertise and best practice guidelines"

"Perhaps a reduction in the 'postcode lottery' problems in care for this condition? The chance for the clinicians to use the group for research purposes?"

"Can work on an international basis with other centres of excellence to advance knowledge of the disease. Can work collaboratively internationally towards clinical trial. Of especial value with a rare disease. "

"The national access to services will be helped by the clinicians advising their experiences"

While it is not feasible to present all of the comments specific to each respondent, by way of collating data we were able to categorise comments which appeared to share common thread, and go on to extrapolate the key emergent themes. These were as specified below:

- Pooling of information and expertise specific to the condition
- Equity of access to services and expertise
- Consistent and agreed standards of care
- Facilitating research and increasing potential for clinical trials

When examining the disadvantages our members expressed we observed a subtle polarisation of opinion. Whilst 56% had no concerns whatsoever, 44% took a more critical approach- and commented;

*'Trying to see all the patients in one day may prove difficult. Also making sure you have all the specialists that are appropriate for our condition. I would imagine that it could take an awful lot of organising which is time consuming'*

*'The differences in service provision, care, and expertise means that queries can be very location specific so this expertise needs to be shared locally and links forged and shared with the initiator of the enquiry'*

*'It can mean travelling a long way to be seen'*

*'By having such specialist centres it can mean less involvement for professionals in the community- then when they do get involved they have little knowledge.'*

Examining the whole body of evidence, one could deduce that although centres of excellence were thought to be the “gold standard” of care, patients were realistic about the logistical restraints on gathering so many health care professionals together. Further, respondents also seemed keen to ensure that their local health care practitioners were empowered with knowledge and skill needed to manage the day-to-day management of their respective genetic conditions.

In line with the feedback obtained, the FNE project will need to consider how best to ensure the devolution of care, where appropriate and effective whilst also acknowledging the limitations of local expertise.

## Measuring Patient Satisfaction with Centres of Excellence

GIG's ability to gauge the level of patient and family satisfaction with networks of excellence was a critical element in validating the rationale for this project. Due to the difficulties that come with asking patients to give their time and energy to engage in such work, the extent to which the project has been able to explore this has been limited. With that said, the information obtained presents coherent research findings that demonstrate unequivocal support for this work.

The FNE was able to guide two focus groups which facilitated focused discussion topics with Ataxia patients, family members and carers. Interestingly, not all the participants were aware of the Ataxia accredited centres- one of which is located within the National Hospital for Neurology in London and the other in Sheffield. Some of the comments with reference to these centres include,

*"... presumably the thing about it is, once you're in touch with that with that sort of centre they can refer you to the odd expert because your there and they know what is available or who the people are..."*

*"Who are the real Ataxia consultants- if there is any particular ones around the country- we need to know that- it's very important"*

*"I know there are so many Ataxia consultants... actual Ataxia, I know there's maybe six or ten... but we need to know where they are"*

When the discussion topic was focused on specialist centres and whether individuals were aware of expert Ataxia clinicians there appeared to be some tension between the participants and the facilitator (who was an Ataxia UK member of staff). This frustration seemed to arise from acknowledging that there were Ataxia specialist known to the support group and the participants wanted them to be a lot more forthcoming with this information. The persistent comment, 'we need to know who they are and where they are' appeared to resonate within the group, and reinforce the idea of self-advocacy when taking control of one's own care management- which had reflected in some of the previous comments.

In addition to our own research efforts, GIG are pleased that SENSE UK has shared patient feedback from their members who attended an Ushers clinic (a single clinic combining audiology, vision and genetic services) - the first of its kind. Of the one hundred and eighteen members who responded to their questionnaire, ninety-six percent were in favour of the single Usher Clinic, with ninety-two percent expressing their willingness to travel to London annually to attend it. Some of the comments shared included

*"I would be willing to attend a clinic in London if help available from mainline station to clinic"*

*"My local hospital has no idea – I think I'm their only Usher patient"*

*"People with Usher have specialised (and changing) needs which could be much better met through a single clinic"*

SENSE UK's evaluation of this feedback led them to propose,

*“Respondents to the questionnaire felt that a joint clinic would alleviate their current problems of receiving disjointed service in multiple locations, often from staff that are not Usher-aware”*

With that said the feedback also revealed reluctance from some members who did not wish to attend and central clinic and would rather receive their care at their hospitals. These comments included;

*“At our current hospital we know all the staff and feel happy so no change please”*

*“Travelling during winter daylight is an issue”.*

*“I would be willing to attend a clinic in London if help available from mainline station to clinic”*

By adopting a sensitive and critical evaluation of the feedback they received SENSE UK deduced the following essential issues to address if the single usher clinic were to be continued;

- “Selling” the benefits of a London location. People need to feel that the Usher expertise of London-based medical experts outweighs the inconvenience of travel.
- Ensuring the clinic lives up to its ‘one stop shop’ promise.
- If multiple appointments on different days are required, this will reduce the clinic’s appeal.
- Allowing patients the choice to remain with local services because attending the clinic should be an option, not a requirement.

This feedback reinforces the information obtained from the analysis of general members which indicated that longer journeys to centres of expertise were seen to be worthwhile as long as the healthcare provision offered at such centres were perceived as superior *and* all encompassing. Not-with-standing these acknowledgements, another main concern expressed highlighted the need for expertise and knowledge to be shared with clinicians at a more local level so to lessen the gap between the two, where this was possible.

## **Translational Research: Working with FNE Patient Groups**

In the project's first few months the FNE project officer began contacting each of the groups who had previously expressed an interest in partaking, and notified them that GIG had secured the funding permitting the project to go ahead. These groups were;

Rare dermatological conditions; including Xeroderma Pigmentosum and Tuberous Sclerosis.

Rare Cancer conditions; including Costello Syndrome and Familial Adenomatous Polyposis of the Colon (FAP).

Rare neurological conditions; including Neurofibromatosis, Rett Syndrome, Cavernous Angiomas and the inherited Ataxias.

Between the period of enquiring which GIG's members would be interested in participating in a project of this kind (when composing the project BID), and subsequently attaining the funding for this work, an eighteen month time lapse had ensued. During this time, the agendas of our original groups had inevitably moved on thus calling for the project to respond to their present needs and transformation in service provision. These changes are detailed below:

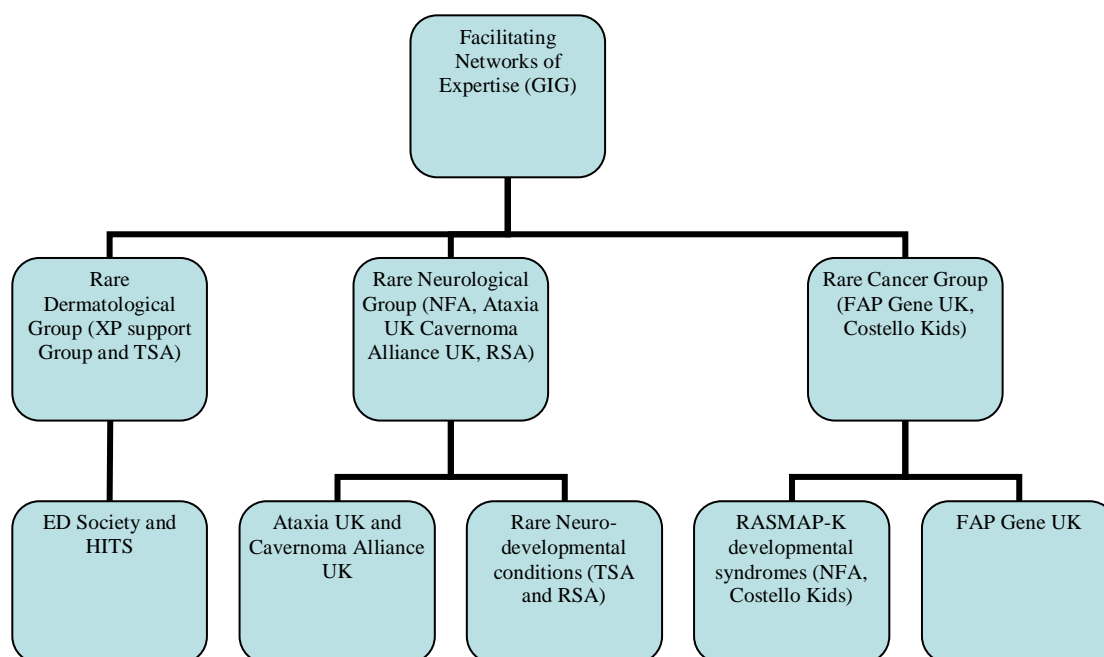
Rare Dermatological condition group; this group originally consisted of Xeroderma Pigmentosum (with the XP Support group representing this condition) and Tuberous Sclerosis (with the TSA representing this condition). With reference to the former, we were informed that since our funding application the group had begun developing a network of expertise with the potential National Commissioning Group (NCG) funding to establish two designated centres of excellence. With regards to the latter, having discussed our preliminary classification of the condition within the dermatological group, we decided that this categorisation misrepresented the complex as TSC is neuro-developmental condition which would most appropriately be aligned within the rare neurological grouping.

The aforementioned activity created a vacancy within this condition group and provided an opportunity for two new GIG members to get involved in this work. Having carefully considered two groups that would benefit from participating in the FNE and fit the criteria of representing a rare dermatological condition (deemed as 1 in 2000) the Ectodermal Dysplasia Society and HITS Support groups were selected.

Rare Neurological condition group; Following the change noted with the TSA above- this condition had been added to this group fairly early on in the project's first quarter. With this additional group, forming internal lines of similarities became much clearer- focussing on the neuro-developmental conditions- i.e. Rett Syndrome and Tuberous Sclerosis.

RasMapk condition group; following a meeting with a lead clinician championing the establishment of two National Commissioning Group funded centres for complex Neurofibromatosis type one and a geneticist heavily involved in Costello syndrome research, the FNE was enlightened about recent research of the RASMapk pathway (a genetic pathway mutation upon which Costello Syndrome and NF1 can be found). The work of the FNE has interested these clinicians who have advised us to align these two conditions in a separate network.

The subtle modifications made to each of the three condition groups can be seen in the schematic diagrams seen below:



Throughout the project's first year, the network configurations have continually evolved beyond our initial assumptions which anticipated three neatly categorised condition groups. The factors that have mediated these changes have been outlined below;

- The intra-group relations (i.e. how do the patient support group representatives relate to their members? what is the primary mode of support and communication?)
- The inter-group relations (i.e. across the parameters of specific disease classifications where are the potential commonalities? Where is the synergy between groups where partnership work across the classifications of specific genetic conditions can focus network objectives?)
- Was there an existing network (informal/formal) emerging?

The questions posed have been crucial to ascertaining the configuration of the network groups. They have also been used to stimulate discussions amongst specialist clinicians known to the FNE support groups. Although such meetings were not scheduled to commence until the project's second year, in light of the progress made with patient involvement we decided that such consultations were well placed.

These initial considerations will be revisited in Year two when patient representatives and clinicians from across the grouped conditions participate in workshops aimed at formulating the purpose of the forthcoming networks and developing the terms of reference for named stakeholders.

## **Conclusion: Closing thoughts and Next Steps for Year Two**

The objectives met during this project's first year have illuminated the complex yet coherent rationale for a networked approach to aspects of healthcare provision for individuals affected by rare genetic conditions. The multi-system complications that result often require patients to see many various clinicians for different symptoms and as one Ataxia patient very succinctly expressed "the problem may be that my condition overlaps several areas of expertise- dermatology, spinal problems and possibly neurology.

This body of information reiterates the persistent plea for joined-up service services that are integrated in a way which facilitates communication between the many different specialists one patient might need to see over a period of time.

'The whole is greater than its constituent parts'.

From the theoretical proposition of Gestalt, to its practical application, the challenge for the project's second year and our networks will be their ability to devise ways to engender this holistic approach to care in a way that is economical for commissioners, feasible for clinicians and crucially, the most effective care management for patients and families.

Next steps for the second year are very much in line with what GIG had envisioned in the original project proposal. These are detailed below:

- Clear objectives for each network will be developed. These objectives will be based on the information gathered in Year One.
- Forming networks of clinicians for particular disease areas will involve working closely with the Patient Support groups which in many cases have excellent medical contacts. The networks will be multi-disciplinary and the GIG Project Officer will act as the main contact point for all discussions and correspondence.
- Each network will have an inaugural meeting and workshop. This meeting will outline the terms of reference and plans for each group over the coming year and also agree interaction points through GIG. Further correspondence is likely to be facilitated by GIG using online forum and discussion boards and/or simultaneous phone calls (conference calls) between the members.
- GIG will encourage members of the network to attend patient conferences to highlight the work of the network. The Project Officer will also be available to do this.
- GIG will facilitate the Networks of Expertise on behalf of the patient support groups in this patient-led project.
- At the end of Year Two of the project, the Project Officer will prepare a progress report to ensure that the aims and objectives set out for the groups are being met.

## **Appendix A**

### **Semi Structured Interview - Professionals already working within a network/centre of excellence. Cystic Fibrosis Trust**

**Initiation; each network begins with some kind of initiation process involving selection and recruitment- how did this evolve? (Looking at the core roles and function of the network...)**

The network was born out of the Cf 'User Involvement' project which was designed in an effort to consolidate the work of the Trust in improving specialist services available to Cf Patients and families. The five Patient Advocates were based in one of the Cf Adult Specialist centres with their main duty being engaging the Patients and families within the designated region, acting as their advocate within the centre in which they were based. For the most part their involvement seemed to remain at a purely 'house keeping' level (issues such as hospital parking, and dissatisfaction with the quality of the food), reflecting the importance placed on such matters by the patient and families concerned. This project was funded through the big lottery begun in 1996 and came to an end in 2004. Due to the marked successes of the project the Cf Trust received further funding from the community grant (1996) which looked at creating roles to continue the good practice which the Advocates had pioneered. The Expert Patient Advisors (EPA) have since seen a progressive move towards having a greater influencing on decisions at a strategic level, particularly where the commissioning of specialist services are concerned.

**What constituent organisations/ professionals did you identify to have involvement with the network?**

Campaigning to achieve optimum care standards for Cf patients remains at the centre of the Expert Patient Advisors' undertakings. The strategies employed to do just that have altered throughout the years and generally tend to reflect changes made within the NHS. Their work necessitates liaising with various stakeholder groups and across organisational boundaries, namely; representatives of the Cf Trust; Patients and Families; multidisciplinary teams; hospital managers; patient advice and liaison services; specialist commissioning representative; external working groups; healthcare commission; local commissioners (primary care trusts); governmental bodies and the Dept. of Health.

**How is the strategic direction determined...? (Leadership undertaken by whom?)**

This is a joint process lead by the Cf Trust's Medical Advisors in close consultation with member's of the Cf Board and indeed the EPA's. The EPA's have regular weekly teleconferences with the Chief Exec for the purpose of getting up to speed on the work they are currently involved in.

**In what way does the network partake in patient pathway development?**

The work of the Cf Trust's Medical Advisory Board of Clinical Specialists encompasses work with both paediatric and adolescent care and has led to the publication of Consensus Standards of Care Guidelines. These are made available to download from their website and are promoted amongst Health Care Professionals involved in

the care of Cf patients. In order to survey whether these guidelines are adhered to, the EPA's use questionnaires which are sent to each of their Specialist Centres and the clinics which they have shared care arrangements with. On an annual basis they also conduct peer reviews where the lead clinician from one of their centres along with other members of the clinician's multidisciplinary team will visit another centre and share best practice. Although in the initial stages of this peer review practice was undertaken with some reluctance, it is now welcomed and has proven beneficial for all professionals involved.

The EPA's have also developed care pathways (as seen in the schematic diagram below) which are still under development but have been hailed as a useful tool.

**How is information disseminated within the network? Further to that, how is it then to their patient group? - Is this a fluid and reciprocal process?**

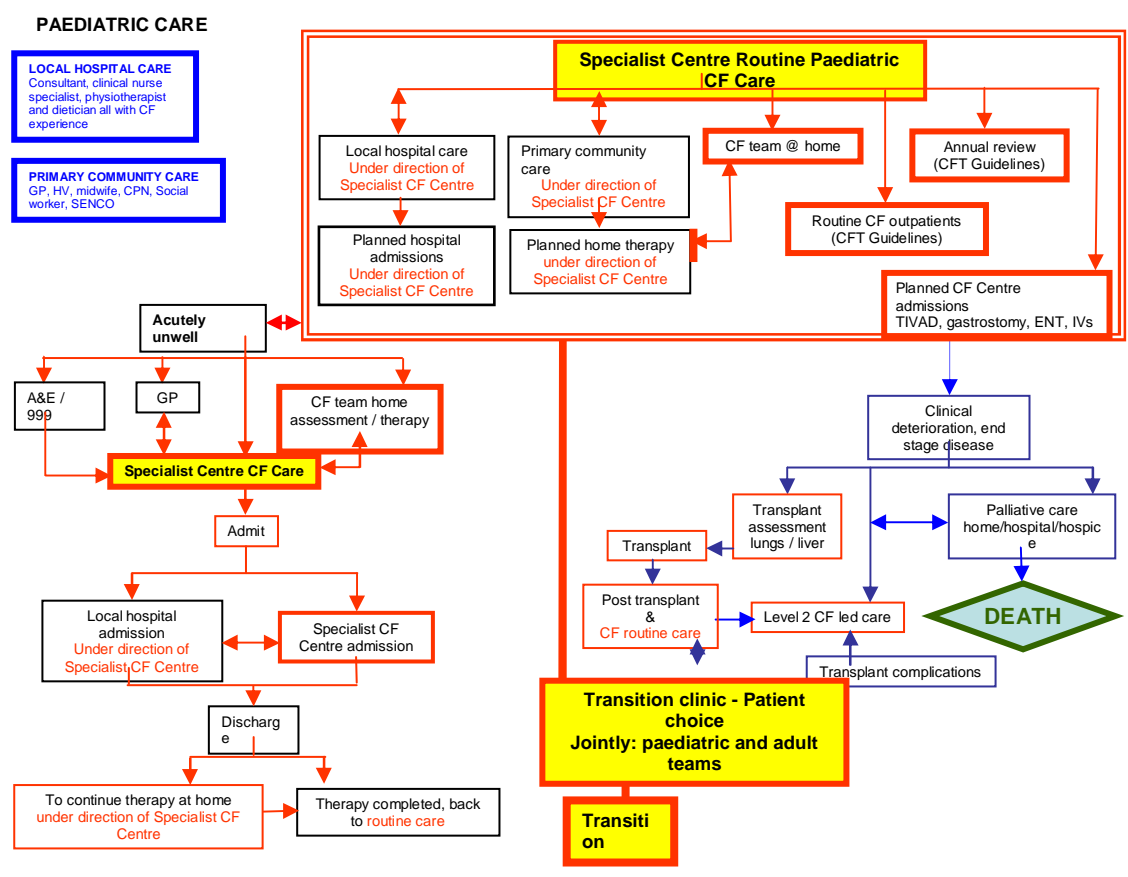
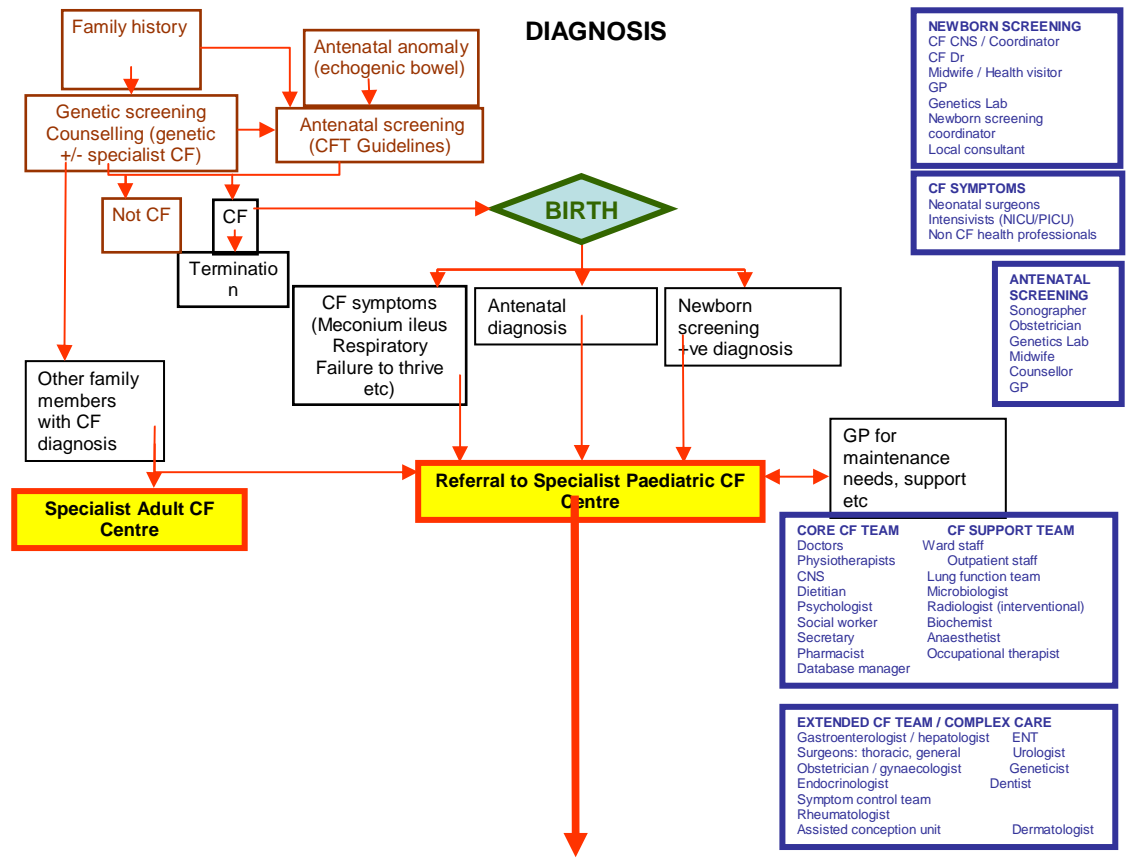
To facilitate the flow of information detailing the work the EPA's are involved in and the resulting improvements in service provision (i.e. the increase of physiotherapists in Cf multidisciplinary teams) the EPA's produced reports made available online (on the Cf website) and disseminated widely to Healthcare professional working within one of their specialist centres. The benefits of this practice have been manifold, not only in enhancing the legitimacy the EPA's network but also by way of contributing to the body of evidence based recommendations in a systematic manner.

**Boundary Spanner; this term has been used to denote the individuals who work in the interface of different agencies and manage the inter-organisational/ inter-professional relations...**

The EPA's are the 'go-between' allowing the priorities identified by the Trust and the Medical Advisory board to be a direct reflection of consultation and review conducted with Cf patients within the clinics in which they receive their care.

**I.T.C.; repeatedly noted as a key enabler in the creation of networks of geographically dispersed professional specialists to enhance learning and innovation... How is it utilised within the context of your network?**

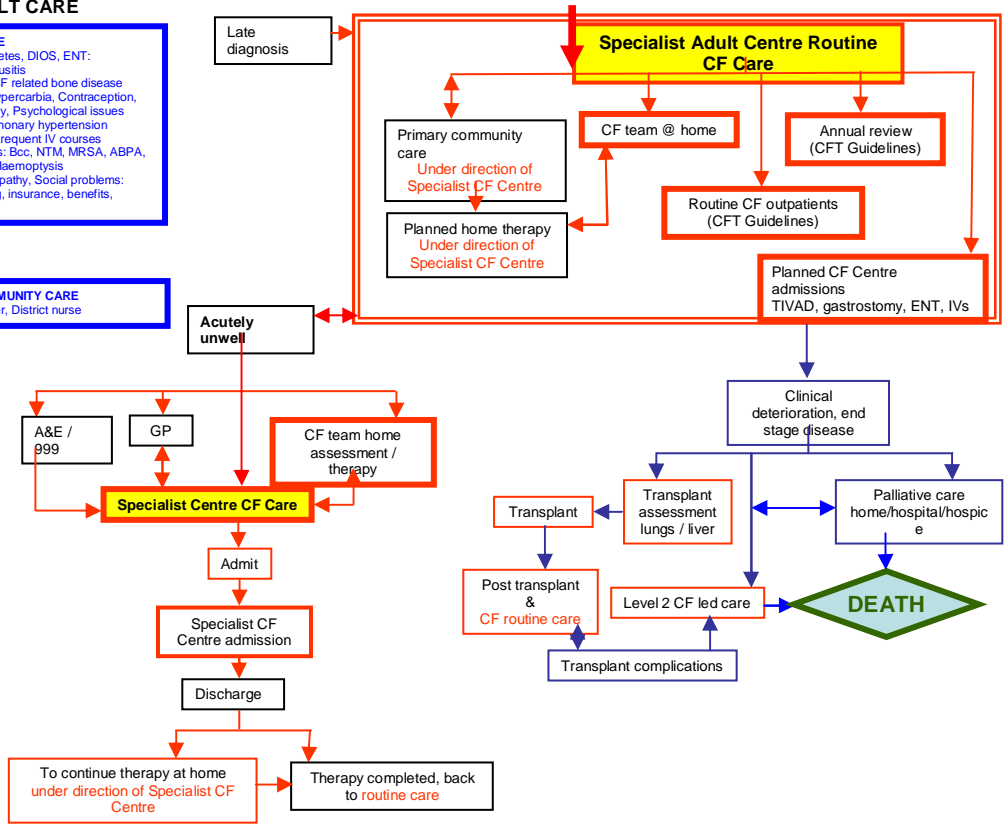
Cross-infection presents a great risk for Cf patients making the use of Information Technology evermore pivotal in the communication and coordination of the work the network conducts. Traditional mediums such as phones for teleconferences are used in addition to email, internet forum facilities with the occasionally the use of videoconferencing where appropriate and feasible.



**ADULT CARE**

**COMPLEX CARE**  
 CF Related Diabetes, DIOS, ENT: polypectomy, sinusitis  
 Renal disease, CF related bone disease  
 NIV, Hypoxia / hypercarbia, Contraception, fertility, pregnancy, Psychological issues  
 Malnutrition, Pulmonary hypertension  
 Cardiac failure, Frequent IV courses  
 Difficult infections: Bcc, NTM, MRSA, ABPA, Pneumothorax, Haemoptysis  
 Vasculitis, Arthropathy, Social problems: financial, housing, insurance, benefits, travel

**PRIMARY COMMUNITY CARE**  
 GP, Social worker, District nurse



**Appendix B**

**Section A: Your Support Group**

1. What genetic condition does your patient group support?

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2. What is the name of your patient support group?

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3. How many members do you have?

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**B: Clinical Networks**

Clinical networks can be described as linked groups of health professionals from across all sectors of health care who work in a coordinated manner to ensure equitable provision of high quality and clinically effective services.

1. Do you think a network of clinicians who have experience and knowledge of treating and managing this genetic condition is a good idea?

YES

NO

UNCERTAIN

2. Does your patient support group currently work with a network of clinicians who have expertise in the care management of this genetic condition?

YES

NO

UNCERTAIN

Go onto Q.3

Go onto Q.8

Go onto Q.8

3. Would you describe the network's remit as?

a. National

b. Local

c. Other, please explain \_\_\_\_\_

4. How often does this network meet?

- a. Once a month
- b. Once a year
- c. Twice a year
- d. Ad hoc basis, please explain \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. Where do these clinicians meet?

- a. In a physical space (i.e. a centre of excellence, specialist clinics, patient support group)
- b. In a virtual space (i.e. via the internet, satellite technologies)
- c. Over the phone (i.e. conference calls)
- d. A combination OR none of the above. Please explain. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

6. Is there a lead person that coordinates communication between the network of clinician and the patient support group?

YES

NO

If yes please detail (e.g. specialist nurse, consultant, member of the patient group)

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7. Do you know how this network is funded?

YES

NO

If yes then please explain \_\_\_\_\_

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8. In which of the following ways do you think a network of specialist clinicians can be of benefit to patient support group? (Please note you may circle as many of the options as deemed appropriate)

Research updates

Access to better services

Better quality genetic advice

Other, please explain \_\_\_\_\_

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9. What drawbacks (if any) do you think a network of specialist clinicians could have on the patients and families you represent?

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