

# ***Health Human Resources Guidelines: Minimum Staffing Standards for CF Healthcare Teams***

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*Cystic Fibrosis Canada is the health authority on cystic fibrosis and the leading funder of cystic fibrosis research and clinical care in Canada.*

## 1 Introduction

Cystic Fibrosis Canada, in collaboration with professional medical and clinical advisors, developed these guidelines and standards in an effort to ensure that all Canadian cystic fibrosis (CF) clinics are able to operate at appropriate levels, with adequate personnel resources available to the population being served, regardless of city or province. **The goal is to provide the best care possible to Canadians with CF and their families.**

CF Clinics are not to be restricted or bound by these guidelines and standards, particularly if their current staffing allocations exceed the suggested guidelines, albeit an unlikely situation. However, the development, adoption and distribution of guidelines for use across the country provide clinics with documented, **minimum requirements** with which to approach their hospital administrators, to illustrate and support the need for more resources, if required.

That said, these guidelines should be considered just that – *guidelines*. If a particular staffing complement is currently higher than the nationally suggested minimum, it is probably that way for a reason, and should not be reduced or restricted in light of these guidelines. **Local circumstances must prevail.**

Other jurisdictions have developed minimum staffing guidelines – including Australia, Europe, New Zealand, the United Kingdom, and the United States (see Appendix III) – and although observance has been given to them, these guidelines aim to be exclusively Canadian. With involvement from leading authorities on CF clinical care in Canada, participation from clinics across the country, and in consultation with numerous clinicians who treat those with cystic fibrosis on a daily basis, **these guidelines and standards are a fully representative Canadian initiative** (see Appendix I and II).

Ultimately, **the objective of this document** is to provide a **measurement tool** for use when accrediting and evaluating each clinic's resources and services, and to provide **advocacy support** to help obtain these resources.

## 2 Partnership of Care

Although this document has been developed primarily for the benefit of clinicians and healthcare administrators, it is important to remember that **CF care is a partnership**: it must be acknowledged that patients and their families are responsible for their health, and that the role of clinic personnel is to educate, guide and support them in their efforts.

Clinics must be sensitive to the needs of the patients and families they serve, and there must be accountability on the parts of those both giving and receiving care.

Clinics are expected to act on behalf of the patients – in their best interest – and opportunities are encouraged for patients to participate in, and advocate for their own care.

### 3 Principles of CF Care

Cystic fibrosis clinics provide specialized multidisciplinary care for individuals with CF. In Canada, there are out-patient clinics in most major cities, all within a hospital setting, and many with a university affiliation. When hospitalization is required, CF individuals are typically admitted by the CF clinic director, and in- and out-patient facilities are generally part of the same institution.

Some CF clinics deal exclusively with paediatric or adult populations, while others serve all ages, in a combined clinic setting. In cities where there are separate clinics, there is usually a close relationship between the paediatric and adult services, and interaction amongst the multidisciplinary counterparts is encouraged, to ensure continuity of care.

**Individuals are seen by various healthcare professionals at each clinic visit.** This type of multidisciplinary approach optimizes the care delivered, and with frequent, regular interaction with these healthcare professionals, clinic visits that include all team members offer convenient, comprehensive care, and promote a long-term association with CF clinical care. As cystic fibrosis is a multisystem disease, having a significant impact on lifestyle and emotional status, each healthcare team member has a **specific area of expertise**. CF must be treated throughout life, and it is important that affected individuals develop a comfortable, trusting relationship with all clinic personnel.

CF clinics take place according to a regular schedule, which depends on the size of the patient population. Ideally, CF individuals **attend clinic once every three or four months**, and consult with all healthcare team members at each clinic visit. In some cases, however, individual team members will be consulted outside of clinic times, during a separate appointment, on the telephone, or on a drop-in basis.

### 4 CF Clinic Support

Cystic Fibrosis Canada, through its Clinic Incentive Grant program, provides **incentive funding** to accredited CF clinics based on the number of CF individuals served. These funds are intended to **enhance the standard of clinical care** available to Canadians with cystic fibrosis, by providing funds to initiate a comprehensive program for CF patient care, research, and teaching; or strengthen an existing program. The accreditation and granting processes fall within the jurisdiction of Cystic Fibrosis Canada's Healthcare programs.

Beyond the incentive funding awarded by Cystic Fibrosis Canada, clinics are financially supported by their host institution. Often, members of the CF healthcare team are loaned to the clinic; for example, the physiotherapy department will designate one physiotherapist to work specifically with the CF population, both during and outside of clinic times. Local circumstances dictate what personnel resources are made available to each clinic, and these are often defined by the administrations of the hosting institutions. The most common consideration in allocating staff resources is financial, that is, how much money is available to support each team

member, and whether the population being served is of a size that can sustain – and warrant – specific time allocations for personnel. In other circumstances, actual availability of personnel is a deciding factor; for example, if a psychologist is not available within the institution or community, no amount of money will ensure such an individual's involvement in CF care, although this does not preclude the need for this service.

As part of the Canadian CF clinic community, each clinic is expected to participate in the Canadian Cystic Fibrosis Registry, by **providing data** annually on all consenting patients registered with the clinic. Involvement with the Registry, which is linked to the Clinic Incentive grant program, ensures that a **comprehensive statistical profile** of the Canadian CF population is available, for research initiatives and clinical evaluation, and to help improve knowledge of disease patterns and care.

Physicians and clinicians across the country are continually **upgrading their knowledge and skills** to ensure the most current treatments for those whom they serve. Participating in local, regional and national **meetings and conferences**, along with attendance at the annual North American CF Conference ensures that each clinic is up to date with current treatment trends and research initiatives. Cystic Fibrosis Canada strongly encourages such professional development and continuing education, and provides financial support specifically for this purpose.

## 5 Cystic Fibrosis Canada Accreditation

As members of the Canadian CF clinical community, CF clinics participate in the **Accreditation Site Visit program**. Linked to the Clinic Incentive grant program, Cystic Fibrosis Canada manages this peer review program, to ensure that therapies and standards of care are consistently high across the country.

By hosting an Accreditation Site Visit approximately every 4-7 years, all medical and clinical personnel at a given clinic are able to discuss their roles, treatment protocols, and limitations with medical and clinical leaders from CF clinics in other areas. This information exchange is of benefit to those both hosting and conducting the visit, and provides further strength to the Canadian CF clinical network. It also allows Cystic Fibrosis Canada to add a voice to local efforts for increased resources.

Sponsored by, and with involvement of Cystic Fibrosis Canada, recommendations are provided to encourage and enhance all aspects of every clinic's services, whether personnel, facilities, practices, or medical care. Recommendations are made not only to the clinical personnel but to the administration of each hosting institution, and progress is monitored periodically, following each visit.

These guidelines have been developed in an effort to ensure adequate and consistent standards across the country. As such, they will serve as **benchmarks** by which clinical services are evaluated, during each Accreditation Site Visit. With a recognized set of Canadian standards, clinics – and their administrators – are expected to justify staffing levels, where deficiencies exist.

## 6 A CF Clinic by Definition

A clinic is both a physical space, and a structured arrangement for the delivery of care.

Along with the **required healthcare workers**, a CF clinic must have **appropriate physical space** in which to function. There must be an adequate number of private, individual consultation rooms in which to meet with, and examine patients. For infection control purposes, patient waiting rooms are not recommended – to minimize patient interaction – but the overall clinic area should include a place where team members may hold pre- and post-clinic meetings, and conduct administrative tasks while the out-patient clinic is taking place. There must be adequate facilities to access and store confidential patient files and charts, if these extend beyond those kept through the hospital's general medical records department or electronic storage.

It is important that there is unrestricted **access to hospital beds** when admissions are necessary, and that facilities are in full observance of infection control protocols. Typically the CF clinic coordinator, in collaboration with the ward nurses, ensures continuity of care.

**Laboratory and testing facilities** must be available, either within the institution, or through a referral system to another centre. Pulmonary function testing equipment, including a portable spirometer and a plethysmograph must be readily available to the clinic; microbiological testing facilities are necessary to identify important pathogens; and diagnostic sweat chloride testing, and genetic testing and counselling are required for making CF diagnoses. It is important that every clinic establish lines of communication with a lung transplant program in order to make referrals as necessary.

In addition to the overall **infection control policies** in place at every institution, CF clinics must have in place specific policies addressing the reduction of cross-infection of *Burkholderia cepacia* complex and other infectious pathogens that are of particular concern to the CF population. Specifically, there must be procedures in place to ensure limited interaction among patients – including, for example, through staggered clinic scheduling; isolated clinic examination rooms; and visits outside of clinic times – along with procedures for clinic personnel, in-patient nursing staff and family members. Infection control policies must be developed and enforced, and all those associated with the clinic should have full understanding of the implications of good infection control.

As an extension of its services, each clinic is encouraged to participate in **research initiatives and clinical trials**, as resources and patient involvement allow. CF clinics are expected to be active participants in the development, testing and/or discussion of new medications and treatments.

## 7 Multidisciplinary Care – a Team Approach

As a multisystem disease with a **proven model of multidisciplinary care**, all components of the CF clinic must be available to the patients being served, in order to ensure that care is being delivered appropriately and completely, in a combined, all-inclusive approach. Patient care becomes compromised if sufficient access to services is not available.

A typical **CF healthcare team is comprised of several professionals**, each of whom has a specific area of expertise that relates to the care of individuals with cystic fibrosis. Often a combined paediatric/adult clinic will share healthcare professionals, but this is not always the case – certain health issues, although common in CF, are different with age: learning to swallow pills is different from addressing osteoporosis.

Likewise, in-patient and out-patient CF care are best delivered by the same individuals, to ensure consistency of care, and to reinforce principles of care both in and outside of the hospital setting. When team members are not able both to attend out-patient clinics and see in-patients, collaborative communication amongst their counterparts is encouraged to ensure consistent and seamless care.

Although overall availability of personnel, and support within each institution can vary widely across the country, there are certain **minimum staffing requirements** that must be met in order for CF care to be delivered adequately. As the guiding authority on CF clinical care in Canada, Cystic Fibrosis Canada provides these guidelines to ensure that all clinics and institutions are aware of the **necessary components of CF clinical care**.

Where possible, a recommended guideline is indicated below for the minimum staffing standard for each individual role. These guidelines have been developed considering current availability – and current need – from clinics across the country, and comprise **a standard that is acknowledged across the country**.

### 7.1 Primary personnel

The following multidisciplinary team members make up the core of a CF clinic:

#### 7.1.1 Clinic director/CF physician

The clinic director, or medical director, is the **physician responsible for all medical aspects of care**. The clinic director makes all medical decisions and referrals, and in the case of paediatric clinics, is often the individual who initiates and/or confirms the diagnosis of cystic fibrosis, typically in collaboration with a provincial newborn screening program. The clinic director outlines each patient's medical profile, prescribes all medications, and oversees all the associated treatments administered by the healthcare team members. The clinic director has admitting privileges, and can hospitalize patients when necessary.

The clinic director or designated, named CF physician, sees all CF individuals at every clinic visit, and in many cases, is available for patient visits outside of clinic times. Few physicians are involved with the CF clinic on a full-time basis, but many devote a significant portion of their time to CF; many are also involved with CF research initiatives, either as a principal investigator or collaborator.

As a leadership role, the clinic director is typically involved in the selection of clinic personnel, and the development of clinic policies. This role represents the clinic within the institution; and is the administrative lead, applying for and authorizing disbursement of Cystic Fibrosis Canada's Clinic Incentive grant, and ensuring appropriate follow-up financial reporting.

Oftentimes a clinic director is a respirologist, although this is not a requirement: other subspecialist physicians may also assume the role of clinic director, including Infectious Disease physicians, Gastroenterologists and Paediatricians.

In larger CF clinics, the clinic director works with one or more associated CF physicians. The associated physicians, like the clinic director, are involved with the clinic only on a part-time basis, but share the medical load with, and provide back-up medical support to the director.

Recommended minimum staffing standards:

Number of patients	Full-time equivalent	
	Clinic director	CF physician
<=20	0.18	0.02
21-75	0.29	0.25
76-150	0.63	0.61
151-249	0.5	1.67
250+	1.0	2.83

### 7.1.2 Nurse coordinator/Clinic coordinator

The clinic coordinator, who is often a Registered Nurse or Nurse Practitioner, plays a pivotal role in **coordinating the healthcare team's daily operation, from a nursing perspective**. The clinic coordinator provides the critical element of continuity between out-patient and in-patient services. The coordinator is often the first to recognize and alert other team members to changes in the psychological and medical condition of the patient with CF, and is a source of support for patients and family members, discussing and explaining diagnosis, hospitalization, or changes in therapy.

The coordinator plays a key role in **arranging, organizing and formulating treatment regimens** developed by the physician and other team members, and ensures that all procedures and therapies are understood and promoted; and is

commonly the first point of contact for patients and families, when questions or concerns arise.

Encouraging communication among the clinic, hospital care teams, patients, and families, the coordinator also provides considerable **education** to all parties, as well as to other medical and healthcare professionals, and lay groups.

Recommended minimum staffing standards:

<b>Number of patients</b>	<b>Full-time equivalent</b>
<b>&lt;=20</b>	0.4
<b>21-75</b>	0.78
<b>76-150</b>	1.53
<b>151-249</b>	2.5
<b>250+</b>	3.17

### 7.1.3 Dietitian/nutritionist

The dietitian monitors the **nutritional status** of each CF individual, and encourages appropriate dietary habits. As nutritional status is closely associated with survival, the dietitian constructs specialized diets, and works with patients and families to optimize nutritional health. As well, the dietitian recommends nutritional supplements, and offers advice on at-home preparation of meals, high fat recipes, and additional dietary resources.

The dietitian instructs CF individuals on the proper use of pancreatic enzymes: what dosage to take with meals and snacks, and when to take them, to derive the most benefit.

The dietitian works with a gastroenterologist, particularly where there are complications such as malnutrition. In extreme cases of nutritional deprivation where oral intake is inadequate, tube feed procedures may be prescribed, and are monitored regularly by the dietitian and gastroenterologist.

Recommended minimum staffing standards:

<b>Number of patients</b>	<b>Full-time equivalent</b>
<b>&lt;=20</b>	0.15
<b>21-75</b>	0.28
<b>76-150</b>	0.59
<b>151-249</b>	1.0
<b>250+</b>	1.67

### 7.1.4 Physiotherapist

The physiotherapist educates individuals and families in the area of **physical airway clearance techniques**. This person sees all CF individuals at every clinic, conducts in-patient physiotherapy sessions, and should be available outside of clinic times for assistance.

Although there are several methods of physiotherapy available, both manual and mechanical, the clinic physiotherapist is familiar with all methods, and will tailor physiotherapy regimens to each individual's needs. The physiotherapist will vary or rearrange certain procedures or introduce new methods over time, to add variety and help encourage compliance.

Once a person has been taught appropriate techniques, the physiotherapist concentrates on monitoring the manoeuvres and making adjustments to maintain and improve effectiveness.

The physiotherapist stays abreast of new therapy techniques and devices, and their usefulness, as well as the CF individuals' responses to and experiences with such new approaches. The physiotherapist is knowledgeable about provincial coverage for equipment and devices, and can provide direction for those seeking financial assistance.

Recommended minimum staffing standards:

Number of patients	Full-time equivalent
<=20	0.15
21-75	0.3
76-150	0.59
151-249	1.15
250+	1.83

### 7.1.5 Social worker

The social worker plays an important role in addressing **psychosocial issues** and **financial issues**.

The social worker is the main resource person available to CF individuals and families who have psychosocial issues. Counselling is provided most often for three main issues: diagnosis of CF, and the subsequent lifestyle changes required for optimum health; compliance with prescribed drug and physical therapies, and the time and energy they involve; and living with a chronic disease. Along with these issues, social workers can be involved with counselling and referral on a wide variety of topics from day-care and baby-sitting services to career counselling to sexuality.

Other CF healthcare team members often look to the social worker for emotional support when a CF individual has died.

The clinic social worker may refer to, and liaise with a psychologist or psychiatrist to organize and provide additional counselling support.

The other aspect of the social worker's role is helping to address financial concerns. Being well-acquainted with provincial programs for coverage of drugs, equipment and oxygen, as well as with private insurance plans, the social worker offers advice and assistance to individuals and families for accessing these resources. As well, the social worker is instrumental in arranging social assistance, and is available for counselling on financial matters.

Recommended minimum staffing standards:

<b>Number of patients</b>	<b>Full-time equivalent</b>
<b>&lt;=20</b>	0.15
<b>21-75</b>	0.3
<b>76-150</b>	0.53
<b>151-249</b>	1.5
<b>250+</b>	1.33

### 7.1.6 Pharmacist

In jurisdictions where pharmacy services are not decentralized, the pharmacy is one of the most frequently utilized services in the hospital, as it is responsible for dispensing all the **drugs, vitamins, enzymes**, and, in many cases, **nutritional supplements**, to the CF population. Ideally, drugs should be available for CF individuals to pick up at clinic; a message to the pharmacy a day or two in advance of a clinic visit is the most convenient arrangement. Most pharmacies send medications to distant CF individuals or families, either by courier or other means, although there is sometimes a service fee involved on the receiving end.

A pharmacist who works closely with the CF clinic is familiar with the signs and symptoms of the disease, and is able to provide advice on drug therapy, and other important education, to patients, families, and other healthcare workers. Similarly, a pharmacist designated specifically for the CF clinic can teach families of newly-diagnosed CF children the purpose of each drug, the dosage and best routine for administration, and can suggest alternate brands, when applicable. A pharmacist can caution about interactions and adverse effects, and can teach about new medications.

In centres where pharmacy services are computerized and each individual's drug use is tracked, the pharmacist is able to monitor compliance with drug therapy, and can help to ensure that costs are kept to a minimum.

The pharmacist is knowledgeable about new drugs and drug therapies, and should be able to provide information about provincial drug coverage programs, and how financial coverage can be obtained.

Recommended minimum staffing standards:

<b>Number of patients</b>	<b>Full-time equivalent</b>
<b>&lt;=20</b>	0.12
<b>21-75</b>	0.17
<b>76-150</b>	0.31
<b>151-249</b>	0.88
<b>250+</b>	0.73

## **7.2 Additional personnel**

A number of other key roles comprise a complete CF healthcare team, although often on a less frequent basis. Involvement can depend on the size of the clinic and the local resources that are available. These roles include:

### **7.2.1 CF clinic nurse**

In addition to the clinic coordinator, some larger CF clinics have a **designated CF clinic nurse**, who works with the coordinator, providing additional nursing support. A clinic nurse provides continuity of care when the coordinator is unavailable, and provides additional support during busy clinics. An additional CF nurse often concentrates on one component of the clinic's operations, such as educating and treating those with CF-related diabetes, or treating CF in-patients.

### **7.2.2 CF clinic secretary/administrator**

A designated clinic secretary deals specifically with the administrative tasks associated with the clinic, such as completing correspondence, filing, dictation, booking appointments, and organizing charts. In some cases, the CF clinic secretary also arranges referrals to other healthcare team members and to services in the hospital, for example, the diabetes clinic or allergy clinic, or specific laboratories.

In addition, the CF clinic secretary/administrator may be responsible for the preparation and submission of data to the Canadian Cystic Fibrosis Registry, often in tandem with the coordinator.

### 7.2.3 Respiratory technician

Working alongside the CF clinic physiotherapist, a respiratory technician conducts **lung function measurement testing**, and is able to track patients' lung function test results, either manually or electronically, and can recognize warning signs when individuals' lung functions begin to decline. Often respiratory laboratories produce graphic representation of patients' longitudinal lung function status, that is useful for the clinic director and others in evaluating a patient's background and progress.

When possible, it is advantageous to have the same individual performing all procedures and tests to establish lung function measurements. These procedures are often done at every clinic visit, up to four times each year, and consistency of results is crucial. For the paediatric CF population, establishing a comfortable relationship with the respiratory technician can help to alleviate the fear of performing the tests, and can help ensure usable responses.

### 7.2.4 Psychiatrist, psychologist

When special psychosocial concerns arise, a medical professional specializing in **mental health** should be available to the CF clinic, and the services of a psychiatrist or psychologist will often be requested by either the clinic director, coordinator, or social worker.

A psychiatrist or psychologist is available for consultation any time, often outside of clinic times, but generally works in conjunction with the CF healthcare team members.

### 7.2.5 Other medical subspecialists

Subspecialists – or physicians with a specialized focus of medical care – are commonly associated with CF clinical care. Access to these physicians can be either on referral from the clinic director, or in some cases, through a more formal attachment to the clinic, such as attendance at out-patient CF clinics, according to a pre-determined schedule.

Subspecialists most typically involved in CF care may include gastroenterologists, endocrinologists, otolaryngologists, infectious disease specialists, and others.

When a formal attachment is developed with a CF clinic, a subspecialist not only can become familiar with the patients and their individual circumstances, but with the disease itself and complications as they relate to CF care.

Given that availability of certain subspecialists may be limited – for example, not every clinic may have access to a paediatric gastroenterologist – it may sometimes be necessary to make referrals outside of the institution.

### 7.2.6 Child life worker

Working alongside the social worker, psychologist or psychiatrist, the child life worker primarily **counsels young children**. Working in ways best understood by a child, issues of pain, daily therapy routines, and death are approached. The format of a child care worker's therapy is often play – using games and crafts that are more accessible to a child, and that can help to normalize a hospital experience.

### 7.2.7 Chaplain

Typically working with the clinic's social worker, a chaplain or other **spiritual counsellor**, is of particular value to a CF clinic during times of death and dying. Family, friends and other CF healthcare team members may all feel the need for **emotional support** during times of grief, and a designated chaplain who is familiar with the disease is better able to provide personalized support.

A chaplain may offer counselling of a more religious direction than a social worker, when appropriate circumstances arise.

## 8 Acknowledgements

Thanks are extended to the members of the following advisory bodies, who reviewed and provided input on this document:

- Clinic Subcommittee of the Medical/Scientific Advisory Committee
- Healthcare Advisory Council
- Cystic Fibrosis Canada's Nursing Advisory Group

## **APPENDIX I: A Canadian Perspective – how the country contributed to these Guidelines**

Cystic Fibrosis Canada awards Clinic Incentive grants to 42 CF clinics in Canada. Each clinic includes a team of healthcare professionals, who have specific interest and expertise in the care of those with CF who attend their clinics.

A survey was developed to determine from clinics the total number of patients served, and what current CF clinic staffing allocations are available at their respective centres (“Have”). By contrast, they were asked what allocations are realistically required (“Need”). All usual staff disciplines were listed, for both “Have” and “Need” and respondents were requested to indicate the allocated full-time equivalent (FTE) at their clinic for each discipline. (“Have” and “Need” are displayed as “Current” and “Optimal”, respectively, in Appendix II.)

The survey explained that 1.0 FTE equals five full-time days per week, protected for CF care, in-patient and/or out-patient. Using this measurement, all staff complements across the country could be compared equally.

The survey was kept brief, in acknowledgement of already burgeoning workloads – another task would not be welcome! – but with enough detail to provide useful results. The survey was posted on SurveyMonkey.com – a free on-line survey utility – and an e-mail message was sent to clinic directors and nurse coordinators of all CF clinics in Canada, requesting their participation, and explaining the purpose and website address of the survey. Separate English and French versions of the survey were available, and a two-week turn-around deadline was given.

The response rate to the survey was high; however, it was important to ensure that all clinics had a representative voice in the process. In a second wave, all non-responders were contacted and reminded to complete the survey. A third and final effort was successful in soliciting responses from the remaining non-responders. Ultimately, **every CF clinic in Canada participated in the development of these guidelines.**

### **Observations**

Responses were received from all 42 CF clinics in Canada, and were submitted from 12 nurses, 13 clinic directors, 3 clinic directors along with other team members together, and 10 respondents who did not identify themselves. Four combined responses were made on behalf of separate paediatric and adult clinics located at the same site, or prior to a formal split.

The majority of responses to the initial survey announcement were received through the SurveyMonkey.com survey, with the exception of two clinics who were unable to use this utility as a result of local IT restrictions; they responded by fax to an adapted survey. Responses obtained through the subsequent follow-up attempts were by telephone, fax and in person.

All responses for “Have” and “Need” staffing allocations were entered into an Excel spreadsheet. In many cases, FTE allocations had to be modified or interpreted, in order to enable standardized comparisons; however, two clinics were unable to specify allocated full-time equivalents, and therefore were not included.

Using patient population sizes, the results were sorted and grouped. The same population size groupings were used as established for the formula to calculate Clinic Incentive grant amounts:  $\leq 20$  patients; 21-75; 76-150; 151-249; and 250+. These groupings reflect acknowledged limits at which the population load requires additional human resources. For each staff discipline within each range, minimum, maximum and average FTE complements were determined.

Finally, staffing allocations of ‘other’ disciplines were indicated, both as “Have” and “Need”, but with no calculable consistency or frequency. These included research personnel, genetic counselling, diabetes education, and resources for newborn screening. The only ‘other’ staffing allocations noted by more than one clinic were those of psychiatrist and child life worker: these were available – and sought – predominantly at larger centres.

## APPENDIX II: Survey results\*

CURRENT STAFFING LEVELS																									
Patient Population	Number of Clinics responding**	Clinic Director		Clinic Physician		Physician Total		Nurse Total		Dietitian		Physiotherapist		Social Worker		Pharmacist		Respiratory Therapist		Psychologist		Secretary			
		MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG
<20	3	0.05/0.3	0.15	0/0.05	0.02	0.1/0.3	0.17	0.05/0.5	0.25	0.05/0.2	0.12	0.05/0.2	0.12	0.05/0.15	0.10	0.05/0.2	0.10	0/0.1	0.05	0/0.1	0.03	0.05/0.1	0.07	0.05/0.1	0.07
21-75	12	0/1	0.20	0/1	0.16	0/2	0.36	0/1.1	0.59	0.05/0.4	0.14	0/1.1	0.19	0/0.5	0.15	0/0.15	0.04	0/0.25	0.08	0/0	0.00	0/0.2	0.04	0/0.2	0.04
76-150	15	0.1/1	0.53	0/2	0.41	0.15/3	0.94	0.4/2.1	1.01	0/0.8	0.37	0/0.5	0.28	0/0.7	0.30	0/0.6	0.13	0/0.4	0.11	0/0.4	0.06	0/1	0.34	0/1	0.34
151-249	2	0.2/0.5	0.35	0/2.33	1.17	0.2/2.83	1.52	1/1	1.00	0.6/0.8	0.70	0.8/1	0.90	1/1	1.00	0/1	0.50	0/0.3	0.15	0/0	0.00	0.9/1	0.95	0/1	0.95
>250	3	0.5/1	0.67	0.75/3.5	1.92	1.25/4.5	2.58	2/3	2.33	0.8/1.8	1.37	0.4/2	1.30	0.8/1	0.93	0/1	0.40	0/1.8	0.60	0/0.3	0.10	1/2	1.33	1/2	1.33

  

OPTIMAL STAFFING LEVELS																									
Patient Population	Number of Clinics responding**	Clinic Director		Clinic Physician		Total Physician		Nurse Total		Dietitian		Physiotherapist		Social Worker		Pharmacist		Respiratory Therapist		Psychologist		Secretary			
		MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG	MIN/MAX	AVG
<20	3	0.05/0.3	0.18	0/0.05	0.02	0.1/0.3	0.20	0.1/0.6	0.40	0.05/0.3	0.15	0.05/0.3	0.15	0.05/0.2	0.15	0.05/0.2	0.12	0/0.2	0.08	0.05/0.2	0.12	0.1/0.2	0.13	0.1/0.2	0.13
21-75	12	0/1	0.29	0/1	0.25	0/2	0.54	0/2	0.78	0.05/0.8	0.28	0/1.25	0.30	0/1	0.30	0.05/0.5	0.17	0/0.5	0.12	0/0.5	0.14	0/0.75	0.22	0/0.75	0.22
76-150	15	0.1/1	0.63	0/2	0.61	0.3/3	1.24	1/4	1.53	0/1.5	0.59	0/2	0.59	0/1	0.53	0/1	0.31	0/1	0.29	0/0.5	0.21	0/1.2	0.61	0/1.2	0.61
151-249	2	0.5/0.5	0.50	1/2.33	1.67	1.5/2.83	2.17	2/3	2.50	1/1	1.00	0.8/1.5	1.15	1.5/1.5	1.50	0.75/1	0.88	0.3/0.5	0.40	0/0.2	0.10	1/1	1.00	1/1	1.00
>250	3	1/1	1.00	2/3.3	2.83	3/4.5	3.28	2/4.5	3.17	1/2.5	1.67	1/3	1.83	1/1.5	1.33	0.5/1	0.73	0/2	1.00	0/0.5	0.33	1.5/2.5	2.00	1.5/2.5	2.00

\* Based on survey results provided from Canadian CF clinics, information current as of 2010.

\*\* Does not include incomplete or unusable information.

## **APPENDIX III: Guidelines from other jurisdictions**

- Australia

[http://www.thoracic.org.au/imagesDB/wysiwyg/CF\\_standardsofcare\\_Australia\\_2008.pdf](http://www.thoracic.org.au/imagesDB/wysiwyg/CF_standardsofcare_Australia_2008.pdf)

- Europe

[http://www.elsevier.com/framework\\_products/promis\\_misc/2005.pdf](http://www.elsevier.com/framework_products/promis_misc/2005.pdf)

- New Zealand

[http://www.thoracic.org.au/imagesDB/wysiwyg/CF\\_StandardsofCare\\_NZ2010.pdf](http://www.thoracic.org.au/imagesDB/wysiwyg/CF_StandardsofCare_NZ2010.pdf)

- United Kingdom

<http://www.cysticfibrosis.org.uk/media/448939/cd-standards-of-care-dec-2011.pdf>

- USA

Infant Care (Abstract only)

[http://www.jpeds.com/article/S0022-3476\(09\)00881-6/abstract](http://www.jpeds.com/article/S0022-3476(09)00881-6/abstract)

Adult care

<http://www.cff.org/UploadedFiles/treatments/CFCareGuidelines/AgeSpecificCare/CF-Adult-Care-Chest-2004.pdf>