Record number	Question (in the format it was submitted in)	Lay (L) Professional (P)
1	Does IV antibiotic therapy increase patient-reported QoL	P
2	What is optimal adherence to therapies; oral and inhaled medications, dietary and physiotherapy recommendations and guidelines on IPC	P
3	Which antibiotic is most effective for PsA, collomycin or tobramycin	P
4	What strategies could simplify a nebuliser regimen to make it easier for people with CF?	P
5	Where does infection from Pseudomonas aeruginosa come from?	P
6	What makes an individual susceptible to Pseudomonas at a given time, compared to other times when they may clear the organism?	P
8	What is the cause, consequence, and best treatment option for chronic (or very requent) Haemophilis paranfluenza infection.	L
10	Bacteria like Pseudomonas Aeruginas, and many others, are very harmful for lung CF patient. Today antibiotics are not enouth effective to completely eradicate such bacteria. Is there a real chance to find an effective antibiotic, or treatment (phage therapy), in short term	L
11	Is lung function (FEV1) really a good indicator for my health and why does it almost never relate to how I feel, and how much activity I am able to do in daily life.	L
12	Is anything being done to address the infertility problem with males with CF?	L
13	If a cure were to be found, would it be a one off treatment (therefore with a one off fee) or would it be an ongoing course of treatment over a period of time, or even possibly forever?	L
14	The majority of people with CF have raised sweat chloride, in infancy surrogate measures of total body sodium are frequently low yet there is huge variation in opinion and practice with regards to supplementation. Should all people with CF in the UK take sodium chloride supplements and if yes at what dose?	P
15	Why doesn't the UK have a prescribable easily obtainable range of vitamin supplement that more closely matches the nutritional needs of people with CF in 2015 - less vitamin A , more vitamin D and containing vitamin E	P
16	Why can't the UK have a range of pancreatic enzyme supplements - lack of competition also leads to complacency on the part of pharma	P
17	Do drug combinations stunt growth in children with Cystic fibrosis	L
18	Is inhaled Tobramycin the best treatment for Pseudomonas?	P
19	Are there treatments that work better than others for airway clearance?	P
20	What is the best Vitamin for the pediatric population?	P
21	How can we best help parents manage treatment time, to help them get it done in the fastest but still effective time frame?	P

22	Will personalized antibiotic therapy based on therapeutic drug monitoring improve clinical outcome?	P
23	Why isnt more being done to teach community midwifes, health visitors and GP's more about CF?? Where is the support when a child is diagnosed??	L
24	My main question is when is remote care going to happen? Attending hospital where there are other patients with CF is one of the biggest risks to my health.	L
25	Is there any research into starflower oil as a supplement? Could the anti-inflammatory properties be beneficial to people with CF? Additionally, and possibly as another point, I, as a person with CF, cannot take NSAID's or steroids (as im post liver transplant steroids would affect my immunosuppression), so alternatives to aid airway inflammation would be extremely useful - are there any current alternatives? And would starflower oil work?	L
26	Why is cystic fibrosis dealt with in respiratory hospitals with respiratory doctors, given its a multi - system condition? I have recently found my CF centre lacking in knowledge regarding other aspects of my CF, mainly my liver / kidney / gynaecology issues. These are then referred to other hospitals, but the difficulty in cross-hospital communication makes my care very fragmented, with messages lost and issues not dealt with. Especially with my liver transplant hospital. This results in mistakes, oversights and prolonged admissions. Is there a way this can be fixed to ensure maximum standard of care?	L
27	Is it true that children and young people with CF have better lung function/ long term health/fewer hospital admissions-eg- if they and their parents/primary carer receives regular supportive emotional and family support to talk over the day to day challenges Cf adds to a family? Not a Clinical Psychologist but more a family therapist concentrating on the family 'system' of managing challenges/resilience	L
28	Do young people attending a Young People's CF Clinic- ie distinct between paediatric and adult, do better than those who do not have access to this level of clinic care?	L
29	What are healthcare professionals (doctors and nurses) attitudes and practices towards addressing the psychosocial needs of patients with CF	P
30	Could there ever be a surgery to correct or even insert a vas deferens in males with Cystic Fibrosis?	L
31	Wich molecule or product could correct the faulty gene and bring enough CFTR protein up to the membrane of the cell ?	L
32	The effects of orkambi	P
34	Does aerobic exercise at a high level halt or slow the progress of lung deterioration in CF?	L
35	What treatments can eradicate the presence of NTMs like abscessus? Or, at what point does abscessus need to be treated vs left alone? What are the risks of NOT treating it? What are the impacts of abscessus on lung function over time?	L
36	What treatments or exercise or diet can be used to prevent the development of CFRD in people with CF? Are there treatments (like exercise?) that can help the damaged pancreas to better utilise the insulin that it does produce?	L

37	What is the impact of probiotics on the lungs? Do people with CF grow the same bugs in their lungs that they grow in their guts and, if so, is there a transference that occurs? Can probiotics prevent or slow this occurrence if so? Can they be used to reduce the amount of bacteria in the lungs, if so?	L
38	What is the impact of communication between patients/families and CF teams on outcomes? Does respectful communication lead to both/either better experiences of health care or better health outcomes?	L
39	Why are there different genes that cause cystic fibrosis ?	L
40	How can we be certain of a persons lung capacity just by doing PFT's?	L
41	How can a patient with lung transplantation benefit from new treatments?	L
42	What effect does supplemental salt have in the first year of life?	L
43	Are viral infections more common in cf than in the normal young child population?	L
44	Does breastfeeding improve growth in the first year of life?	L
45	Are there particular foods that increase the thickness of secretions/should be avoided?	L
46	Is there a benefit to physio in well children with cf?	L
47	Where the money raised actually goes	L
48	How to improve the motivation of young people (adolescents) with CF to SYSTEMATIC treatment / physiotherapy?	P
50	Are islet cell transplants somethig that will be available to people with CF related diabetes in the future? Including people who have had a pancreas transplant but are diabetic again.	L
51	I feel the high calorie / high sugar rule for CF weight gain is very outdated, and healthy eating, healthy calories and nutrition should be focused on a lot more. Especially with the extra vitamins and minerals debate - surely we can supplement these vits through food, instead of relying solely on tablets. Is there a possibility this all-rounded view on nutrition could be bought in, to encourage an all-round wellness / well being? For eg avacados and nuts are equally if not more calorific than a chocolate bar, and much better for health.	L
52	We know exercise is hugely beneficial, why isn't there more emphasis on finding exercise for patients, as part of a clinic review (physios)? Help patients actually explore, find and enroll in an activity they would LOVE to do - from the gym to dance to swimming to yoga to doggy walking. If possible help financially - at present its only GP's I believe that can offer free gym passes etc. (Can this be extended to CF nurses for ease and higher follow-through rate? If someone is reluctant, being given a form there and then would possibly encourage them to join an activity, rather than having to make an appointment to see a GP etc...) Also, have exercise programmes available from physios, preferably personalised as people with CF have many different issues ranging from muscle strengthening to posture. Posture is extremely important and often brushed over. Tips and advice as part of seeing the physio at clinic would be a quick and easy way to keep people on track with exercises they can do at home to gently help issues and therefore improve lung function, with regular follow ups at each clinic visit. Aim to see exercise as important as medication (which it is), and monitored by team.	L

53	Is there a correlation between educational achievement and adherence to CF treatment?	P
54	Can a robust CF identity help adolescence adhere with treatment plans?	P
55	What do we know about body image in people with Cystic Fibrosis? What are the rates of eating disorders in this population and what can be done to prevent them?	P
56	Should Motivational Interviewing be used more frequently with patients to encourage adherence?	P
57	Quality of Life based on environment - city v. countryside / town v. coast / cleanliness of living environment, namely can the quality of life for someone with CF be improved by changing their environment	L
58	What is the potential impact into the continued research of effective CF drug treatments by the pharmaceutical companies as a result of health authorities funding rejections. Will they channel their research into different health conditions?	L
59	Can the impact of any side-effects of long-term medication be measured with any certainty on how it will effect an individual	L
60	What is the psychological impact of CF on children / teenagers / adults? Are there 'markers' a parent &/or carer can watch out for to head off potential issues/conflict?	L
61	CF is abhorrent, why is nature so cruel?	L
62	How does non tubercular mycobacterial infections affect long term outcome in CF?	P
63	Can we prevent the development of CF related diabetes with early institution of medications such as Kaledeco and Orikambi?	P
64	Does a gluten free diet decrease the needs for pancreatic enzymes?	P
65	How aggressively should we treat NTM's in CF?	P
66	Does treatment with Kalideco or Orikambi prevent, or help pts better clear NTM infections:	P
67	Does the result of the sweat test affect long term survival?	L
68	The effect of orkambi on patients with abscessus	L
69	The optimum stage of disease progression to avail of lung transplant?	L
70	How to manage the often symbiotic mother-child collusion in families with CF during puberty, transition and young adulthood?	P
71	How to councel the whole family of the CF-Patient, especially if the child grows up?	P
72	prevention of cross infection of "bugs" such as Cepacia, pseudomonas and mycobacterium in hospitals. If you have one of these bugs you are treated as a "leper" by hospitals and the trust. Unable to attend meetings and access specialists facilities in hosp	L
73	Management of infections that prevent access to lung transplants (eg mycobacterium)	L
74	Drug combinations that fight endemic bugs (pseudomonas, mycobacterium, Cepacia, aspergillosis	L
75	Can foods high in PUFA raise the levels of essentiell fatty acids in blood?	P

76	Why do people with the same mutations (eg double df508) have different outcomes even if both are compliant ?	L
77	all research is geared to curing CF - how about we research how to stop it from being inherited by each generation?	L
78	How do we prevent pseudomonas?	L
79	Can pancreatic enzymes be made more effective with lower doses?	L
80	Can UV light be used in some way to kill bacteria in the lungs???	L
81	Does dairy cause more mucus production and should people with cf be on a dairy free diet?	L
82	Is there a direct cause and effect between lung function and body mass index?	P
83	How CF and the repeated antibiotic treatments impact on the gastro intestinal function and how could this function could be taken in account more and improved for a better absorption/digestion and a better nutritional status of Patients ?	L
84	How connected device could be used in home monitoring of life habits (physical activity, nutrition...), treatments compliance and health outcomes (weight, cardiac frequency...) to inform patients and health teams and educate patients on optimal way of life with CF ? I guess we would learn a lot by collecting and analyzing these data in the patient real life.	L
85	Compare the care model (care teams, staffing, location and premices) between countries and CF centres in the sema country, and assess the gap with the ECFS standards of care.	L
86	What are the best protocols for antibiotic treatments and especially for IV cures according to général pharmaco vigilance considerations or/and individual pharmaco vigilance results in order to be efficace and to reduce side effects and improve quality of life ?	L
87	What is the situation of CF transplanted patients who are more and more numerous, and generally not included in the Registry reports? Or if they are included in the Patient Registry, their results are not looked at specifically. In France 700 patients are transplanted, they represent 20% of the adult population recorded in the Registry. Their epidemiology is not well known.	L
88	What about the implementation of the new model of care (Collaborative Chronic Care Model) in CF ?	P
89	Use of e-Heath for improving heath in CF patients	P
90	What are the short/medium/long term side effects of the intestinal microbiote changes due to recurrent antibiotic treatments ?	P
91	How CF European Standards of Care (Framework, Best practice, Quality Management) recently published in J of CF are applied and funded in European CF countries	P
93	Can exercise replace the need for physio and / or other treatments?	L
94	How effective is psycho-social support for children with CF?	L
95	why is life expectancy so different from country to country?	L

96	I think lung function should be done on the same model machine at all hospitals and the same guidelines followed, because how can you compare stats and figures/averages if they all use diff machines that have slight differences and inaccuracies and diff s	L
97	Does Cf have enough awareness... Do people actually know the complete picture of Cf and what it entails?	L
98	how can we make using a PEP device more appealing?	P
99	is there a difference in effectiveness of PEP with mask or mouthpiece?	P
100	is the aerobika effective for children?	P
101	is there an amount, type or intensity of exercise that is effective to use as airway clearance?	P
102	Does use of Dnase/hypertonic saline have a short term effect on lung function. If so should it be used prior to lung function tests as reading are falsified	L
103	Are there certain times of the year when exacerbation is more common in patients, particularly spring and autumn for example?	L
104	Observation tells me that when siblings both have CF, the second child is often the worse off healthwise, can this be confirmed, and secondly why might this be?	L
105	At what age should pulmozyme be started	N
106	lived experience of carers of cystic fibrosis diagnosed patients	P
107	Experiences of Cystic Fibrosis diagnosed patients with dementia	P
109	How is absessus spread?	P
110	Why does one sibling with cf gets abessus and another doesn't?	P
111	How can anxiety be reduced in CF parents/Patients?	P
112	To what extent do other life events [outside of CF itself] impact on the mental health of the CF patient?	P
113	What message is the detiorating patient who refuses 'to engage' with psychological support giving? Is this refusal healthy and protective or is it damaging and destructive? Who is affected more by this behaviour- the patient, the CF team or the psychologi	P
114	What is the effectiveness of various airway clearance methods available? Autogenic drainage, Active cycle breathing, manual percussion, Flutter, Acapella, Aerobika, PEP devices, different vests since each use different wave forms, Frequencer, etc.. It seems clinics know little about many of the options and studies comparing methods are few and not reproduced. E.g. Canadian study comparing PEP to InCourage vest concluded PEP to be superior but the study has not been reproduced.	L
115	Level and type(s) of exercise needed for effective airway clearance. Is there an exercise type and intensity level that can replace other airway clearance techniques?	L

116	Effectiveness of probiotics for CF patients chronically or occasionally on antibiotics. Which are the useful probiotics and how should they be spaced from antibiotic doses? Bacteria-based probiotics? Yeast-based probiotics? Which bacteria? Which yeast str	L
117	Comprehensive study of carriers of CFTR mutations. Incidence of one or more symptoms among carriers. Can carriers harbour similar lung or sinus organisms to those of people with CF? Can they cross-infect people with CF (e.g. family members).	L
118	Are omega 3 supplements helpful to people with CF or to carriers of CFTR mutations? If so, is DHA or EPA more effective? Other supplements (e.g. glutathione, magnesium)?	L
119	Does probotics help people cf immunity, absorption of vitamins and digestive inflammation?	L
120	What research has been done into treatments to break down the mucus in lungs digestion?	L
121	What real prospects are there for a cure / better treatments in 5, 10, 20 years?	L
122	The impact of pregnancy on lung transplanted women and their children.	P
123	How strict should be the hygiene rules concerning pseudomonas infection risks?	P
124	Appropriate level of physical exercise for patients with CF suffering from underweight/low BMI?	P
125	Is physio more beneficial that exercise?	L
126	What is the best	N
127	Duration of oral antibiotic course during an excerebation Duration of IV antibiotic during a during an exacerbation	P
128	Which foods should CF patients be encouraged to eat in order to help increase energy levels?	L
129	Is exercise more beneficially than physiotherapy?	L
130	Does Ursodeoxycholic acid really have effects on an enlarged/damaged liver, how many years will it help for?	L
131	What exercise for cystic fibrosis is best for airway clearance and how much exercise would need to be done in a week to not warrant doing physiotherapy/ treatments. For example, if someone with Cf never did pep or accapella but did intense exercise each day would it be less beneficial or would the lungs be kept in the same condition as doing standard physiotherapy. Would intense cardio exercises be better than breathing devices?	L
132	Would it really be bad meeting others with cystic fibrosis if you were both healthy? Cross infection is important but what if two people were healthy with their condition and met out in the open would they immediately be affected by the other persons bugs?	L
133	Will having hypoglycaemia and low blood sugars be followed by cystic fibrosis diabetes always? And will The need for a high calorie diet/ high sugar diet cause cf related diabetes in the long term anyway?	L
134	Are there distinctive dietary needs in people with CF to do with allergy and intolerances? (Myself and others have intolerance to diary and gluten) are allergies in cf to do with thick mucus build up in the gut or lack of absorption?	L
135	What are the benefits of providing safe and sutainable means for young people with CF to communicate with one another about their experiences of living with CF?	P

136	Are there any standardised protocols for schools on informing pupils / parents if there is another pupil present with CF in the same school?	P
137	When is the right time to have children?	P
138	What about mental health after transplantation?	P
139	What impact does breastfeeding have versus formula on weight gain in newborns who have cf?	L
140	Does breast feeding help protect babies lungs?	L
141	What is the advice on babies with cf mixing with immunocompromised grandparents?	L
142	Does the research for "Vertex/KALYDECO/ivacaftor" (I do not know the exact name) treatment continue to get better results for patients with F508del mutation (further improvement of the medicine)?	L
143	Would it be possible to "plant completely new lungs" and transplant them, is this technology mature enough to be used for CF patients? When is it expected artificial lungs can be created?	L
144	Which psychological models of therapy are best suited for a CF popululion?	P
145	Does early management of glucose intolerance in CF children- diet/ good lung function/ wt has effect in reducing incidence of CFRD.	P
146	Does routine vitamin k supplements need to be given in CF children?	P
147	What is the pravelance of CF asscociated nepropathy/ renal dysfunction in UK?	P
148	Can you determine who is likely to get haemoptesis and when it is likely to happen? .	P
149	how can we best evaluate treatment efficacy? is it improvement in lung function or fewer exacerbations?	P
150	identifying suitiable career options for young people in education early enough to avoid disappointment	P
151	Can we start normal saline nebs as soon as my son with CF starts having a moist cough?	L
152	how can we make them hungry and smell and tast food better more info about blood sugar and diabetties in cf	L
153	How can mindful based stress reduction strategies help those with CF?	P
154	What role does azithromycin play in CF?	P
155	What research is currently being done that will give Vertex a run for their money? What company is going to have effective medication that targets the degault of CF but in an affordable range for parents?	L
156	What does each bacteria do to lungs? What is the top 10 tips from an adult with CF for an 8 year old with CF? What would they do differenly knowing more now?	L
157	Why is appetitie in CF so poor for many people? (?Medications decreasing appetite, swallowing mucous, depression, part of the disease) This is also interesting because people with higher BMI survive longer - are their appetites better?	L
158	Has the incidence of haemoptasis increased in CF? Are some patients more prone to it than others?	L
159	Is family breakup more common in families with CF than other families?	L
160	What is the financial impact on families of having a child with CF?	L

161	Which are the modifier genes, and how will they effect longevity in CF?	L
163	The potential musculoskeletal impact of CF medications (with our without- how do medications guide PT treatment decisions making	P
165	How much salt do people with CF need?	P
166	how to check if PERT is working simply & in a clinical setting	P
167	how much extra sodium is required by individuals to meet requirements	P
168	if treating IGT is helpful & prevents CFRD	P
169	how does ivacaftoir improve nutrtional status?	P
170	Not a question but I think more research and info could be done on raising o2 saturation. And also lung transplants.	L
171	Does CF related Pseudomonas infections cause rheumatologic effects such as skin lesions and joint swelling	P
172	If you have CF, how do you know if you are pushing yourself too hard when doing exercise? Can you do too much physiotherapy/airway clearance?	L
173	Do some foods stimulate inflammation or mucus production and should people with CF avoid them?	L
174	Do personalised treatment plans help people with CF stay well?	L
175	One of the hardest parts of living with CF and managing relationships/finances/career is knowing whether you are going through a "bad patch" and your health will improve or whether your health has declined in a way that is not reversible and you have to adjust to a "new normal". This makes it difficult to know your capacity to do things and plan for the future. How can we tell the difference between a bad patch and a new normal?	L
176	Is cysteamine a beneficial therapy for people with CF?	L
177	I think we are in desparate need of a biomarker or index of biomarkers that can show whether new CFTR modifying therapies are working, especially in young children. Existing outcome measures are too organ-specific, effort-/technique dependent and fail to map onto how patients actually feel. As a result, data from clinical trials is inadequate and fails to provide the data needed by clinicians, patients and NHS to make informed decisions.	L
178	How much FEV1 variation is normal? How do we know?	L
179	Is there a link between HbA1c and lung health?	L
180	As a 40 year old with CF, I can say that 100% adherence is impossible to achieve in the real world. How much adherence is enough? Are some treatments more important than others? Some people give themselves a day off from treatments once a week and feel it is good for their mental health - is this very harmful?	L
181	How much water should a person with CF drink each day and when should we take salt tablets?	L
182	Do CF patients have different degrees of pancreatic insufficiency?	P
183	How can nutritional needs of CF patients be more accurately and objectively determined?	P

184	Is it possible to preserve functionality of other organs than lungs? I mean liver, pancreas and other endocriner organs. For example to dilute mucus in pancreas...I suppose that functionality ot these organs are getting worse and worse during time so why not to treat them as well as lungs? I understand that lungs and enzymes are the most important part. But new functional treatment like Kalydeco is only for a small part of CF people and development for each mutation is expensive and not possible for everyone. If there will be a simple possibility to treat other organs regardless of the mutations it could also be helpful. Human body works as a complex and it should be treated like this.	L
185	does taking a multivitamin (e.g. Aqudec) rather than separate vitamins (A and D, vit E, vit K) improve the complicance for young adult CF patients	P
186	patients often receive dietary advice for constipation. How long after the advice do they adhere to the treatment?	P
188	Are hospital iv antibiotics any better than home IVs....obviously when someone is having routine 3 monthly IVs and fairly stable?	L
189	What research is being carried out into the rarer genetic mutations?	L
190	Is one form of airway clearance better than others (including exercise)?	P
191	What medicine can correct the CFTR dysfunction?	P
192	Do you need to take both Hypertonic Saline AND Pulmozyme?	P
193	At what BMI is it most effective to start enteral feeding ?	P
194	What other treatments could be made available to alleviate stomach pain	P
195	As people gt older access for IVs seems to become more problematic, Could alternative delivery systems be developed for IV antibiotics , Portocath seem to cause problems	P
196	Ivacaftor has been a breakthrough for those with the appropiate genetic type. I know research has been done on the most common genetic type but could more be done using the knowledge gained for the more common genetic type	P
197	Could an easier enzyme therapy be developed such as patches to be replaced every month to save taking the creon tablets at meals.	P
198	Are there side effects from some CF related drugs that cause issues with the musculoskeletal systems? Is there drug induced vestibular ototoxicity in patients receiving aminoglycosides? Does a decrease in ribcage mobility effect pulmonary outcomes?	P
199	Cause of CFLD	P
201	do breathing exercises help asthma	P
202	Can exercise replace physiotherapy in the maintenance of well-being in CF?	P
203	Does Vitamin K therapy from birth give rise to improvements in bone health?	P
204	What is the impact of parental mental health on child physical health outcomes	P

205	Do prophylactic antibiotics help patients with cystic fibrosis preserve lung function? Aside from very few studies on Staph, which are controversial because the UK uses prophylaxis and the US does not, and perhaps the EPIC trial, very few studies have looked at whether constant, prophylactic antibiotics prevent lung decline in patients regardless of pseudomonas status.	P
206	Does stepping up antibiotic coverage at the very first signs of a pulmonary exacerbation i.e. 1 day of increased cough or sputum improve the number of patients that get back to baseline? I think the AKRON exacerbation scoring system is dead wrong and that they wait far too long before acting. I think we are focusing too much energy/money in figuring out how long to treat, using steroids during exacerbation or not. It's really about starting antibiotics right away.	P
207	I'd like to know about the effects of cysteamine. These studies should be done pretty quickly because this drug is FDA approved already.	P
208	I don't know if you are asking about triple combo CFTR modulators or if you are asking about other types of studies. I obviously want these studies completed as quickly as possible. I have noted tremendous improvement with ORKAMBI. I am heartbroken for British and Australian patients who will not be able to benefit.	P
209	What is the correct amount of exercise for someone with CF to get to improve pulmonary status? Is there a dose/response relationship, or a minimum threshold?	P
210	How important is regular exercise (aerobic, resistance, flexibility) to outcomes in CF?	P
211	Do PPIs increase risk of pulmonary excaberation in CF?	P
212	Are PPIs really effective in improving enzyme efficacy	P
213	I'm not sure how to phrase this, but after my wife has been to the toilet it is costing me a fortune in air freshener to cover the smell. Why do they smell so bad?	L
214	Does most kids with c.f grow up with diabetes ?	L
215	Is Orkambi affecting weight gain and growth positively?	P
216	Is Orkambi causing GI symptom improvement?	P
217	Is Orkambi reducing insulin needs in CFRD?	P
218	More research on vitamin d deficiency in CF and decrease in lung function or increase in lung infection. Is low vitamin d a result of lung infections or a causative factor?	P
219	Does ursodeoxycholic acid prevent progression to advanced liver disease in CF (cirrhosis with portal hypertension)	P
220	Can probiotics improve nutritional outcomes in CF	P
221	Do CFTR correctors or potentiators reduce liver involvement in CF	P
222	allergy management	L
224	Are their certain medications to help with the fevers I get that can also help me in the long run?	L

225	does early diagnosis and earlier hospital admissions and surgeries result in more resilient parents for future burden of CF or do they create more traumatised parents with a diminished ability to cope with future burden?	P
226	do coping strategies differ for parents whose children undergo early surveillance for CF lung disease than for parents whose children do not undergo early surveillance procedures?	P
227	Does weight/resistance training improve body mass and lung function? What motivates families of kids with CF to stay physically active?	L
228	what are the most effective ways to improve vitamin d levels in CF?	L
229	What is the optimum treatment of inpatient pulmonary exacerbation (duration, antibiotics etc)	P
230	What is the best method of daily airway clearance (chest PT vs vest vs other)	P
231	What intervention work best for weight gain in CF patients?	P
232	What is best vitamin D repletion strategy to maintain serum levels in normal reference range?	N
233	What is the long term consequence of "self prescribed" once daily dosing inhaled antibiotic used 365 days a year incorrectly?	P
234	Will adding a psychologist to the care team (RN, SW, RD, RT MD etc.) quarterly CF appointment for ALL help with QOL, overall health, survival, reduce hospitalizations?	P
235	How do we combine study many CFTR modifier therapies?	P
236	Do probiotics help with poor gut function?	P
237	Is exercise more effective than traditional breathing exercises for airway clearance	P
238	How do we eradicate Mycobacterium Abseccus?	L
239	What is the best/definitive physio therapy treatment to clear sputum?	L
240	How can be provide the best palliative care to patients with CF?	N
241	If weight is really the best indicator of nutrition	N
242	How should patients with bronchiectasis and a normal or intermediate sweat chloride and a single (or "non disease causing") CFTR be treated if all other causes of non CF bronchiectasis have been excluded?	P
243	What type of physical activity do adults with CF find easiest to be involved in given the other challenges for CF management?	P
244	Does transition from a Pediatric CF Clinic to a new and/or separate Adult CF Clinic contribute to a decrease in adherence to treatment regimen?	P
245	How does lack if oxalobacter formigenes in cf gut affect oxalate levels and production of kidney stones?	L
246	How does polymorphisms like cyp450 affect drug m metabolism in cf patients?	L
247	How does gut micribiota change from birth in cf patients according to antibiotic use?	L
248	Can high dose dha affect inflammation in cf?	L
249	Can inhalation of bicarbonate affect bacterial load and growth of new bacteria?	L

250	Could research into polymorphisms like mthfr, cyp450,and slc26 help with understanding wider implications of cf in relation to sulfate cycle and drug metabolism?	N
251	Does daily aerobic exercise impact lung function over time?	L
252	Does the order of inhaled therapies matter?	L
253	Does advance care planning improve patient experience at the end of life?	L
254	Does performing routine CT or X-ray scans change the course of intervention?	L
255	How often should patients be seen in CF clinic and does more contact improve outcomes?	L
256	Why do some people with cf get bad liver disease	P
258	does the medication after lung transplant seriously harm the child during the pregnancy?	N
259	Role of Exercise in improving lung function in CF?	P
260	Do we need to reduce lipid intake in CFTR modulator therapies to prevent cardiovascular disease in later life?	P
261	How best to define a respiratory exacerbation in CF?	P
262	How best to address emerging threat of NTM?	P
263	Role of NIV in adolescent CF?	P
264	Can any of the more standard medications be combined to reduce the treatment burden?	P
265	Which of the emerging bacteria are important to treat, for how long and which drug?	P
266	With new adult problems (high cholesterol/lipids for example) does the dietary advice need to change?	P
267	Could behavioural programmes to improve treatment adherence and nutritional intake in the pre-school, primary school, high school, college be developed?	P
268	Would the use of thermal laminar airflow technology reduce cross-infection (particularly in families where more than one child has CF)?	P
269	What is the appropriate management for Mycobacterium abcessus and how long do you continue when not getting a response?	P
270	How aggressively should we treat recurrent presumed viral respiratory exacerbations in young children	P
271	Should we supplementing all CF pts with Vit K?	P
272	Are prophylactic antibiotics safe and effective?	P
273	How do we manage the patient with a CF lung attack who does not get back to baseline with ivabs	P
274	What is the best way to treat an exacerbation?	P
275	What are the most effective NTM therapies for people with CF	P
276	Is there any clinical implications of impaired glucose tolerance?	P
277	What treatment can "cure cystic fibrosis?	P
278	What is the best strategy to help with adherence?	P
279	Can we safely reduce the treatment burden on people with CF?	P

280	Are patients with CF managed as well as they can be managed?	P
281	Do asymptomatic patients (paediatric/adults) need to perform airway clearance	P
282	How to improve/assess adherence to treatments in CF patients	P
283	Is exercise enough for asymptomatic patients?	P
284	Does rib mobilization improve and maintain chest wall expansion?	P
286	What is the role of steroids in the treatment of pulmonary exacerbations?	P
287	What is the best treatment regimen for Mycobacterium abscessus?	P
288	What is the importance of Aspergillus on routine sputum cultures, in the absence of ABPA or aspergilloma?	P
289	What is the optimal use of hypertonic saline and DNaseI in CF?	P
290	How can we identify patients who suffer rapid decline in lung function prior to their decline?	P
291	Now that children are living longer (thankfully) what are the major side effects to watch out for from all the meds they take for so long ?	N
292	How do we increase motivation and participation levels in children with CF who are pre-teen and teenagers in order to increase compliance with exercise and activity levels while they are in hospital for 'tune ups'???	P
293	Does the type of muscle fiber change in their respiratory system over the course of time; do the inspiratory muscles get more fibrotic with increasing disease complications.	P
294	What is the relative efficacy of different therapies for CF? E.g. Hypertonic saline versus pulmozyme.	P
295	Efficacy of inpatient versus outpatient treatment of exacerbations	P
296	Dual rotating abx versus single	P
297	What is the proper number of care givers for a CF center?	P
298	What is the best way to track/measure how a multidisciplinary team interacts with one another?	P
299	What enzymes are in the future pipeline?	L
300	Aging process for lung transplant recipients?	L
301	Male sexual performance and fertility issues.	L
302	Emphasis on adult aging issues, I.e. Diabetes, cancer risks, etc. that may be associated with aging adults with CF.	L
303	How does perception of illness affect patient adherence to therapies?	P
304	How much treatment needs to be done to retain optimal health?	P
305	with administration of Orkambi or Kalydeco, can CF patients decrease their treatments safely without significant loss of lung function?	P
306	will Orkambi use decrease incidence of CFRD?	P
307	Is Orkambi really an effective drug, considering its expense?	L
308	How can we best help families to understand the importance of good nutrition and its relationship to better PFTs?	L
309	Where do we stand on treatments to eradicate Pseudomonas?	L

310	Is there a way to reduce inflammation in CF (preferably without involving blood thinners)?	L
311	Is it better to have regular IV antibiotics for prevention, or to wait as long as possible between IV treatments?	L
312	What kind of exercise, or chest physical therapy technique most improves lung function?	L
313	What are key reasons for fatigue in Cystic Fibrosis and how can they be addressed?	L
314	Does doing hypertonic saline more than twice a day help clear the lungs?	L
315	What is the best way to manage pain in CF without getting patients "hooked"?	P
316	What is the best way to estimate a CF patient's energy needs?	P
317	Is there a safer way to reduce acidity in the CF gut than using PPIs and H2 blockers?	P
318	What effect does CF on menopause or vis versa?	P
319	What is the prevalence of ADHD in CF?	P
320	What are the risks of ADHD treatment in CF?	P
321	DIOS how common is this happening? Should we treat all patients as having the potential of DIOS?	P
322	Does recognizing depression and anxiety with the new mental health guidelines actually make a difference in treating our patients and families. Do adherence rates improve once identified and treatment has been sought?	P
323	Will Orkambi help lung transplant patients to prevent the onslaught of symptoms as patients age?	L
324	Now that most patients with CF are diagnosed through newborn screening, what support services do these families need?	P
325	What is the most effective approach to educating newly diagnosed families about CF and their infants' care needs?	P
326	How can treatment compliance be increased in those that are admitted multiple times per year for CF exacerbations?	P
327	Can lung function improve over time with consistent exercise?	P
328	What is the role of Omega 3 and Omega 6 FAs in inflammation in the CF lung/GI tract?	P
329	I feel there is general uncertainty or a lack of evidence-based guidelines for the dietary management of adults with cystic fibrosis.	P
330	Should we continue to rely on BMI as the indicator of nutritional status in adults with CF?	P
331	Why does the patient so young (baby under 2) continue to test positive for cultured bacteria even after parents clean and are so conscious about contaminates.	P
332	CRMS - uncertain about telling a patient they actually have CF - but if you don't then they are uncertain if anything is wrong with child	P
333	How can we support and empower patients to be more self managing of their care?	P
334	Are the new devices such as the VibraLung or the Aerobika, as effective with airway clearance as vest therapy?	P
335	The affects of taking long term medicines for over 10 years that are being prescribed as safe. I have left side CHF and believe long term meds have affected my heart	L

336	The affects of pulmonary stabilization and being a parent with CF.	L
337	How does psychotherapy affect the management of CF? Or, does screening for depression and anxiety have a positive effect on health outcomes for caregivers and individuals living with CF?	P
338	What are truly effective ways to prepare young people to be successful in adult care?	P
339	Are there long term affects of the prescribed CF medicines that have been used for long periods of time? I currently have left side CHF and believe long tem meds may be linked.	N
340	Do breathing exercises help airway clearance?	L
341	Chronic coughing, and perhaps CF itself, promotes poor posture (thoracic kyphosis) which in turn can limit the mobility of other joints which predisposes those with CF to develop chronic pain limiting participation in life. Can physical therapy reduce or eliminate poor posture? what age is ideal to start PT? How often over the lifespan should patients with CF seek PT interventions? Can PT help to improve participation levels in adults (work, school, family life, recreational activities) which is especially important with increased lifespan projections?	P
342	Does regular exercise training impact expressions of elevated inflammation levels in persons with CF?	P
343	Does exercise training improve effectiveness of CF potentiator medications?	P
345	AIRWAY CLEARANCE EFFICACY IN CF	P
346	Does Ivacaftor in people with gating mutations provide protection from 'picking up' or growing new bacteria? We know Ivacaftor doesn't necessarily help to eradicate already present bacteria in the lungs, but does it help to prevent people with CF from picking up bugs/bacteria from the environment or other patients.	N
347	Comorbidity ADHD and CF in childhood/youth?!	P
348	Is fatigue a significant problem for end stage CF patients?	P
349	The impact of infertitlity on males with CF in relationships	P
350	What predisposes young people with CF to experience psychological distress?	P
351	Does living with CF become more of a psychological burden as you get older or as your lung function declines?	P
352	How do CF patients feel the new drug therapies have impacted on their lives?	P
353	How does CF influence decisionmaking regarding a woman or man's thoughts about getting children? The prospect of her/his own life to be shorter than average for the population - how does that influence the thoughts about perhaps being a parent?	P
354	How does it influence parenthood to have a child with CF? The ambivalence between wanting to protect the child against pain and wanting to facilitate, potential painful, treatment - how does it influence the upbringing and relations between the parents and the child, and its siblings?	P
355	The needles - do they, and if so, how do they, symbolize the perforation of the identity? How do they symbolize an unavoidable aggressiveness against the body - and does the patient dissociate in order to survive the repeated attacks?	P

356	For the young and adult patient with CF - how does existential thinking become part of life; the thinking of death as part of living. Perhaps inspired by Yaloms litterature.	P
357	Do upper limb ventilation demand exercises and thoracic mobility exercises enhance inhalation therapy when these two therapies are combined?	P
358	Does regular postural intervention prevent or reduce respiratory exacerbations or decline in lung function?	P
359	Should all young children be investigated for silent GOR?	P
360	What can be done to reduce critical adverse reactions to tobi podhaler including sudden excessive mucous production, which often buld up during the 4 week course, more and more quickly with each passing treatment month.	L
361	Is much of the intravenous treatment unnecessary should it be replaced by nebuliser antibiotics. Intravenous treatment was introduced before Creon revolutionised health and robustness in patients, with normal childhood growth and development. Over treatment by IVs is a current problem as a result, with some over zealous consultants and CF Trust guidelines. This causes resistances and serious side effects, and can breakdown the immune ststem causing long term chronic fatigue, inability to move properly or exercise, depression and suicidal thoughts, spiralling one way - down.	L
362	Improve patients understanding of Creon. Forget about patients weight and think about fat consumption. If something has 7g fat, needs 1 creon 10,000 capsule. simple as that . (based on lipase concentration and average requirement for lipase per g of fat ingested in food). My daughter has always done this and has normal weight and normal amount food intake as carefully calculated for several days. ie no extra food required compared to normal digestion - the creon is working efficiently.	L
363	Knowledge on what to do when going abroad to study or work for a year or more - how to get meds and treatment, who pays? cant find anything online or from cf team about this.	L
364	Accelerate ivacaftor+ research for df508 patients.	L
365	1. What are the patient en family perceptions on living donorship?	P
366	2. Will new born screening be associated with the prevalence of more psychological problems, as denial, depressive symptoms in families, do we take away the chance of a more mental healthy life?	P
367	3. Would couples with a child wish choose more for adoptions of carrier-mothers, if it was more accessible, accepted, payable and legal ?	P
368	5. what is the prevelance of pain pre and post transplant and what would be good multidisciplinary treatment options?	P
369	4. Would adults benefit from more intensive, frequent contacts with the psychologist in the team ? aspecially if he or she is also psychotherapist?	P
370	how to best improve compliance in teenagers and the proven benefits of compliance in this age group	P

371	the effects of exophiala on lung function and the usefulness of treatment	P
372	does new born screening leads to more psychological problems ? the knowing of a shorter statistic live expectancy can cause more mental problems with parents and childeren alltough there a 0 clinical symptoms	N
373	Does prophylaxis for staphylococcus aureus improves outcome?	P
374	Does probiotic in infancy improves outcome in CF by influencing gut / lung microbiome?	P
375	Which air way clearance physiotherapy technique is best at promoting adherance	P
376	Is there any evidence for completing airway clearance physiotherapy in non-productive, asymptomatic, stable CF patients with normal lung function	P
377	Does reduced physiotherapy input during an admission increase length of stay/ Does increased physiotherapy input during an admission decrease length of stay	P
378	Have you read and what do you think to the blog "the Dutch magic factory"?	L
379	Is a variety of physio each day better than just using one type? For example we only use a pep mask twice daily,would using pep once and the acapella once be more beneficial?	L
380	When prescribing medications is there any thought about the long term affect on the person, or is it just a case of 'what's best right now'	L
381	Can exercise on NIV increase the duration of exercise while it is on and is there any carry over for future exercise sessions with/without NIV? We could also look if there is a direct impact on FEV1.	P
382	Why do adolescents and young adults have the most rapid fall in lung function?	P
383	How can we best treat difficult airway infection with non tuberculous mycobacteria?	P
384	why and how do patients with CF acquire difficult infections such as non tuberculous mycobacteria?	P
385	Do emerging fungal organisms in patients with CF contribute to lung disease?	P
386	We know now that Pseudomonas aeruginosa eradication can be very successful in delaying the onset of chronic infection with this organism and we have established treatment strategies for eradication with early infection however we do not yet know the best strategy to eradicate recurrent or persistent infections and clinics use many different approaches.	P
387	I have baby with Cf how do I determine a cough from just a normal seasonal cough ? Should I Always get a prescription for when he has a cough? My baby is very cranky and agitated a lot is this no I'm look for Cf babies or does he feel sick from the Cf ? What should I do? is there any other alternative medications Or probiotics I should be giving my baby to help him and given the best start?	L
388	In the internet There is so much information about Cf and I don't understand a lot of it . I would like a basic information on what I need to do what I should be looking out for especially when it's comes to baby as they can't tell you what happened with them.	L
389	Why do CF patients get acid reflux	L

390	How to get the best CFTR modulator treatment to every patient with CF	P
391	When should antibiotics start for an exacerbation and when should they stop? In other words what is a pulmonary exacerbation?	P
392	Whats are the benefits (and risk) of inhaled antibiotics long-term when given for chronic infection?	P
393	Is it better to have a lung transplant when the FEV1 reaches 30%, even if quality of life is steady? Points to the question of risk/benefit of long-term use of specific treatment esp antibiotics such as systemic aminoglycosides and impact on renal function esp post-transplantation.	P
394	How often should a CT be performed in a stable adult patient...should it only be performed only when there is clinical deterioration which is unexplained or to investigate a specific microbe?	P
395	Should IV antibiotics be decided on by the susceptibility pattern results from sputum or other airways culture results?	P
396	As there are many different genetic subtypes in CF, it would be useful for each of the drugs currently licensed for this condition, or in common use, to ascertain which are effective for any given genetic subtype.	P
397	I think it would be useful for patients and carers to know what is the average functional level for each age group eg how far would be expect the average 30 year old man with CF to be able to walk without assistance.	P
398	What is the role of immunotherapy in CF?	P
399	What causes pulmonary exacerbations?	N
400	How could treatments be made quicker and more effective?	N
401	Are 10 days of IV antibiotics as effective as 14 days for CF exacerbations?	P
402	Socially, what would be the biggest issue for people with CF?	P
403	Does Non-Invasive ventilation improve survival in CF adults?	P
404	Is NIV more effective at clearing sputum than other physiotherapy techniques?	P
405	Can moderate CV exercise improve lung function?	P
406	What are the experiences of parents with CF?	P
407	What are the needs and experiences of patients who received the diagnosis of CF as an adult?	P
408	I have 2 adult children with CF. Whilst various treatments have improved their lives, the only reason they are still alive is because of anti-biotics. The effectiveness of these has steadily decreased and the time on IVs has increased. What is being done to overcome this issue? I have brought this up in CF Trust meetings and it has never been adequately answered.	L
409	What is the best palliation therapy for end stage CF	P
410	which infections are lethal and how to prevent them ?	P
411	not sure	P
412	Is there any advantages of taking omega 3 suppliments?	P

413	more studies available for rarer genetic mutations	P
414	more collaborative research with our global partners (i.e USA)	P
415	How do you increase energy levels and exercise within cf?	L
416	If a drug is claimed in a clinical trial to correct or change the defect of the genetic mutation, why is a sweat test not a primary goal?	L
417	Is percussion a good form of physio to loosen mucus?	L
418	what are the clinical predictors of early lung disease in CF?	P
419	what therapies prevent or delay the progression of lung disease in early life (preschool children)	P
420	What is the optimum length of antibiotic treatment of respiratory exacerbations	P
421	Elective versus reactive interventions to treat CF lung disease say when FEV1 falls below 70%	P
422	What is the role of fungi and yeast in the progression of lung disease in CF?	P
423	What methods are best for venous access to deliver IV antibiotics? In patients with PICC lines or TIVAD's - what is the incidence of complication? Can these be reduced? In such cases is there a role for VET prophylaxis?	P
424	Should we supplement Vit K routinely?	P
425	Do early attachment experiences predict adult 'adherence'? Could early and intensive support improve adherence in the long-term?	P
426	Development of CFTR potentiators that can alter the progression of CF liver disease	P
427	Does Vitamin D deficiency lead to progressive fibrosis in CFLD?	P
428	Should UDCA (Ursodeoxycholic acid) be started and if so what is the best time to start it if there is concern about development of CFLD?	P
429	Which current treatments and management plans result in the best outcomes in length and quality of life for homozygous delta 508 and other mutations	L
430	How can governments implement a screening DNA test for CF gene carrier status in girls at the time of rubella vaccination?	L
431	What is mechanism of CF related liver disease, can the disease course be altered and how	L
432	How can lung colonisation by pathogenic bacteria be prevented? Can the immune system be taught to tolerate some pathogens in order to exclude others? What other factors are involved in progression of CF related lung disease and specifically can they be modulated?	L
433	How can treatment for CF be simplified? What are the most important treatments with respect to longevity and quality of life	L

434	What is the gold standard for sterilising nebs? No one seems to tell you at any clinic and everyone approaches it differently. What method is best? Should you use tap water or distilled water? How often? After every treatment? Once a week? There is never much discussion on this and I know many families in Sydney Australia (in our groups) feel the same.	L
435	What level of sinus care should form part of daily care? We focus on clearing the lungs, maintaining lung health but the sinuses are also a reservoir for infection. How should we be approaching daily preventative sinus care?	L
436	What is the most effective combination of alternative therapies look like? (ie. fish oil, curcumin, genestein, NAC,)	L
437	What gut health strategies should we be employing early to encourage gut health resulting from both the CF condition and the long term antibiotic use?	L
440	If currently there is no cure, what is the best ways to at least manage living with cystic fibrosis and how such treatments can be incorporated into a persons everyday life?	L
442	- does Omalizumab have a place in the treatment of ABPA in CF	P
443	- does AB profylaxis started after CF diagnosis in young babies improves prognosis	P
444	- what is the best treatment for lung infections with A xylosixidans in CF	P
445	would earlier start of insuline therapy before overt CFRDM improve long term outcome	P
446	would early start of therapy with Kalydeco in class 3 mut or Orkambi in F508del hom patients prevent the development of CFRDM ?	P
447	How can we compare the performance of different CF centres so that people with CF can make an informed decision regarding where they are receiving care?	P
448	How can we improve the quality of CF care to ensure people with CF are getting the best deal?	P
449	A lot of focus has been given to medication adherence, but just how much adherence is enough?	P
450	How do CF and CF treatments affect the aging process? Do CF and/or CF treatments change the incidence/severity of aging-related conditions such as prostate enlargement, dementia and heart disease?	L
451	Are there incompatibilities between standard treatments for age-related conditions and CF care? For instance, do treatments such as statins have interactions with CF treatments or CF complications?	L
452	How aware are CF teams of the problems an aging population of pwcf encounter? Given that many pwcf are reluctant to see GPs because of a fear that CF complications will be misdiagnosed, are CF teams equipped to deal with age-related issues - even if all they do is give an authoritative "this is not CF, you really need to see your GP"? Are staff trained to be able to do this? (An example: CF teams ask about stress incontinence - but don't ask about urine retention in men.)	L
453	How can Burkholderia cepacia and related bacteria be better treated?	L
454	How can effects of glandular fever be reduced? Can it be diagnosed and treated early to prevent severe disease progression?	L

455	How can we get better results after transplant for those with cepacia and related bacteria?	L
456	How are families supported following the death of their child or partner who has cystic fibrosis?	L
457	What support is offered to the person with cystic fibrosis around the time of death eg spiritual support, emotional support, counselling etc	L
458	Will we find new medicines to fight inflammation?	L
459	Should we emphasize muscle building exercise alone with cardio to promote better health?	L
460	What natural supplements are good for CF?	L
461	What other Easteren Modalities compliment Western Medicine to help improve overall health?	L
462	How great an effect does depression have on health outcomes? How can we screen more patients and earlier to intervene to prevent major depression?	L
463	What is the optimal lung function to opt for transplant listing? How relevant is O2 saturation?	L
464	What is the best way to integrate CFRD care	P
465	Does short term, high dose vitamin D supplementation work / what is the most effective way to boost vitamin D levels	P
466	Can exercise replace airways clearance ?	P
467	1. How effective is infant PEP compared with positioning and percussion in the first three years of life?	P
468	How safe is underwater PEP in relation to water contamination?	P
469	is exercise alone as effective as other airway clearance techniques?	P
470	efficacy of medical management (i.e. sinus nebulisers, sinus flushes etc...) v surgical procedures for sinus disease (for those referred for surgery)	P
471	comparing airway clearance therapies (but done as patient selected v randomly assigned techniques) - i.e. one group are able to trial and then chose a technique they find the most effective and then the other groups are assigned a technique randomly	P
472	anything to do with exercise and CF-related diabetes (i.e what are the benefits of exercise?, which types of exercise are best in improving blood glucose levels?, what are the best nutrition guidelines concerning exercise in those with CFRD?, can exercise be helpful in preventing CFRD in those with only insulin resistance?)	P
473	anything to do with bone density (e.g. what medical, dietary and physical treatments/exercise work best in prevention/treatment of osteopaenia/osteoporosis?)	P
475	What is a detailed explaination of the condition? As many people I've spoke to do know what it is and it's hard to explain!	L
476	Why can't the body digest food properly, is it because of the excess mucus in the digestive system which is why creon tablets are needed?	L
477	Are many patients with cystic fibrosis likely to suffer from mental health related problems	L

478	Would modified dietary salt help improve cystic fibrosis symptoms?	P
480	What is the significance in rate of weight loss/gain on increasing/decreasing symptons	L
481	How can we help people with Cystic Fibrosis?	L
482	Does human calcitonin enhance bone function in osteoporosis management?	P
483	How do diabetic therapies impact on bone resorption in Cystic Fibrosis Diabetics	P
484	How important are levels of calcium, magnesium, vitamin D3 and zinc?	L
485	Should infants with CF be on antibiotics all the time or given in a more targeted manner?	P
486	Does frequent exercise realistically improve lung function & reduce exercise?	L
487	What are the chances of new antibiotics being manufactured to fight multi resistant pseudomonas?	L
488	Why is it so hard to get new treatments ie, orkambi or tobi podhaler especially if you live in wales?	L
489	Gene therapy success rate	P
490	Why it is less common in Asians and Africans. Could more research on this help us find its cure?	P
491	Is there a treatment which could reduce the excess production of phlegm due to CF-induced bronchiectasis?	L
492	How can people with CF develop automatic habits of adherence to support treatment taking (Note adherence can be supported by self-regulation or habit. Self-regulation uses will power and is burdensome whereas habits are free. Thus habit formation is a key goal in learning how to support adherence)	P
493	How does CF care vary between CF centres (you might put this another way, which CF centre provides the best CF care) Knowing the answer to this question is important for patients and once best care is defined allows centres to becnchmark and improvement science to be used to support change	P
494	What is the most effective way to support adherence in CF (this is different to habit formation since it includes multi-faceted interventions aimed at capability , opportunity and motivation that will change behaviour sometimes thru habit formation and sometimes thru self-regulation	P
495	What is the optimal traetment for ABPA	P
496	What is the optimal treatment for the rarer and difficult to treat organisms : abscessus, etc	P
498	Can we identify an 'optimum window' for treatment of Pseudomonas infection based upon biofilm state?	P
499	What interventions are helpful for achieving better adherence	P
500	Can biofilm status of Pseudomonas be altered in vivo?	P
501	What is the ideal method of determining healthy weight in children/adults with CF	P
502	How to fight infections - especially by Pseudomonas aeruginosa. Control Avian immunoglobulin against Pseudomonas.	P
503	How to cure different mutations	P
504	Nutrition - especially need of polyunsaturated fatty acids	P
505	Ways to get rid of sputum etc. High activity, breathing exercises, west - combination of these activities	P

506	Saving time	L
507	How to prevent the conversion of Pseudomonas aeuruginosa into the most aggressive forms	L
508	How to assess the viability of lungs for transplant before the candidate recipient enters the surgery room	L
509	How to clean the aerosol devices efficiently in the shortest time	L
510	How to prevent aspergillosis	L
511	Can you assist persons outside of major countries like the USA and UK get their CF meds to them possibly via courier agreements.	L
513	What causes lung pain? Is there a better, more effective way to treat it than oral painkillers?	L
514	Not so much of a question, but more about an idea related to psychological support. As an adult with CF I find it difficult when I lose a friend to the disease. But what makes it harder is that the grief process feels different and confusing because in the majority of cases I have never even met the person that I have lost. Sometimes I don't know the reason why a person has passed away. I find it hard that I'm not able to share my grief with others and this is quite different to those who knew the person with CF beyond the virtual environment, who can attend the funeral for example. I just think there needs to be more support in this area. As I get older, I am having to deal with losing sometimes several friends a year, alone.	L
515	Does heated humidification eg optiflow or water via ultrasonic neb aid sputum clearance	P
516	Can yoga improve physical and emotional health in people with CF	P
517	Can exercise be used as a primary means of airway clearance? (I realise this will be down to the individual - but is there evidence to suggest it really is sufficient for some)	P
518	Can an online community forum be used to improve adherence (with the right behaviour change and persuasive tech!)	P
519	Would nebulise get antibiotics via the pair sinus be safe, effective and tolerated?	P
520	Research why some medication works on some people and not others.	L
521	Are we giving too many (oral) antibiotics - particularly to young children? Parents and CF team often want expect antibiotics with every cough or cold. With increasing antibiotic resistance we should be more cautious?	P
522	What bacteria should we give (oral) antibiotics for - when grown on routine swabs from very well children.	P
523	Are we using too much PPI / for too long - eg risks on bone health or changing the gut/lung microbiome.	P
524	Now that children with Cf are so much healthier how can we work with those parents who don't think they need to give routine treatment to their child and only realise when their child is sick - so we lose the advantage of newborn screening.	P
525	What are the biological factors that contribute to decline in lung function in teenagers even when they are doing good treatment?	P
526	Does diabetes or high sugar levels effect lung function?	L

527	Do you think research should be done to look at any kind of treatment to allow males with cystic fibrosis have children naturally rather than ivf?	L
528	Flucloxacillin liqued tastes horrible and children stuggle to take it - is there a better alternative for the first 2 years when on it as prophylaxis?	P
529	Is specific exercise as good as regular chest physio using devices like the acappella?	P
530	which nebuliser device is best?	P
531	Does correction of hypovitaminosis D decrease the risk of aytpical mycobacterial infection in CF?	P
532	Is the use of unlicensed (generally intravenous preparations of) antibiotics via the nebulised route safe and effective in CF?	P
533	Does treating allergic bronchopulmonary aspergillosis with antifungal drugs improve outcomes?	P
534	What pharmacological treatments prevent or treat osteoporosis effectively in people with cystic fibrosis? (Oral bisphosphonates, intravenous bisphosphonates, calcium and vitamin D etc)	P
535	Is the use of parenteral iron in people with CF who are anaemic safe and effective? Is there a real risk of "feeding" infection by giving iron to someone with CF?	P
536	Should people with Cystic Fibrosis who grow Mycobacterium abscessus in their sputum be treated aggressively with antibiotics. If so: at what point? and with what antibiotics? for how long?	P
537	Given that we know tobramycin is safer given once a day is amikacin given once daily safer than multiple daily dosing?	P
538	Would a combination of inhaled antimicrobials given concurrently be more effective than a single antimicrobial in the suppression or eradication of Pseudomonas aeruginosa	P
539	What treatments make people with CF nauseated? How do we best treat nausea +/- vomiting in people with CF, and is that different in different people (age, gender, precipitating emetic etc).	P
540	How do people with CF want to be supported in taking their medication?	P
541	Despite dietary intake accounting for around 10% vitamin D levels why is deficiency so common in CF?	P
542	Does having a dedicated on site chef improve patients nutrition during an exacerbation?	P
543	Is azithromycin an effective prokinetic in patients with CF?	P
544	Does food education in CF patients lead to better nutritonal status and PERT efficacy?	P
545	What is the most effective vitamin D regimen to maintain vitamin D levels post repletion?	P
546	Evidence based treatments for CF related liver disease. How does ursodeoxycholic acid work in CF?	P
547	What are the barriers to adherence?	P
548	Are we taking a social or medical model approach to cystic fibrosis?	P
549	Are high doses of pancreatic enzyme use safe for patients with CF?	P
550	Does home IV therapy have a reduced impact on educational outcomes compared to hospital IV therapy?	N

551	Does parent academic level have an impact on patients disease severity/life expectancy?	P
552	Does patient academic levels have an impact on their disease severity/life expectancy?	P
553	Does geographical location have an influence on patients microbiology colonisation? (within UK and globally)	P
554	Does commencing regular venupuncture from birth reduce needle phobia/anxiety compared to starting at preschool age?	P
555	Is there an increased predopsition to develop autism if have CF mutation?	P
556	Does routine physiotherapy improve respiratory outcomes in "asymptomatic" infants?	P
557	effect of non medical prescribing in CF	P
558	How can I control exacerbations without promoting antibiotic resistance?	L
559	What makes bigger difference? Genetics, environment or behavior? Choose one.	L
561	Many people with CF (PWCF) like myself, who are in end-stage, are facing double lung transplantation as our only viable option. At present there are only so many immuno-compatibility features that can be identified and taken into consideration when attempting to find a good match. Post-transplant, the extent of the compatibility appears to determine to a large extent the risk of organ rejection. I would like research to find methods of increasing the amount of compatibility between donor lungs and recipients. This could be achieved by either treating the donor lungs somehow to make them more like the recipient, and/or increase the ability to understand and identify immuno-compatibility factors in donor lungs so that better matches with recipients might be achieved.	L
562	I would like to see research result in better management of an exacerbation from start to finish! Measuring sensitivities to antibiotics in-vitro for sputum samples is an art, not a science. A sample might originate from one lobe, whereas the exacerbation is centered in another for example. My experience has been hit or miss. But misses are costly in terms of financial resources, and time and quality of life as I spiral downward until some antibiotic or cocktail of two or more is successful in combating the infection. Sometimes it has been a fungal infection that was the culprit, while the standard assumption of a bacterial infection being the root cause was tried for several courses to no avail. I would like to see research that allowed a better identification of the particular bacteria causing an exacerbation, and a better method of selecting appropriate antibiotic(s) to deal with and defeat the infection first blow. But often lung function is slow to respond even after the infection has been cleared due to the inflammation that results from the treatment, and the ineffective manner in which CF lungs deal with the disposal of leukocytes (white blood cells). Controlling the inflammation more effectively (when, if and how much prednisone for example) would help patients return to a good quality of life far more quickly.	L

563	How can we detect, better treat, and, better yet, prevent PWCF from developing CF related diabetes ? While these complications only affect a portion of the CF population, their occurrence may increase as we see increases in lifespans of PWCF. Dealing with lung and pancreatic issues are sufficient for one person! I am concerned that such focus goes into dealing with the primary causes of death - lung issues - that we may find an effective control/cure for the lungs, funding for CF dries up, and diabetic issues are left unaddressed.	L
564	I was diagnosed with CF at 8 months. I am homozygous xxxx. I credit my active lifestyle and exercise as one of the main factors that allowed me to lead a relatively normal life, work up until my xxrd year, and outlive so many... basically all of my CF friends in my age group. I find that endurance and cardio exercises are stressed most for PWCF by our clinics and even the few personal trainers I have dealt with. However, in my case at least, it is lifting of heavy weights that induces coughing and is most effective in getting rid of sputum. I think ALL exercise provides benefits to PWCF. However, I think it would be worthwhile to study what types of exercise are most beneficial in terms of mucus clearance, stamina and maintenance of optimal FEV1, minimal hospitalizations and maximal quality of life. Maybe the answer is that one size does not fit all?	L
565	Kalydeco and Orkambi hold out much promise for those who are qualified to receive these drugs. While the upsides in FEV1 may seem modest in light of the hefty price tags that must be paid on an annual basis, the fact that they appear to be able to stabilize the risk of further deterioration might be of considerable benefit for those with FEV1 <40%, or especially for those with <30%, who are either in end-stage and not considering or not eligible for transplant, or to better manage the declines in health of someone awaiting transplantation until suitable lungs become available.	L
566	Does autogenic drainage help more than other adjuncts in airway clearance	P
567	What is the optimal time for dornase alfa to be nebulised before physio	P
568	What kind of exercise is best for patients with cf, and also pancreatic insufficiency who have a hard time gaining weight?	L
569	Do the new drugs (gene therapy) reduce burden of therapy (including time spent in physiotherapy) in cystic fibrosis?	P
570	Do you get a better outcome if you stay on inhaled/nebulised antibiotics while on IV antibiotics?	P
571	Are PWCF more adherent to a particular inhaled/nebulised antibiotic over another (eg Colobreathe over TIP or Cayston over TIP)?	P
572	Should asymptomatic infants be asked to start airway clearance as well as activity?	P
573	What treatments are PWCF who are non adherent most likely to take/do? (ie what treatment should I ask them to start with, then which to add in - eg exercise then tablets then DNase then airway clearance then inhaled/nebulised antibiotics?	P

574	Is there an additional benefit to adding high frequency chest wall oscillation to another technique such as PEP? (The McIllwaine and Osman studies point to HFCWO being less effective than other airway clearance techniques but don't show what happens when	P
575	What social/behavioral differences are there in non-White CF patients versus White CF patients that may contribute to differences in FEV1 percent predicted outcomes?	P
576	Differences in induced sputum versus expectorated sputum in adults	N
578	How do we define Cystic Fibrosis liver disease	P
579	How do we define DIOS, "suspected" and/or "confirmed	P
580	How should we treat "suspected" and /or "confirmed" DIOS	P
581	Does PPI treatment help fat absorption	P
582	Does PPI treatment increase chest infections	P
583	Impact of high fat diet on long life	N
584	What role do dysfunctional CF macrophages play in the initiation and progression of lung disease?	P
585	Should all children with CF take Staph prophylaxis from diagnosis and if so, for how long?	P
586	Is the emergence of NTM as a major pathogen in CF related to prior antibiotic therapy?	P
587	Are probiotics useful in helping CF patients' digestion and/or immune system?	L
588	Is ionic or colloidal silver a useful addition to antibiotic therapy?	L
589	Should cf hospital teams be more open to supplementary and holistic treatments alongside traditional treatments?	L
590	Does having a PEG feed overnight help underweight adults with CF gain lean body mass?	P
591	Does giving insulin to patients who have a raised 1 hour OGTT glucose level help them to gain/stabilise their weight/lean body mass and lung function?	P
592	What is the most effective composition for an enteral feed to promote weight gain in patients with cystic fibrosis ?	P
593	Does giving essential fatty acids to a patient with CF improve their weight gain/lean body mass gain/absorption of nutrients ?	P
594	Would the development of a patient reported outcome measure for gut symptoms in CF patients help to measure effectiveness of different gut treatments and diet therapies?	P
595	Disease modifying treatments	P
596	Is there an exercise plan that will help prevent osteoporosis in CF?	P
597	Is CGMS better than OGT for diagnosis of CFRD	P
598	Should we routinely supplement Vitamin K as well as A, D, and E	P
599	Does PEG placement lead to a gain in weight/ through the centiles or does it reduce oral intae	P
600	Optimal Vitamin D level	P
601	When, if ever, should flucloxacillin prophlyaxis be stopped?	P

602	What role is there for oral antibioitcs for new cough in CF?	P
603	level of comrbidity in family members, especially mental health	P
604	When should itraconazole be used for aspergillus - at first notification, scanty, +, ++, or +++, simlar fo stenotromonas and achromobacter	P
605	What is the benefit of using oxygen for patients with CF	P
606	Something about the physiological effects of prescribed exercise programmes to assist with exercise prescription.	P
607	How can we best promte compliance through the teenage years?	P
608	What makes the biggest difference to patients quality of life?	P
609	How can technology be best used to enable better deliver of CF care?	P
610	How can people with CF be best enabled to improve their adherence to medications, exercise and physiotherapy?	P
611	How can we use biomarkers to enable people with CF to detect early pulmonary exacerbations?	P
612	Is behavioural therapy a more effective treatment for eating 'issues' than a surgical intervention?	L
613	At what age should prophylactic flucloxacillin be stopped? Does it really prevent Staph infections?	L
614	Is exercise more beneficial for chest clearance than 'traditional' physiotherapy?	L
615	Is aerobic exercise more beneficial than muscle building exercise for people with CF?	L
616	Would a more considered/balanced dietary approach to weight management reduce the risk of developing cystic fibrosis related diabetes?	L
617	Does having cystic fibrosis affect the metabolism of mood regulators and hormones?	L
618	what is the best way for testing for pseudomonas	P
619	how should we educate children and young people about cf	P
620	what is the best way of diagnosing CFRD	P
621	What role does curcumin offer in cystic fibrosis?	L
622	What benefits does Orkambi actually provide in vivo?	L
623	At what BMI centile should enteral feeding be initiated?	P
624	Large multicentre trial of the use of appetite stimulants in CF eg cyproheptadine hydrochloride	P
625	Use of antioxidants in CF	P
626	Multicentre essential fatty acid supplementation study	P
627	Does sodium supplementation improve weight gain and growth in infants with CF? Large multicentre RCT	P
628	Does early insulin therapy improve nutritional and respiratory outcome measures in patients with impaired glucose tolerance?	P
629	Does a diet high in fat and sugar lead to an increased incidence of diabetes	P
630	Would a low FODMAP diet help with IBS like symptoms in CF (i.e. bloating)	P
631	What is the best practice in the field of sterilization of material employed for aerosol terapy at home?	L

632	Is lean tissue mass an important nutritional outcome in cystic fibrosis	P
633	What are current energy requirements in different genotypes of CF (studies looked at energy requirements many years ago but there is no new information in recent years and especially none for specific genotype)	P
634	Does it really mater if an individual is taking more than 10,000 IU lipase per kg?	P
635	Is there any evidence between the use of water soluble and fat soluble vitamin K suplementation in CF?	P
636	Does a high fat diet impact on heart health in later life?	P
637	Is there a link between breastfeeding & reduction in no. of courses of oral/IV antibiotics?	P
638	Can children be supported to learn fat-based Creon dosing from an early age?	P
639	Should we be doing DXA scans earlier?	P
641	Are probiotics indicated in all CF patients? Are they linked with improvements in lung function i.e. is there a relationship with lung and gut microbiota?	P
642	Is creatine supplementation associated with improvements in lung function?	P
643	Does exercise help with lung function	P
644	How people manage well with CF- qualities about those who live well despite CF	P
645	Getting older with CF - living through different life stages	P
646	Undiagnosis and CF	P
647	CF and boundaries in the family and in CF teams	P
648	1) What is the optimum amount of cardiovascular exercise a CF patient should do each day in order to aid secreation clearance?	P
649	2) What age should hypertonic saline be used in conjuction with Chest physio? - Studies into lower ages, but what is the best	P
650	3) Can low lung function be used as an idicator that a patient needs to be using positive pressure (IPPB) during treatment?	P
651	4) If an infant/ child is symptom free should parent's be doing physio anyway? - hazey area, conflicting opinions	P
652	What type of physiotherapy treatment has the best outcomes?	P
653	What type of exercise is best to recommend for CF patients?	P
654	What is it like to live with CF from a gastrointestinal/ bowel symptom perspective	P
655	What are the best exercise programmes to help improve lean body mass in people with CF?	P
656	What is the significance of being overweight and obese in peole with CF?	P
657	Is the initial improvement in FEV1 seen maintained in patients treated with Ivacaftor over time ?	P
658	When checking out the lungs all the time why don't you check on the heart ? There should be more test done on this area. The heart will work harder when the lungs are having a problem and sometimes you don't know it when it's to late	L

659	in which categories of CF patients powder antibiotics are better than inhaled ones?	P
660	long term efficacy and safety of Orkambi (phase IV clinical trial)	P
661	Do the benefits of oral steroids outweigh the risks for people with CF?	L
662	Do the benefits of high-dose ibuprofen outweigh the risks for people with CF?	L
663	Do the benefits of N-acetyl cysteine outweigh the risks for people with CF?	L
664	Are probiotics helpful for people with CF?	L
665	Is Bronchitol (mannitol) more effective than hypertonic saline as a mucolytic for people with CF?	L
666	Do breathing exercises help asthma	L
667	What is the best alternative to sinus surgeries to maintain clearer sinuses?	L
668	How can we improve the bowel performance of people with CF?	L
669	How can we improve the digestive system of people with CF?	L
670	Why do some people with CF produce much more sputum than others and is there a better way to clear the lungs for those who produce so much more sputum?	L
671	what are the other factors that make a person with CF produce sputum, other than the bacteria and fungi that are the usual reasons? We need a better understanding of the flora and fauna that is produced in the lungs of a person with CF.	L
672	Does the stomach flora of a person with CF have an impact on their digestive system and how can this be improved?	L
673	Why can't they make a man made protein identical to the protein people with CF don't produce	L
674	Why is there not more education/awareness on telling the public about CF	L
675	What Drugs Can improve Livers of patients with Chronic Liver Disease caused by Cystic Fibrosis	L
676	In Males that have a Vas Deferens, Is there a treatment that can flush or clear the tubes in the sperm duct to improve the sperm count of males with cystic fibrosis.	L
677	What causes the Blood pressure in the Right Ventricle to be increased in adults with cystic fibrosis	L
678	Are there any tests that can be done to ascertain Pancreatic function.	L
680	Do people with CF build muscle in a different way to non-CF patients? Does it take longer to build?	L
681	In a similar way to blood glucose monitoring, is it possible to identify a biomarker which can be monitored in order to quantitiatively state how much creon a patient should take for any given amount of food?	L
682	Given that it is known that liver damage has a tangible effect on hormone balance, should all adolescents with CF related liver disease have their hormone levels monitored on a regular basis.	L
683	Is CF primarily a disease of the gastrointestinal system with secondary pulmonary side effects?	L
684	How close are we to a cure?	L
685	Which airway clearance device is the most effective?	P

686	Does an increased awareness of cf & medications improve compliance?	P
687	Why is there so much inconsistency between centres re treatments given?	P
688	What key predictors are there for treatment adherence/success?	P
689	Does inhaled bicarbonate have a substantial impact on lung ph and change the environment for bacteria in the lungs of people with cf?	L
690	What is the impact on physical health and overall quality of life when anxiety and depression are more fully addressed	L
691	Do asymptomatic babies need to start chest physiotherapy at diagnosis?	P
692	What is the optimum time period for a course of intravenous antibiotics	P
693	Is a once daily nebulised antibiotic as affective as twice daily nebulistion in suppressent therapy for pseudomonas infection	P
694	Is once daily chest physiotherapy as good as twice daily in maintaining the asympyomatic airway (we routinely recommend BD chest physiotherapy)	P
695	Does ursodeoxycholic acid really do anything?	P
696	Are the time saving devices that combine nebulised medicines with physiotherapy, such as aerobiKA, just as effective as separating these things out? And does the medicine being nebulised by these machines reach as far down in the lungs?	L
697	Is there an optimum time to send on physiotherapy a day?	L
698	Does CF research cover investigation into the various different mutations of the CFTR gene?	L
699	1 At which point when your poorly do you call the team to say you need help 2 How does the patient know of Colmyicene is working or not ?	L
700	Why cf people often losing their voice...and have different one from other people?	L
701	Does the Tobipot inhaler works the same way as nebuliser antibiotics ?	L
702	Why does someone with cf who is dry when they cough still told to do phsio?	N
703	Why do cf patients still having to share bathrooms? Without adequate wards for cf specialist units.	L
704	Why does it take so long for your cf team to tell you of new treatments research In enhancing your wellness and quality of life	L
705	How to treat Burkholderia cepacia complex infectiion?	P
706	If a person with cystic fibrosis follows all their treatments as advised will they prolong their life and be healthier than someone who doesn't? Or can a person follow all their treatments and still decline in health at a young age e.g. 18-30.	L
707	Which airway clearance technique is best and for what age group?	L
708	If you do more airway clearance/physio than advised will this benefit you or be a waste of time?	L

709	Will there be improvements in equipment to have less impact on daily life e.g. smaller and discreet, enabling people to get on with tasks while using it?	L
710	What physiotherapy method is best for the tricky to treat pre school child?	P
711	Is exercise a sufficient substitute for more traditional airway clearance techniques?	P
712	What treatments can be withdrawn when disease-modifying drugs are initiated e.g. what nebulisers, antibiotics, supplements can be reduced or withdrawn with ivacaftor and/or lumacaftor? There is a tendency just to add and add treatments without taking away the ones that weren't working, or aren't needed any longer.	L
713	We often see exercise and different types of physiotherapy compared with each other. However I would like to see a pragmatic trial in which patients get to choose the form of treatment they do for lung clearance, then to see how that actually helps in practice. If people don't like what they are supposed to do, they won't do it. So this would not be intention to treat or randomised, it would be patients being taught or shown all of the options and then selecting their treatment and see whether this produces improvement over a period of time when compared with imposed treatment of one kind or another.	L
714	Are 14 day courses of IV antibiotics significantly better than 10 day courses? This could save disruption, time, money. It would have to be an equivalence or non-inferiority trial design.	L
715	Modification of treatment for older patients: as patients reach older age, some treatments offered to young people are no longer feasible or acceptable e.g. strenuous exercise, difficult and demanding physiotherapy. How can a treatment regimen be adapted for older and more frail patients? Initially there would have to be suggestions from patients as to what they find harder as they get older, and then suggestions for improvements, and finally trials. It isn't a simple question but one that needs addressing.	L
717	Does creon/enzymes work effectively any new enzymes??	P
718	Is airway clearance necessary in non productive patients?	P
719	what is the risk of cross-infection between people with CF	P
720	To improve understanding PKPD of common and new antibiotics and antifungals in CF patients- how do we know we are providing optimal dosing?- also in different special groups eg pregnant CF patients	P
721	Should all CF patients be prescribed the same baseline therapies like Omeprazole and Acetyl cysteine? How does CF impact on the digestive system as a whole, and what can be done to imorove related symptoms?	L
722	If my child jumps on the trampoline a lot and runs around does that qualify as Physio?	L
723	Can bicarb change the ph level in the lungs?	L
724	Does doubling or increasing airway clearance during an exacerbation help?	L

725	What is the effect of female hormones on CF symptoms and exacerbations? I ask this question due to personal experience of having a drop in lung function around the time of menstruation and increased digestive issues. I have recently started taking the mini pill (POP) and symptoms have improved. My understanding is that there is little research that definitively answers this question.	L
726	What role do psychosocial issues play in CF exacerbations and other undesirable symptoms, and how can these be managed? (Examples of psychosocial issues might be, housing, relationships, bereavement, education pressures etc)	L
727	Is exercise ever an acceptable alternative to physiotherapy? If so, in which patients? What type of exercise (Cardio, weight training, interval training etc)	L
728	What is the best form of exercise to increase lung function in patients with CF?	L
729	CF is different for every individual, is there any way to know to what extent a particular gene of cf affects lungs and or digestion?	L
730	Optimum time for initiating tube feeding - the time at which to strongly recommend that tube feeding be started. Patients/parents are usually very reluctant to consider this and often see it as a failure. Production of litrature to help people to see it as a more positive treatment.	P
731	Vitamin D supplementation when levels are low - lots of different protocols produced in different centres. Which one is the most effective?	P
732	How to administer PERT in patients who require tube feeding due to unsafe swallow/babies who are not yet able to swallow - again lots of advice from different centres but no concencus statement.	P
733	Fat soluble vitamin supplementation during pregnancy - what should we be doing particularly if levels are low	P
734	Does using a no. of enzymes to fat ratio improve malabsorption in PI patients? What to do if patients are exceeding 10,000lipase units per kg per day.	P
735	The optimum time for starting tube feeding?	N
736	Sodium supplementation - what is the national concensus?	N
737	Vitamin D supplementation when repletion required - lots of different protocols have been developed by different centres - which should we be using?	N
738	Vitamin supplementation in pregnancy.	N
739	Does using a no. of enzymes per g fat ratio help improve absoption in PI patients?	N
740	Concensus around administarition of PERT with tube feeding, when the patient is unable to swallow.	N
741	Is treating CFRD with diet and oral hypoglycaemic medication as effective as treatment with diet and insulin in terms of outcome measures for patients with CF ?	P
742	what is the prevelance in the use of unprescribed anabolic steroids in male patients with CF ?	P

743	In patients with CF who are identified as having hidden fat free mass depletion, can an diet and exercise programme increase fat free mass?	P
744	Can I do a lot of excerise instead of physio?	L
745	Surely doctors should be promoting healthy diets for people with cf rather than the junk filled diets they recommend. It is still possible to eat high calorie and stay healthy.	L
746	Does the monitoring of infant PFT using LCI etc, assist in better individual treatment and personalised care? Why is infant PFT not measured?	L
747	Why are probiotics not encouraged?	L
748	Is there a more accurate, non invasive way to check for the presence of pseudomonas etc in infants aside from cough swabs?	L
749	Does beginning PFT as infants using LCI etc, assist in better individual treatment and personalised care?	N
750	Are they any better, non invasive ways to check for pseudomonas etc in infants other than a cough swab?	N
751	What role can vitamin C have in keeping a strong immune system in individual with CF?	L
752	Although medications have been important, and some improvements have led to supplements for CF patients (ADEK, probiotics, digestive enzymes, glutathione, etc), more research is needed on additional supplementation (vitamins and minerals), specific important foods and nutrient based diet(egs. coconut oil, green vegetables)other natural substances (herbal remedies). List of harmful foods--artificial stuff, sugar, gluten, etc. CF doctors lack this knowledge, and CF patients who depend on their doctors are missing this information.	L
753	Encouraging (or discouraging) role of a lung lobectomy in CF patient? A doctor who performs the surgery for lung cancer is not qualified enough to assist a CF patient in making this decision. Not enough information is available for CF patients, and it remains a gamble.	L
754	It is difficult to find specific information on various mutations. More research to address mutation my niece was born with: xxxxx Not enough information on the xxxxx, considered rare.	L
755	Greater information is needed on maintaining the health of adults with CF. As the life span increases for CF, quality of life issues become more important. Doctors for adult patients with CF must be required to update themselves and partner with their patients to help them stay healthy.	L
757	Should all centres be using cardio-pulmonary exercise testing at annual reviews to assess ventilatory limitations?	P
758	Are exercise therapists better suited to exercise prescription in the CF population compared to physiotherapists?	P
759	Does exercise supplement airway clearance in cystic fibrosis?	P
760	Is percussion in CF as effective as baby PEP in infants? Or is one treatment more effective?	P
761	What age is appropraite to start using lung function tests as an objective outcome?	P
762	Are genes and environement a predictor of outcome, comparing identical twins with CF, in terms of how well they are? ie lung function, BMI, other CF related problems	P

763	Can nebulizing colloidal or ionic silver provide a synergistic effect when used before antibiotics such as Tobi? There is lots of anecdotal evidence from people with CF who have tried this and had good results & I've seen research that show a synergistic effect in vitro. There also doesn't seem to be any evidence that this is harmful, but the medical community seems to be very reluctant to try anything like this, & I just wonder why?	L
764	When nebulizing antibiotics such as Tobi or Cayston, is it better to use a mask or mouthpiece on the nebulizer?	L
765	There are many different types of nebulizers & compressors on the market, but which one is most effective at getting the medication where it needs to go? Also, is using a higher pressure compressor, such as the Invacare Mobilaire more effective than the smaller compressors like the Pari?	L
766	Is there any benefit to doing an activity like blowing up a balloon, which may produce a back pressure in the lungs?	L
767	Are there better/more effective alternatives to high sugar/carb for weight gain in pwCF?	L
768	What is the long-term impact of high sugar/carb load on CFRD outcomes?	L
769	What is the long-term impact of immunosuppression for non-lung Transplants on CF lungs?	L
770	Is bone fracture a risk in CF patients?	P
771	How to avoid lung infections?	L
773	To what extent are natural supplements (e.g. the combination of curcumin & genistein) able to support established treatments in pwcf?	L
774	How much can probiotics (and which strains) improve the outcome in pwcf?	L
775	Why does my daughter have recurrent stomach aches and loose stools leading to an orange oily discharge	L
776	Are physiotherapy airway clearence adjuncts more beneficial than exercise in the clearence of sputum?	P
777	PI patients rely on PERT to allow digestion and absorption. I have recently read research which suggests that n-3 fatty acids are not digested bY PERT and therefore may not be available for absorption in those with CF to some dgree. What is the likely impact of this on inlammation and general health?	P
778	Does exercise improve long term outcome?	P
779	Does daily airway clearance physiotherapy affect long term outcomes, is one technique better?	P

780	YO SIEMPRE SOSTENGO QUE DE FIBROSIS QUISTICA NADIE MUERE ¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡¡ . la gente fallece por deterioro pulmonar no por FQ. esto quiere decir que si habria un magico antibiotico que elimine las bacterias que colonizan los pulmones nadie estaria hablando de muerte en la fibrosis quisitca. El antibiotico sea el que fuere acelera la muerte de las personas con fq. porque lo unico que hacen los medicos al prescribirlo anticipadamente y para prevenir ante un esputo positivo con por ejemplo pseudomonas es atontar solamente las bacterias , hacerlas entonces mutar con lo cual se han multiresistentes y colonizaran los pulmones para comenzar con el detrioro inevitable e imparable que llevara a la muerte al apciente o al trasplante. (Translation) I have always believed no one dies from pulmonary fibrosis!!! People die from pulmonary deteriorarion not fibrosis. This means that if there were a magic antibiotic that couls eliminate the bacteria that colonize the lungs no one would be talking about cystic fibrosis death. The antibiotic be it whichever one is what accelerates patient death as the only thing drs do is prescribe it preventatively and to avoid incidence of positive sputum with things such as pseudomonas. All this does is mildly affect bacteria which then mutate and become resistant allowing them to colonize the lungs and thus begins the inevitable and unstoppable deterioration that results in death or transplant.	N
781	Are there any medications/supplements which support liver health in cf patients?	L
782	Likely sources of environmental pseudomonas and aspergillis. There are some studies but they are limited and it is hard with young children to know what to avoid.	L
783	Now that people with CF are living longer, the question of marriage and family becomes more of a reality. As a woman (26 yr old), married two years, with moderate, yet manageable CF, the question of family comes up. From research most females are able to conceive, but more research and data on the hardship of pregnancy on a CF mother, the CF drugs that can be modified during pregnancy, risk to the mother, etc would be something I would be very interested in.	L
784	What medicines for Type 2 diabetes are best for people with Cystic Fibrosis? I have discovered that Metformin and Kalydeco counter and cancel one another out since they are acting in opposition to change cAMP proteins in the cells, one trying to increase, the other decrease cAMP.	L
785	What can we as women do for incontinence as we age and encounter leakage due to coughing?	L
786	What are the impacts of CF on Womens aging? Do we enter menopause earlier? How do the changes in hormonal balance affect CF and exacerbation frequency and overall outcomes? Do we have more/worse osteoporosis or earlier onset? How can one distinguish between fevers due to exacerbations / colonized infections and hot flash fevers? Are the aches and arthritis/ inflammatory things common and associated with aging more pronounced when one has CF?	L
787	Continued research into more effective treatments for chest infections	L
788	Research on preventative measures to keep the bugs out of CF lungs	L

789	Research on the extent of pseudomonas and other bacteria in public and private swimming pools and similar	L
790	What will be the issues for adults if lung disease is curbed and they live for much longer? Will there need to be more research on dealing with damage CF causes to other organs (pancreas. liver ...)	L
791	My daughter has issues with her skin, particularly on her hands - it crinkles and peels when she has a bath etc, but I cant find any information on this. Can some extensive literature reviews be done to develop access to information on these "other" issues.	L
792	CF related arthritis and tendonitis - how common, how debilitating, what triggers/causes it, Best way to prevent and treat?	L
793	How exactly does CF affect drug absorption, distribution, metabolism and excretion? Eg what dose of cipro 1g bd actually is utilised in CF bodies, or high doses of iv abx eg tobramycin. More precise data on doses to use to get therapeutic effects similar to non-cf patients	L
794	Female fertility problems in CF. What are all the extra barriers to fertility that CF presents in women. and how to overcome these. Again... Are IVF drugs being used correctly, at high enough doses (ref previous question) to have effect?	L
795	CF linked to faster aging processes? Even in milder cases? If so, Should CF patients, be made aware of likely limitations in 'working life' time, especially when choosing a career path? Unlikely to reach state retirement age for example	L
798	When ll be treatment for Delta f508 ?	P
799	What are the implications and correlation between other conditions for those with CF diagnosed later in life? i.e. I have experienced many differing conditions from eye problems to frozen shoulder which I have been told could have a connection. I would like research to look at these and other issues that will only reveal themselves in those with CF as life expectancy gets longer.	L
800	I would also like to know about associated health problems with 'carriers' of the CF gene. My children both have similar health issues to those experienced with CF and yet they are only carriers.	L
801	Should our clinic be prescribing pro biotics to help compensate for overuse of antibiotics?	L
802	How can I (my child) avoid getting MRSA?	P
803	Should Orkambi be widely used or if not, how should patients be identified you are most likely to get benefit. (sorry only US problem)	P
804	Are combination acts ie ad with acapella superior to the 'pure techniques?	N
805	When should we initiate niv use in cf?	N
806	Does targeted outpatient Physio support ie weekly reviews reduce exacerbation rate / Ip days / days antibiotics in context of frequent admission	N

807	How much and what kind of exercise is optimum to improve/maintain lung function and reduce exacerbation frequency	P
808	What is the optimum duration of IV antibiotics and oral antibiotics?	P
809	Is aerobic exercise as effective as physiotherapy	P
810	Which is more beneficial aerobic exercise or chest physiotherapy to help maintain lung function?	P
811	Do people with CF still need to continue to do the same amount of CF care if they are taking Kalydeco?	P
812	Is the drop off in complience with treatment that we see in adolescent Individuals with CF sigifnicantly different from the lack of complience with treatment programmes in the general population?	P
813	Does environmental aspergillus load affect the incidence of ABPA?	P
814	How can nutrition is improved in childhood and adolescence to optimise growth?	P
815	How does physiotherapy benefit CF patients?	P
816	Does exercise benefit Cf patients	P
817	How can NIV be best introduced?	P
818	Can exercise in Cf influence bone disease?	P
819	Are there lifestyle choices that influence CF disease progression, and if so, how strongly?	P
821	The affect cf has on gastrointestinal problems- my son suffers greatly from reflux, which has caused food aversion and anxiety	L
822	About the affect of rarer gene types and if medications such as Orkambi can be used on the rarer genes e.g my son has heterozygous xxxxx which apparently is rare	L
823	Wether there is an alternative to the high sugar/ saturated fat diet- does it cause other problems if cf patients are living longer?	L
824	Now that my boy wcf is likely to live longer shouldn't our dietician be discussing good fats to avoid diabetes and other related issues.	L
825	What is the effect of long term use of antifungal medicines e.g.itraconazole, voriconazole and pozaconazole on immunosuppressent medicines e.g. tacrolimus and MMF.	L
826	Does the use of antifungal medicines following lung transplantation have a bearing on less successful outcomes and early rejection	L
827	How effective is the long term use of antifungal medicines e.g.itraconazole, voriconazole and pozaconazole in treating aspergillis colonization and delaying increase in lung damage.	L
828	What percentage of people with CF also have rheumatoid arthritis positive factor and do they have a worse prognosis	L
829	Do those with rheumatoid arthritis factor have worse prognosis following lung transplantation	L

830	What are the best sorts of exercises one can do to improve lung function when PFTs are in the 20-30% range (that will help rather than cause strain)?	L
831	Is there any way to prevent lung bleeds?	L
832	Could low testosterone levels be a factor in declining health or ability to carry out physio and treatments in male cf patients? E.g causing depression, muscle loss, appetite, anxiety etc.	L
833	The correct amount or a guide on digestive enzyme usage, how much is needed for meals to achieve nutritional benefit.	L
834	Are there any alternative methods to non-invasive ventilation to reverse or prevent hypercapnia?	L
835	does have regular ivs rather when needed improve lung condition?	L
836	will there be treatments for rarer genotypes?	L
837	What is the effect of antifungal medicines e.g.itraconazole, voriconazole and pozaconazole on immunosuppressent medicines e.g. tacrolimus and MMF and does their long-term use have higher risk and incidence of rejection of transplanted lungs.	N
838	Effectiveness of long term use of antifungal medicines e.g. itraconazole, voriconazole and posaconazole on aspergillosis colonization in lungs and respiratory system and impact on lung damage and lung function.	N
839	What % of people with CF have rheumatoid arthritis positive factor and what impact this has on outcomes.	N
840	Long term outcome for people with CF and Rheumatoid Arthritis who have undergone lung transplantation. Whether this results in higher incidence of early rejection.	N
841	How can we most effectively use antibiotics to treat symptomatic exacerbations without increasing the risk of creating an environment in the lungs that favours reduced microbiome diversity and multi resistant organisms?	P
842	Are sinus infections linked to lung infection/bacterial cultures?	L
843	Does the long term use of strong antibiotics affect joints in the body of young patients?	L
845	The impact of hormonal changes throughout the menstrual cycle on lung function and symptoms in women with CF.	L
846	Causes of chronic rejection in lung transplant.	L
847	Can stem cells be used to repair lung damage? How to lessen inflammation in the lungs? Can stem cells be used to repair the pancreas / can anything unblock the pancreas? Can anything stop CF diabetes from developing?	L
848	Why do so many relatively healthy or stable pwcf not have matching energy-levels in daily life? Aka: the numbers are ok, why do I still feel so crappy?	L
849	What is the most effective form of lung clearance (i.e. pep, exercise, vest, AD)	L
850	Poor compliance and adherence	P
851	Not really a question more a wish that Creon cd be improved so only have to take a few a day. My 5 yr old doesn't 'like people watching at school' and do worry abt future compliance, so wd be much better if could just take one at start of each neck/snack.	L

852	How can we get prompt access to important new drugs such as Orkambi? Do we need a different funding model or insurance scheme for rarer conditions such as CF?	L
853	How can we support/ accelerate getting the work of the UK GTC through to pharma company adoption? Can we ensure that if IP moves to non UK ownership that we ensure this is tied to access for those in the UK where the NHS is not cash rich	L
854	Not so much a question but a wish that Creon cd be improved so only had to take a few a day. My 5 yr old doesn't "like people watching" and even tho is super-compliant now worry abt future with this.	N
855	Are courses of IV antibiotics any more effective than home IV's?	L
856	Is enough research going on into other new small molecule drugs which may help people with class 1 mutations of CF?	L
857	Can anything be done to prevent the onset of CFRD?	L
858	Potential use of vaccines against common bacterial infections in CF.	L
859	Can DIOS be better prevented and treated?	L
860	Pancreatic changes in pwCF with relation to cysts and potential pancreatitis	L
861	Effects of aging. PwCF living longer often post transplant.	L
862	If a lady wcf is on Kalydeco, does it affect the baby during and after pregnancy?	L
864	Is it more dangerous living in London than the countryside? Ie, air pollution.	L
865	Why do certain medications work on some but not others, even with the same genomes and why some medication can have different side effects in different people?	L
866	Some form of physio that works as well as exercise for those who just can't or won't maintain an exercise routine.	L
867	Benefits of exercise in comparison to vest treatment.	L
868	Alternative antibiotic treatment for PA in children.	L
869	Use of natural therapies alongside traditional medication. E.g. benefits of garlic, turmeric, NAC, probiotics etc..	L
870	Access to reliable lung function apps.	L
871	Will there ever be a cure?	L
872	What's the long term risk (if any) of regular chest X-rays on PWCF? (By 'regular' I mean 4-5+ a year and I ask this question as a xx year old PWCF, post lung tx).	L
873	Is it worth it staying do 2 weeks in hospital for IV antibiotics if the lung function goes back after a week or two where it was ?	N
874	Will there ever be a day where medication solves the isolation of CF so other CFers mix?	L
875	Do sinuses become infected with bacteria before the lungs? Are they the first source?	L
876	Are Home IVs better for mental and physical health compared to inpatient stays (where possible)	L
877	Are children and teenagers with CF more likely to exercise if their parents do?	L

878	Are body image issues causing eating disorders and depression among those with CF?	L
879	Are tight hamstrings in people with CF affecting their ability to exercise at their maximum? CF patients are perpetually slow walkers due to their decreased lung function. Walking is one of the principle exercises to stretch and strengthen hamstrings.	L
880	Are children and teenagers with CF more likely to do exercise if their parents do?	N
881	Do probiotics help to keep the stomach healthy in babies on long term antibiotics?	L
883	Is exercise better than doing breathing treatments?	L
885	Isnt clearance of the mucus more important than taking the nebulised antibiotic ? If u could only do one	L
886	Link between menstrual cycle and chest infections and being more symptomatic days leading up to the period due date	L
887	To what degree can steroids immunosuppressive actions stop your bodies natural defence to infections?	L
888	What is the best diet for a person with CF? A high calorie diet or a healthy diet?	L
889	What type of exercise is best for people with CF? Is it all mainly about cardio, or should it just be about strength training so we could build muscle to help fight infection or a big mixture of both?	L
890	Is there any way to have a diet that works for both CF and CFRD that is seens as 'healthy' from the diabetic side of things.	L
891	The impact of CF on mental health and what impact it has?	L
892	Why do different CF infections affect different people.in such variant ways?	L
893	what is the optimum length of time for an elective course of intravenous antibiotics?	P
894	does quality of life and exercise tolerance improve in patients who are eligible for treatment with lumicaftor/ivacaftor Orkambi	P
895	How can we prevent the acquisition of unusual organisms such as Mycobacterium abscesses and Achromobacter	P
896	How can the adherence of young adult patients especially to their nebuliser treatments and pancreatic enzymes be improved?	P
897	Once a patient is established on e.g. Kalydeco/Ivacaftor, with improvement in sweat test and lung function, is it appropriate to stop some treatments, e.g. Dornase alpha	P
898	Do cold temperatures decrease lung function.	L
899	what's the age expectancy of someone who has mild cf?	L
900	One of the most devastating effects of Cystic Fibrosis is the inflammation it causes in the lungs which results in lung damage long term. Could researchers study Marijuana and its strong anti inflammatory properties to find new CF drugs that could reduce	L
901	Can we kickstart puberty using diet and lifestyle only?	L
902	Could cf genes be reprogrammed in utero?	L

903	Something ie one tablet to replace 9 Creon for a typical teenager meal	L
904	Could an implant release antibiotic to reduce daily intake?	L
905	Could he receive inhaler benefits overnight to cover basic daily needs? Top up manually if necessary ensuring lungs don't miss out if busy lifestyle	L
906	Does prophylactic antibiotic use in infancy predispose to chronic pseudomonas infection?	L
907	Are males born infertile or does the damage happen over time?	L
908	What will be the impact of the privatisation of the NHS on CF care/outcomes?	L
909	What interventions are there that can improve adherence during adolesence?	P
910	What is the optimal treatment approach for non-tuberculous mycobateria	P
911	Are antifungal treatments of benefit for CF patients	P
912	What treatment interventions should be provided in the event of low bone mineral desity as identified on bone scans	P
913	Does oral vitamin D improve psoriasis	L
914	How far have we moved forward in the cure for dd508 gene	L
915	Theres never any research on b cepcia, is there any planned for the futures?	N
916	What can make taking medicines more manageable in CF?	P
917	Do people with CF who live in rural environments have better clinical outcomes than those who live in cities?	L
918	What specific categories of exercise (e.g. strength training, interval training, endurance, yoga, etc) are most effective for increasing lung function.	L
919	Can a low sugar diet lead to sustainable health improvement for CF sufferers? (This is to address my concerns about CF dieticians promoting unhealthy eating habits to sufferers with the sole aim of weight gain).	L
920	Can regular psychotherapy lead to healthier (both in body and mind) CF sufferers? (The hypothesis being that chronic illness causes stress/depression/anxiety which in turn weakens the immune system, which in turn causes the physical symptoms of CF to get worse).	L
921	Does city living negatively effect CF sufferers? (Due to pollution, etc).	L
922	Would a nutritionally balanced high calorie diet based on Mediterranean eating patterns be better than current high calorie/low nutrition diets? Given that large trial data demonstrates high calorie med diets are associated with reduced inflammatory profiles and outcomes in a range of CV/transplant conditions, crossover to CF is likely.	P
923	Post-lung transplant care and quality of life issues. As more people are living longer with transplant, research is sorely lacking. All drug development seems to focus on lungs; what about those of us with non-CF lungs, but CF in the rest of our bodies?	L
924	CF diet! High fat/sugar/carb diet doesn't work well with CFRD--more studies into whether a healthier high-calorie diet (minus the difficult to digest animal fats that were always heavily promoted).	L

925	There seems to be little knowledge on CF liver disease and how to treat it--until transplant is necessary.	L
926	Other options for pancreatic insufficiency than insulin and digestive enzymes?	L
927	Why isn't pancreatic transplant more common?	L
928	Why aren't all people with CF screened for mental health issues at an early age? I certainly could have benefited...	L
929	What are the main causes of treatment non compliance in pwcf?	L
930	Which physiotherapy techniques are most effective relative to the time they take to complete?	L
931	How is female fertility impacted by malnourishment or being underweight?	L
932	What is the impact of pregnancy on the long term health of women wcf?	L
933	How many pwcf experience 'rollercoaster' lung function - when it jumps up and down over the course of a year but on average is stable - and what is the impact of this?	L
934	How do exercises such as weight lifting help lung function?	L
935	How have changes in dietry advice such as good fats rather than calorie content been applied to CF dietary recommendations?	L
936	What are the best combinations of antibiotics to treat infections in people with CF?	L
937	I have often found that having the flu jab makes me feel ill and triggers a pulmonary exacerbation. Yet I always have the flu jab because I think getting fully blown flu could kill me. Do the benefits of the flu jab always outweigh the harms for people with CF?	L
938	Alternatively, are there any strategies that could prevent flu jab triggering exacerbations or mitigate the harm e.g. pre-emptive/concomitant courses steroids or antibiotics?	L
939	What is the best form of airway clearance for people with CF and does it depend on the stage of disease?	L
940	What do changes in sputum volume, colour, viscosity tell us about day-to-day health of people with CF and overall disease progression?	L
941	Are all coughs a bad sign for people with CF or are there good coughs and bad coughs?	L
942	Management of heamoptysis	L
943	Which form of exercise is most beneficial for those with CF?	L
944	Is a high fat diet detrimental to health now people with CF are living longer?	L
945	Can the acquistion of NTM infections be causally-linked to bacterial reservoirs in patients' homes / common environments? If so, could some basic measures such as anti-bacterial shower hoses/heads help reduce acquisition of these bacteria?	L
946	Has the efficacy and safety of inhaled and/or ingested silver (colloidal and ionic) and also "essential oils" been established in CF? There are many in the community encouraged - often through Facebook groups - to try these 'natural' approaches as an adjunct to standard clincial care and blanket "possible dangers of..." guidance seems not to deter users.	L

947	Can the Swedish emphasis on use of complex trampoline/rebounder routines in paediatric CF physio be shown to improve heath outcomes over and above the UK standard approaches (PEP etc.). Would the "prescription" of free trampolines and instruction in such routines improve health outcomes for CF children?	L
948	This question is intentionally political and provocative: would a US-style health insurance system be better for pwCF than the NHS, given the US system provides access to high-cost novel medications that NICE rules out on the grounds of insufficient cost/benefit?	L
949	Can the US approch to cross-infection (gloves/gowns for examining physicians and mandatory mask-wearing when out of private rooms for patients) be shown to decrease cross-infection incidents? Ought these measures become global best-practice in CF?	L
950	Does vitamin k prevent kidney damage caused by antibiotics?	L
951	Why do my lungs feel better if I drink dark rum?	L
952	Why is male infertility taken so unseriously?	L
953	Is the suggested CF diet necessary?	L
954	Is physiotherapy necessary in young children when they can run around to clear any mucus. I believe it is early unnecessary treatments that put older children off	L
955	Is there a way of finding a drug that doesn't just treat or help the double genes but the rare genes and people with more than one?	L
956	Which antibiotics are most useful in cystic fibrosis (iv or oral or nebulised) for pulmonary exacerbations?	P
957	Why is there a lack of awareness of CF in the wider community (considering it is our most common genetic disease & 25% of our population are carriers of the CF gene)?	L
958	Does interventions that increase adherence lead to increased outcomes?	P
959	Should adult patients have Pseudomonas or other bacteria eradicated or not?	P
960	Can we manipulate the lung microbiome to "fight" different bacteria?	P
961	Is high calorie fat diet appropriate in the long run?	P
962	How can probiotic use help with GI function in CF?	P
963	How to treat depression in CF? is there an anti-depressant of choice in CF?	P
964	Pain control in CF.	P
965	Treatment of Burkholderia infection	P
966	Prevenction of kidney injury in cistic fibrosis?	P
967	Phishioterapy in asyntomatic newborns with CF screening diagnosis	P
968	Does alterted blood sugars effect Cf patient to same degree as non CF patients	P
969	How effected if Dnas any new treatments	P
970	Do alternative therapies such as Bowen therapy/ acupuncture etc have a value in CF treatment?	L

971	How important is phsical activity in relation to respiratory outcomes?	P
972	What proportion of children with CF take what proportion of their treatments (including physio), and which do they take? What interventions really make a difference to treatment concordance?	P
973	How you I explain CFRD to people?	L
974	I have CF are all my children carriers?	L
1029	What is the best type of exercise for babies with cf?	L
1030	At what age do breathing problems normally start?	L
1031	why is each person affected so differently? Is it due to genetics or surroundings?	L
1032	Do nebulised aminoglycosides cause hearing loss? (I am often asked this by the clinical team).	P
1033	What is the per course risk of hearing loss in patients treated with aminoglycosides and does it differ between drugs (e.g. tobramycin vs. amikacin)?	P
1034	How often should we monitor hearing in CF patients on aminoglycosides (both IV and nebulised)?	P
1035	Wie werden die Problemkeime wie z.B. Pseudomonas a. übertragen und welche Vorsichtsmaßnahmen müssen unbedingt im Alltag eingehalten werden bzw. welche sind überflüssig? Translation: How are the pathogens e.g. pseudomonas transmitted and what preventive measures should be implicitly adhered to in everyday life and which measures are unnecessary?	N
1036	Energy requirements in Cystic Fibrosis. We need large trials to measure energy requirements when stable and during chest exacerbation. There is insufficient evidence currently and patients require frequent clinical reviews for assessment for nutritional status.	P
1037	Do probiotics help improve bowel symptoms in cystic fibrosis? Which ones specifically help.	P
1038	How to treat a cf bowel with Dios including recammended diet and supplements	L
1039	How to keep symptoms of reflux disease under control to prevent surgery using diet. Currently oy way of treating is using medication and nissens fundiplication surgery which isn't hugely successful. There nees to be research into diet and eating for healthy digestion especially with aging population. Cf is not only a respiratory disease	L
1040	What type of enteral feeding product/formula is most beneficial to the majority of people with CF?	P
1041	What pancreatic enzyme replacement regimen including amount, timing, enzyme form (eg crushed, dissolved, added to feed) is most efficacious with enteral feedings?	P
1042	What is the effect of probiotics in CF? If there is a benefit,which probiotics are most beneficial?	P
1043	Does improve knowledge about adult age sexuality, pregnancy	P
1044	What the best way to sharing with patient transplant time?	P
1045	a difficult comparison with food in no well patients	P
1046	does improve the team communication	P

1047	Is there any research into natural remedies to augment (not replace!) current treatment? Things like garlic, starflower oil, cutting out milk, turnip - things that naturally reduce inflammation, loosen mucus. Could it be made more acceptable to incorporate natural remedies into daily life, without medics poo-pooing the idea? Is there any research that shows it could be beneficial? To me I'd try everything to help inflammtion / loosen mucus on top of existing treatments and vitamins, which may or may not aid what we do already. Eg, does milk really make mucus stickier, and if possible, should some people with CF (PS?) be encouraged to cut down; could peppermint oil be used in conjunction with laxatives to reduce bloating? What other supplements have been proved (or could be proved) to aid digestion / airway or gut inflammation / bowel mobility / mucus mobility.	L
1048	Should pancreas sufficient people with CF be taking supplementary vitamins, despite good absorption? Would it be beneficial? Vitamins including but not restricted to the fat soluble vitamins.	L
1049	What's the best course of action to treat a severe chest infection when kidney and liver function are already unstable, and may be for the foreseeable future? Currently it seems the course of action is to give reduced IV antibiotics (dose and time), but this can result in recurring infection and long term damage to the liver from the infection. Is there a way around this?	L
1050	Can we get islet cell transplants to treat CFRD? Please? Especially those who are already immunosupressed.	L
1051	Hängt der sinkende FEV1 Wert mit der Verstärkung von Schmerzen in den Gelenken zusammen? Tr: Can the decreasing value of FEV1 be linked to an increase in joint pain?	N
1052	Would compliance increase if all nebs were portable like an Ineb? Especially 3x a day drugs, such as azli, which currently can only be done through an Eflow (which despite reasonably small and fast) isn't as portable and cable-free as an ineb. Can all nebs be made more portable, for example like electronic cigarettes?	L
1053	Should physiotherapists be asking CF patients to routinely do airway clearance when they are asymptomatic?	P
1054	why administer to a baby girl of 3 months an antibiotic for the presence of the bacterium streptococcus ?	L
1055	What are the most appropriate antibiotics for infants with CF	P
1056	How much salt should children with CF have in their diet	P
1057	How do we prevent CF liver disease?	P
1058	How do we detect and treat CF related diabetes	P
1059	Should we be eradicating MRSA from the airways?	P
1060	Developing ways to engage teenage girls (11 yrs to 17) in sport/ activity/ exercise in the community.	P
1061	Breathing pattern dysfunction rates in CF and effects/benefits of breathing pattern retraining and relaxation	P
1062	Musculoskeletal issues in CF and common practice treatments, how to up skill physiotherapists with MSK skills and confidence.	P
1063	Use and benefits of holistic therapies in CF (yoga/massage/acupuncture/reflexology)	P

1064	Ways of utilising undergraduate physiotherapist and community based exercise professionals to improve pwCF activity levels.	P
1065	In the USA, respiratory physiotherapy is not an essential part of the care in CF. Here in France it is one of the most important part. Has the impact of respiratory physiotherapy been evaluated and if yes can we explain why in the USA patient who do not have respiratory physiotherapy are nevertheless in the same global condition than the French patient in the end ?	L
1066	How can you prevent liver and gall bladder from "damage"? Is "Ursofalk" effective?	L
1067	Phage therapy	L
1068	Which cf patients are more healthy: The ones who are very eager with their therapy an do inhalation, breathing exercises, vitamins as often as recommended - or the ones who take therapy only as second important after having fun?	L
1069	What are the influences that prevent the lungs from pseudomonas aeruginosa and the influences that make the lungs more prone? I wonder why someone get an infection though they didn't even know there was a "dangerous situation" while others don't get an infection though they made "serious hygienic mistakes".	L
1071	Help with stomach cramps	L
1072	Is there any treatment under development for patient with Delta F508 combined with 1811+1,6KBA mutation?	L
1073	How can be reduce the negative impact of antibiotic?	L
1074	Does combining PEP and nebulised hypertonic saline help with airway clearance?	P
1075	Does baby PEP have any adverse effects particularly in a baby with an increased work of breathing?	P
1076	Does CPET correlate with HR QOL better than FEV1?	P
1077	Would combining a Vest with ACBT or another ACT enhance the effects of that ACT?	P
1078	Bringt Homeopathie etwas bei der Behandlung von CF? Zum Beispiel Symbioflor 1, für die Verbesserung des Immunsystems Tr: Can homeopathy yield positive results for the treatment of CF? E.g. symbioflor 1 for the improvements of the immune system?	L
1079	Wie sieht es aus mit der Antibioutika Resistenz von CF Patienten? Tr: 4.What is the antibiotic resistance like in patients with CF?	L
1080	Mit welchen Inhalationsmedikamenten erzielt man dei beste Wirkung? 0,9 oder 3 oder 6% NaCl dann auch: Salbutamol und Atrovent Tr: 5.Which of the inhalation medications have the best effect for patients with CF? 0,9, 3 or 6% NaCl? What about salbutamol and atrovent?	L
1081	Welche Nebenwirkung hat die Langzeitbehandlung von (inhaliertem) Cortison? zum Beispiel Sanastmax oder Pulmicort, Gibt es dort Unterschiede? Tr: What are the side effects of a long-term treatment with cortisone (inhalers)? E.g. sanastmax or pulmicort. Are there any differences?	L

1082	Gibt es Möglichkeiten die Fruchtbarkeit von CF-Patienten zu erhöhen? Translation: 7.Are there any known measures for increasing the fertility of patients with CF?	L
1084	Should children be given daily antibiotics ie flucloxacillin?	L
1085	Should probiotics be given as part of cf daily treatment?	L
1086	Does a diet high in dairy products potentially increase mucus build up?	L
1087	Which treatment is best for a 19 month old, baby pep or patting?	L
1088	What form of exercise is more beneficial for CF patients?	P
1089	is FEV1 reliable? is exercise capacity a greater predictor?	P
1090	Is poor hospital food during admissions detrimental to health and well being- including financial stress of having to pay for own food which is often costly?	L
1091	For patients with CF-related diabetes, why are they told to follow the CF diet rather than the diabetes diet? The CF team do not address the diabetes.	L
1092	Is the use of Ventalin effective for CF patients?	L
1093	At what point do oral antibiotics become ineffective?	L
1094	Is exercise better than physiotherapy?	L
1095	What is the best way to increase the amount of vitamin D in a CF patient?	L
1096	What is the actual treatment for cf arthritis	L
1097	At what point is there no going back with treatment	L
1098	For patients with CF-related diabetes, why are they told to follow the CF diet rather than the diabetes diet? The CF team do not seem to address the diabetes.	N
1099	How do you balance a weight-gaining diet with all of the side-effects caused by CF? (Liver disease, diabetes, inability to digest fat properly from CF, so on)	L
1100	Why isnt it possible to test all Girls for the Cf Gene? Knowing to be a Carrier would makevCF extinct within 2 Generations	L
1101	What can be done to help with coughing syncope? To prevent the episodes.	L
1103	when will there be a cure?	L
1104	what is research?	L
1105	Does moving infected mucus from deep lobes of the lung cause infection to spread throughout the lung?	L
1106	What is the single most important piece of advice which should be given to people grappling with CF for the first time - parents?	L
1107	With current research vilifying sugar and much press to promote avoiding it, is the impact of a high calorie diet involving high intake of sugar understood for CF patients? If the additional calories needed are obtained from other sources, such as healthy fats, rather than sugar, does this have a positive effect on overall health?	L

1108	Welche Schmerzmittel und in welcher Dosis sind wirklich wirksam bei CF Patienten? Which pain killers and in which dose are highly effective for patients with CF?	N
1109	Wie kann Patienten geholfen werden,bei denen Enzyme nicht helfen?(Ich selber nehme bis zu 80 Kreon 40.000 er und habe trotzdem Durchfall!) Tr: How can patients for which enzymes are ineffective be helped? I take up to 80 Creon 40.000 and despite this, I still suffer from diarrhoea.	N
1110	Can we improve antibiotic susceptibility testing of sputum/BAL samples so that it better predicts which antibiotics will actually work?	P
1111	Is there a similar drug as Kalydeco for those with one strand of DF508 and one non-DF508 strand?	L
1112	Is there a benefit to reducing sugar intake in CF diets?	L
1113	How effectively is the research and understanding into the CF digestive system. Are there planned drug advancements for improving/replacing Creon/pancreatic enzymes.	L
1114	How much more effective are other types of physiotherapy compared to the current standard, breathing techniques.	L
1115	Does travelling by train or in particular aeroplane negatively impact the lungs of people with CF.	L
1116	Are children and adolescents with CF properly supported by their school staff?	P
1117	How do CF pupils relationship with their classmates look like?	P
1118	What is a perceived social support of CF children parents?	P
1119	Does regular intense aerobic exercise e.g cycling improve lung function and general well-being in those with Cystic Fibrosis?	L
1120	How effectively are we addressing the issues of the digestive system. Is a 'junk food' diet still to be encouraged?	L
1121	If e-cigerretes can vaperise a fluid containing nicotine, why can this not be done with antibiotics? Easier to carry about	L
1122	The amount of hospital admisions by a patient on Orkambi?	L
1123	Considering that the life expectancy of people with CF is increasing greatly, will menopause have any adverse effects on women and their disease management?	L
1124	Should/could we be developing vaccines against the most destructive variants of bacteria? e.g. Pseudomonas aeruginosa, B. cepacia.	L
1125	should the use of PPE for patients (particularly face masks - vogmasks) be encouraged when attending clinic and/or inpatient stays.	L
1126	could altering the gut microbiome have a positive impact on a persons appetite?	L
1127	How to Normalise CFTR function	L
1128	Transplants	L
1129	what is the best diet to maintain health with CF.	L

1130	what type of exercise is best for maintaining health, aerobic, strength or stamina is the best for lung function and fighting infection.	L
1131	How can we improve knowledge of the CF gut ?	L
1132	What are the precursors of CF Related diabetes ?	L
1133	What is the best diet (food and liquid intake) for adults suffering from chronic constipation/DIOS?.	L
1134	What can be done to prevent renal toxicity, as result of iv antibiotics ?	L
1135	What is the best diet for renal impairment ?	L
1136	Is liver disease more common in children having been on TPN+lipids than those who had not?	L
1137	What is the best way to clean, dry and store a nebuliser. People use so many different methods. A survey said that bugs were frequently found in nebs - this seems important!	L
1138	Does Buteyko (or other breathing technique) help with CF?	L
1139	Does acupuncture have any effect on improving any aspects of CF?	L
1140	If there ever was a cure, how likely is it that it would be available on the NHS?	L
1141	What are the implications of having two children with cf? Being that people wcf should not come in contact with another.	L
1142	Why are those with certain bacteria excluded from most studies?	L
1143	Are there benefits to people with cystic fibrosis, CF teams and/or economic benefits where non medical prescribing is used in CF services?	P
1144	Why shouldn't people with cystic fibrosis be around smokers?	L
1145	If people with cystic fibrosis can't be together why are me and my brother together?	L
1146	Welche Parameter führen zu einer höheren Infektionsrate mit Problemkeimen? Welche Hygienemaßnahmen müssen in der Schule unbedingt beachtet werden? Translated: Which parameters may lead to an increased infection rate due to pathogens? Which hygienic precautions must be implicitly taken at schools?	L
1147	Wie lässt sich eine gute Therapieeinsicht seitens eines jungen Patienten erreichen? How can one gain valuable therapy insights from young patients?	L
1148	Warum sind viele Patienten mit Pankreassuffizienz untergewichtig? Mögliche Therapien? Translated: Why are so many patients with pancreatic insufficiency underweight? What therapy options are there?	L
1149	Is the vest better than PEP physiotherapy in children/teens?	L
1150	How does a rare, or unidentified gene mutation, affect outcomes in people with CF?	L
1151	What is the best CF diet for children/teens while they are still growing? Particularly interested in higher protein lower carb diets, restricting sugar from processed carbs, and potentially finding a way to gain weight without rubbish food.	L
1152	Would low carb/high protein diet have ANY effect on a person with CF's chances of developing CF related diabetes?	L

1153	What is the best sport to improve lung function?	L
1154	As bacteria feed on sugar, could studies be done on a sugar substitute eg xylitol - can bacteria survive by feeding on xylitol?	L
1155	How best to use parents and carers as a resource in supporting teens and young people with CF	L
1156	is aspergillus under-reported in younger patients?	L
1157	How can parents be best used as a resource in supporting teenagers and young people with CF?	N
1158	Aspergillus has been shown to be more common than thought. What do patients/carers actually know about this infection and treatment. Ditto HC professionals, particularly those caring for younger children.	N
1159	Is an overdependence on high sugar foods detrimental for lung health	N
1160	How does CF change as you get older (over 50) and does treatment need to change to reflect the age of the patient?	L
1163	Why are all children not put on the same preventative medication?	L
1164	Which small molecule (potentiator / corrector) combination is best for each mutation combination?	N
1165	Gastroenterologists should be involved in treating CF. Should there be replacement enzymes to help digestion of Carbohydrates, proteins, fats, and these be titrated to needs and patients diet.	L
1166	Gastroenetreologists should be involved in treating DIOS in CF. What is the role of diet, enzymes, roughage in development and re occurence of DIOS.	L
1167	Diabetes in CF. This is neglected in CF. Is there such a thing as CF related diabetes, or is it type 1 diabetes in patients with CF. Long term damage caused by diabetes occurs in adult cf patients - to the extent that they may not be accepted for lung transplant because of kidney damage (some caused by neglect of diabetes, some caused by aminogylcoside ABs)	L
1168	How to prevent and treat DIOS	N
1169	Is there CF related diabetes , or is it type 1 diabetes (with CF)? The population of adults with CF is getting older, so long term diabetes problems are occuring in CF patients	N
1170	How can we titrate diet to individual needs in CF ?	N
1171	What effect does frequent snacking/high calorific diet have on the development of DIOS/ chronic constipation ?	L
1172	Is the current recommended diet (with sugar/high carbs) REALLY the healthiest for CF patients , particularly those with CF diabetes ? Why isn't MCT oil suggested ? (Voices in the wilderness call for a 'healthy 'diet, on which they keep well. The former 'low fat' diet was preached even when Toronto was getting better survival rates.) Is there room for a rethink & compromise?.	L
1173	Can the control of blood sugars be improved by conventional diabetic education (in rest of Diabetic world) counting of carbs, dietary advice , even continuous glucose metering, rather than the 'poke and hope' of last 25 years?.	L
1174	How to reduce inflammation in the lung in children with CF?	L

1175	How to reduce sinusitus in CF patients?	L
1176	How can we detect, better treat, and, better yet, prevent PWCF from developing liver disease? While these complications only affect a portion of the CF population, their occurrence may increase as we see increases in lifespans of PWCF. Dealing with lung and pancreatic issues are sufficient for one person! I am concerned that such focus goes into dealing with the primary causes of death - lung issues - that we may find an effective control/cure for the lungs, funding for CF dries up, and liver-related issues are left unaddressed.	L