

STIMULATE-ICP Delphi Study

Transition from Survey 1 responses to Survey 2 statements

Table of Contents

Definitions	3
Summary statements about ICP for LC Healthcare provider group review	4
Take a collaborative approach including a range of specialist support (MDT) and agreed criteria for support	4
Provide consistent, comprehensive care which is easy to access and minimises the burden for patients	5
Ensure patients and clinicians have/share knowledge and understanding of symptoms, self-management and services available	6
Provide opportunities for community support	6
Offer support relating to employment and sick notes	7
Offer relevant screening and diagnostic tests and investigations, rule out other problems	7
Ensure team skills and resources are appropriate to provide a multi-service approach	8
Offer patient-centred care	8
Include long-term care with reviews of health, care provision and personalised care plans	9
Provide evidence-based care	10
Share information between services	11
Provide care manager	11
Provide self-management advice	11
Offer staff supervision/managerial support and have resources/funding	12
Summary statements about ICP for LTC Healthcare provider group review	13
Take a Biopsychosocial approach to care	13
Ensure good communication between healthcare providers	14
Provide consistency in care provision (care-manager), ongoing support and monitoring	15
Offer easy access to specialist support for multi-system problems with collaborative care approach	16
Provide evidence-based treatment and recommendations	18
Take a patient-centred approach	19
Ensure services have appropriate resources	20
Support self-management	20
Offer social and community support	21
Use unified electronic healthcare records	21
Offer relevant screening and diagnostic tests and investigations, rule out other problems	21
Summary statements about ICP for LC Patients group review	23
Provide diagnostic assessment	23
Offer easy access to specialist support for multi-system LC problems with collaborative approach	30
Provide patient centred approach	40
Offer reviews of care and provide ongoing support	48
Provide evidence-based treatment and recommendations	51
Provide employment support and sick note	53
Provide access to research	53
Encourage early intervention	54
Ensure services have appropriate resources	54
Provide no psychological treatment	55
Avoid (graded) exercise as a treatment in case of PEM	55
Offer advice on pacing	56

Provide fatigue management _____	58
Provide breathing exercise _____	58
Provide care manager _____	59
Provide psychological support _____	59
Provide biopsychosocial model of care _____	60
Provide self-management advice _____	61
Provide no lifestyle interventions _____	61
Summary statements about ICP for LTC Patients group review _____	62
Provide patient centred care _____	62
Provide evidence-based treatment _____	65
Take a Biopsychosocial approach to care _____	68
Offer appropriate screening/diagnostic tests and investigations and confirm a diagnosis _____	70
Offer ongoing support with reviews of care _____	71
Provide consistent support which is easy to access and offered by a consistent care provider/care- manager _____	73
Provide collaborative care linking services between primary care, hospital and mental health settings _____	74
Provide support with employment, sick notes, access to benefits _____	75
Provide self-management guidance _____	75
The service should be properly funded/have access to resources _____	76
Original statements associated with combined LC or LTC statements _____	77
LC or LTC statements associated with combined statements used in Survey 2 _____	81

Definitions

Abbreviation	Description
AHP*	Allied health professional
BPS*	Biopsychosocial
CBT*	Cognitive behavioural therapy
CFS*	Chronic fatigue syndrome
CMHT*	Community Mental Health team
CNS*	Central Nervous System
CT*	Computerised tomography
EBM*	Evidence-based medicine
ECG*	Electrocardiogram
ENT*	Ear nose throat
F2F*	Face to face
FND*	Funcational Neurological Disorder
GET*	Graded exercise therapy
GP*	General practitioner (Primary care doctor)
HCP*	Healthcare professional
HCW*	Healthcare worker
IBD*	Irritable bowel disease
ICP	Integrated care pathway(s)
ICU*	Intensive care unit
K&S*	Knowledge and skills
LC_HCP	Healthcare professional experience of supporting people with Long COVID
LFT *	Liver function test
LTC_HCP	Healthcare professional experience of supporting people with long-term conditions
MCAS*	Mast cell activation syndrome
MDT	Multi-disciplinary team
ME*	Myalgic encephalomyelitis
MH*	Mental health
MI*	Motivational interviewing
MRI*	Magnetic resonance imaging (scan)
MS*	Multiple sclerosis
NICE*	National Institute for Health and Care Excellence
O2*	Oxygen saturation
OT*	Occupational therapy
P_LC	Patients with experience of Long COVID
P_LTC	Patients with experience of long-term conditions
PEM*	Post exertional malaise
PESE*	Post exertional symptom exacerbation
PH*	Physical health
POTs*	Postural orthostatic tachycardia syndrome
Ps ID	Survey 1 unique participant identification number

*Abbreviations from survey responses. Description is based on general knowledge of the field but may not accurately reflect the meaning of the participant response.

Summary statements about ICP for LC Healthcare provider group review

Statements with associated original survey responses for group comments:

Take a collaborative approach including a range of specialist support (MDT) and agreed criteria for support		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1246	HCP_LC	MH and PH integration at a system/service level but also generic MH/PH K&S including e.g. coaching, MI
S1249	HCP_LC	greater integration of community, secondary and social care for patient pathways
S1296	HCP_LC, HCP_LTC	Joint working between rehabilitation and respiratory services
S1246	HCP_LC	Working with primary care to support learning, screening and using socila prescribers
S158	HCP_LC, HCP_LTC	MDT assessment
S1236	HCP_LC, HCP_LTC	Multidisciplinary support to include physical and mental health impacts
S1245	HCP_LC, HCP_LTC	working with multidisciplinary colleagues
S1246	HCP_LC	integration of MH/PH services
S1249	HCP_LC	multi-disciplinary working
S184	HCP_LC, HCP_LTC	use of inter-specialty MDT meeting - patient stay under the care of one cons/HCP but gain opinion from other specialists in a timely way avoiding ping-ponging throughout various specialties
S1249	HCP_LC	cross sector working
S1242	HCP_LC	multidisciplinary approach
S1187	P_LC, HCP_LC, HCP_LTC	When it is right to use services outside of primary care. Most people can be looked after well in primary care
S1249	HCP_LC	sharing of medical records across sectors
S1236	HCP_LC, HCP_LTC	Treatment/rehabilitation offered in parallel with specialist investigations (where appropriate)
S1182	HCP_LC	Patients would have an AHP keyworker who would be able to speak directly with consultants, not just Respiratory. At the point of referral the AHP would be able to review the referral with a GP advisor to ensure all relevant tests had been completed. The AHP would have supervision with a Clinical Psychologist to ensure that practise acknowledges the trauma that patients experience in having a condition that is poorly understood. The AHPs would have regular in service training fr
S1242	HCP_LC	multidisciplinary team which is hospital based and closely linked with professionals in the community, offering longitudinal support
S1246	HCP_LC	HCWs trained in core skills of MH and PH, coaching, MI. Shared records/ shared patient/shared care - independent of organisation, tiers of care. 3rd sector and e.g. built into pathways. Can't forget the patient voice at all levels

S1182	HCP_LC	Being able to discuss patients with other secondary care specialists: ENT, neurology, cardiology would be helpful
S1296	HCP_LC, HCP_LTC	Strong charismatic leadership, motivated MDT team, good capacity, as unified physical environment as possible
Provide consistent, comprehensive care which is easy to access and minimises the burden for patients		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1182	HCP_LC	An MDT which provides access to a variety of specialists within secondary care, not just a Respiratory Consultant
S161	HCP_LC, HCP_LTC	easy access to therapies
S1182	HCP_LC	Access to a GP advisor and Respiratory Consultant
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Access to all professionals and investigations by each member of the pathway and clearly defined ideas of what each person's responsibility/ area is
S168	P_LC, HCP_LC	single point of access
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Rapid access for assessment
S162	HCP_LC, HCP_LTC	reduce barrier to referral - e.g. long list of mandatory investigations/ long waiting lists
S1249	HCP_LC	breakdown barriers for referral to long covid services, stop GP's being gatekeepers
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Referral
S158	HCP_LC, HCP_LTC	Timely referral to other agencies
S1266	P_LTC, HCP_LC, HCP_LTC	Cover all symptoms, concerns, expectations
S1296	HCP_LC, HCP_LTC	Focus on pattern of symptoms and their fluctuations to reduce the burden of the symptoms
S1204	HCP_LC, HCP_LTC	Try to address multimorbidity in-house and minimise multiple referrals and appointments
S184	HCP_LC, HCP_LTC	holistic approach - complex interventions which can manage LC and pre-existing LTCs - appropriately skilled workforce - avoid duplication of interventions
S1187	P_LC, HCP_LC, HCP_LTC	single appointments to cover all of the health issues in one place. but these must be long enough! e.g. 1 hour per patient
S1142	P_LC, HCP_LC, HCP_LTC	Holistic care
S1245	HCP_LC, HCP_LTC	continue to work holistically with realistic goals
S162	HCP_LC, HCP_LTC	holistic approach
S1187	P_LC, HCP_LC, HCP_LTC	Biopsychosocial model of care

S1187	P_LC, HCP_LC, HCP_LTC	Integrated holistic care across different systems of the body
S1204	HCP_LC, HCP_LTC	proactive approach to holistic health and wellbeing
S1142	P_LC, HCP_LC, HCP_LTC	Screening & referrals & evidence based treatment offered
S1296	HCP_LC, HCP_LTC	Prompt assessment
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	More time is needed than just 10 mins.
S1266	P_LTC, HCP_LC, HCP_LTC	Time to listen
S1249	HCP_LC	one stop shop where a patient is referred into and can access whatever services they need - physical, mental, social, vocational assessments/investigations/treatment/rehab/support
S168	P_LC, HCP_LC	we have time to listen
S1246	HCP_LC	Deliver blended approach of f2f/clinic/App/telephone
Ensure patients and clinicians have/share knowledge and understanding of symptoms, self-management and services available		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S184	HCP_LC, HCP_LTC	Symptom based self-management (I'm assuming in integrated care refers to primary/community care?)
S1204	HCP_LC, HCP_LTC	Maximise opportunities for self-management and to manage LTCs within existing integrated services in the community.
S166	HCP_LC, HCP_LTC	Patient access to up to date information
S162	HCP_LC, HCP_LTC	explanation of condition/treatment
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Make sure referral pathways are clear and information about the service is available to patients before they attend so they know what to expect
S1249	HCP_LC	expectation management of what the patient can do for themselves and what treatment options are available on the NHS
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Practical help
S1182	HCP_LC	Being honest about what the service offers and that there are no quick fixes
Provide opportunities for community support		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1242	HCP_LC	community support
S1293	HCP_LC, HCP_LTC	support groups

S1242	HCP_LC	patient groups
S1246	HCP_LC	be able to offer peer support
S1246	HCP_LC	peer support
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Innovative use of video platforms to educate patients no self-management, lead by other patients
Offer support relating to employment and sick notes		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1249	HCP_LC	better support for return to work, NHS policies on return to work are not fit for purpose
S1142	P_LC, HCP_LC, HCP_LTC	Help with negotiation with employers
Offer relevant screening and diagnostic tests and investigations, rule out other problems		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S161	HCP_LC, HCP_LTC	access to diagnostic tests
S184	HCP_LC, HCP_LTC	Blood tests to exclude / treat other reversible causes of symptoms eg anaemia, hypothyroidism, vit D deficiency, myositis
S1142	P_LC, HCP_LC, HCP_LTC	Investigations to rule out other causes
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Relevant investigations
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Access to testing and expertise.
S1236	HCP_LC, HCP_LTC	Treatment/rehabilitation offered in parallel with specialist investigations (where appropriate)
S1246	HCP_LC	key investigations completed by GP
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Performing relevant investigations and acknowledge their limitations
S161	HCP_LC, HCP_LTC	Rapid access to scans
S166	HCP_LC, HCP_LTC	Unexplained symptoms actively investigated.
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Routine bloods and correcting deficits eg vit D, hba1c etc
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Address the issue of normal investigations doesn't mean isn't a problem and don't dismiss purely on this basis
S1204	HCP_LC, HCP_LTC	Exclude other causes (may require diagnostics)

S1181	HCP_LC	Excluding other diagnoses
S1236	HCP_LC, HCP_LTC	Exclusion of alternative diagnoses
S1266	P_LTC, HCP_LC, HCP_LTC	Exclude other treatable causes
S1182	HCP_LC	Ensuring that other conditions that cause the same symptoms have been ruled out
S1142	P_LC, HCP_LC, HCP_LTC	Considering other causes
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Comprehensive assessment of multiple systems is vital.
S1249	HCP_LC	greater access to diagnostics to exclude acute disease
S1249	HCP_LC	access to acute diagnostic services
Ensure team skills and resources are appropriate to provide a multi-service approach		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1296	HCP_LC, HCP_LTC	Skilled workforce
S1246	HCP_LC	generic skills - coaching, patient centred care, working in the BPS model not medical model
S1266	P_LTC, HCP_LC, HCP_LTC	More professional team in long covid clinic
S1266	P_LTC, HCP_LC, HCP_LTC	Principles developed apply to all conditions
S1266	P_LTC, HCP_LC, HCP_LTC	Model of professional proactive long term condition clinic
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	complex collection of problems that takes time to sort out. Aware from doctors support groups that most of us have held a lot back not wanting to pressurise the system and aware that there weren't any tried and tested solutions
S1182	HCP_LC	Having a dedicated, integrated service to support people with long term conditions.
S1204	HCP_LC, HCP_LTC	aiming for one-stop holistic care when as many aspects as possible can be addressed by one service/ or care is well coordinated so patients feel adequately held and cared for. Close communication with a GP. Maximise opportunities for self management/ peer support/ social prescribing/ vocational rehab/ integrated psychology care
S184	HCP_LC, HCP_LTC	complex interventions which can manage multi-system problems eg develop problem based services not disease specific
Offer patient-centred care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>

S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Learning from patient experience and taking this on board
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Respect patient experience
S1182	HCP_LC	Validation of their experience
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Patients understanding and what they are hoping to gain from input
S162	HCP_LC, HCP_LTC	expectations
S166	HCP_LC, HCP_LTC	Primary symptoms/concerns
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Understand the specific individuals situation and therefore the impact of problems
S1142	P_LC, HCP_LC, HCP_LTC	Empathy & understanding
S1296	HCP_LC, HCP_LTC	Validation
S162	HCP_LC, HCP_LTC	validation
Include long-term care with reviews of health, care provision and personalised care plans		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1187	P_LC, HCP_LC, HCP_LTC	Follow up, ensuring there is capacity in the system to review patients
S1266	P_LTC, HCP_LC, HCP_LTC	Follow up and ongoing support
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Monitoring bp, being, weight etc
S1182	HCP_LC	Consideration of support for patients who have done the rehab but aren't better
S1187	P_LC, HCP_LC, HCP_LTC	Time to ensure the patient is seen for long enough to ensure all issues are resolved
S1204	HCP_LC, HCP_LTC	Define a treatment and follow up plan
S1245	HCP_LC, HCP_LTC	work holistically with patient-based outcomes
S1266	P_LTC, HCP_LC, HCP_LTC	Proactive shared planning with patient
S168	P_LC, HCP_LC	personalised program
S1242	HCP_LC	Patient goals

S1245	HCP_LC, HCP_LTC	work with the patient and colleagues to have realistic goals for patients
S168	P_LC, HCP_LC	goals
S184	HCP_LC, HCP_LTC	Symptom based, holistic, personalised approach to assessment and mx
S1266	P_LTC, HCP_LC, HCP_LTC	Models of proactive care, listening, shared planning apply to all long
S1236	HCP_LC, HCP_LTC	Identification of issues in need of urgent attention (e.g. medical emergencies, suicidal ideation/intent etc)
S1245	HCP_LC, HCP_LTC	monitoring outcomes at a service level
S1246	HCP_LC	patient flow (referral to discharge)
S1204	HCP_LTC, HCP_LC	high quality advanced care planning
S1204	HCP_LTC, HCP_LC	to offer a proactive management/ therapy plan with appropriate psychology input
Provide evidence-based care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Do not use outdated approaches such as GET for people with fatigue and PEM
S1242	HCP_LC	Research
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Research
S1293	HCP_LC, HCP_LTC	research studies
S1293	HCP_LC, HCP_LTC	research available
S1293	HCP_LC, HCP_LTC	research
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Offer hope and be open about limits to current knowledge whilst being aware of latest research
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Be knowledgeable about best practice and new developments
S1245	HCP_LC, HCP_LTC	keep up to date with evidence-based treatments for post-covid syndrome
S1142	P_LC, HCP_LC, HCP_LTC	Keeping up to date with treatments
S1246	HCP_LC	harnessing the 3rd sector and non-medical 'therapy' ENO, yoga - how can these 'prescribed' (SPs) but potential free at point of use
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Acknowledging that following evidence based treatment isn't always an option and be prepared to consider alternatives
S1246	HCP_LC	research into how we can enable the use of digital tech to support recovery

Share information between services		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S161	HCP_LC, HCP_LTC	communication with primary care
S162	HCP_LC, HCP_LTC	communication between primary/secondary care
S1245	HCP_LC, HCP_LTC	Sharing information so patients don't have to repeat themselves
S1236	HCP_LC, HCP_LTC	Information sharing between services
S184	HCP_LC, HCP_LTC	linking with HCPs already involved in care - trying to reduce unnecessary duplicate appointments
S1187	P_LC, HCP_LC, HCP_LTC	Communication across the system ensuring joined up care and information
S161	HCP_LC, HCP_LTC	Co-ordination between sectors
S1245	HCP_LC, HCP_LTC	sharing information including patient outcomes
S1236	HCP_LC, HCP_LTC	Information sharing between services/providers
Provide care manager		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1236	HCP_LC, HCP_LTC	Named care coordinator/single point of contact for patient
S158	HCP_LC, HCP_LTC	Coordination of care
S1236	HCP_LC, HCP_LTC	Care coordinator/navigator to improve flow between service
S1142	P_LC, HCP_LC, HCP_LTC	Perhaps a long Covid care co-ordinator for each patient?
Provide self-management advice		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1204	HCP_LC, HCP_LTC	Maximise opportunities for self-management and to manage LTCs within existing integrated services in the community.
S1236	HCP_LC, HCP_LTC	Early access to self-management support to include support with employment (where appropriate)
S1249	HCP_LC, HCP_LTC	education for patients on what they can do for themselves
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	General healthy living advice, rest, pacing, diet etc
S1293	HCP_LC, HCP_LTC	self help
S1182	HCP_LC	Learning the importance of purposeful, restorative rest and how to do it properly
S1296	HCP_LC, HCP_LTC	Importance of challenging maladaptive coping strategies
S1293	HCP_LC, HCP_LTC	self-help strategies

S1293	HCP_LC, HCP_LTC	coping strategies
S1296	HCP_LC, HCP_LTC	Coping strategies
S1249	HCP_LC	patient self-management
S1242	HCP_LC	symptom management
Offer staff supervision/managerial support and have resources/funding		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1179	P_LC, P_LTC HCP_LTC, HCP_LC	Good staff supervision
S1242	HCP_LC	More staff
S1242	HCP_LC	Resources available
S1242	HCP_LC	managerial support
S1187	P_LC, HCP_LC, HCP_LTC	Funding and how parity of payments can be made across primary, community and secondary care
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Recognising limitations of current models of working, eg 10min Gp appointments for patients with multiple problems
S1182	HCP_LC	Expansion - waiting times are unacceptably high

Summary statements about ICP for LTC Healthcare provider group review

Statements with associated original survey responses for group comments:

Take a Biopsychosocial approach to care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1187	P-LC, HCP_LC, HCP_LTC	Biopsychosocial model of approach
S1287	HCP_LTC	Engaging patients in truly biopsychosocial care - not neglecting psychological aspects
S1287	HCP_LTC	Mental health and physical health services working together and across boundaries
S1206	LC_P, HCP_LTC	Holistic care
S1122	P_LC, HCP_LTC	Clinicians must not assume that physical symptoms being experienced by a patient (e.g. Chronic pains), for which they have no known cause, are therefore caused by their mental health. This blocks the patient from accessing equal healthcare and undergoing further medical investigations.
S169	LC_P, HCP_LTC	I would like dedicated AHP involvement specific to Movement disorders.
S184	HCP_LC, HCP_LTC	basic mental health and rehabilitation programmes
S1142	LC_P, HCP_LC, HCP_LTC	Support & consideration of social aspects of illness
S1122	LC_P, HCP_LTC	Social care issues relating to or from their mental illness.
S1299	LC_P, HCP_LTC	Impact on child and family's day to day life
S158	HCP_LC, HCP_LTC	Environmental and societal factors
S138	P_LC, HCP_LTC	Medication, education, CGA, advance care planning, exercise, physio, OT, case management, supported self-management
S158	HCP_LC, HCP_LTC	It should look like the model defined by rehabilitation medicine specialists over the years which has always highlighted the need for a biopsychosocial model of healthcare.
S166	HCP_LC, HCP_LTC	Ideally with adequate psychological support as standard for those presenting. Due to limitations of this in reality support groups would be helpful. Streamlined communication between secondary and primary care. Community services that can support at home and suggest improvements. Social prescribing.
S169	P_LC, HCP_LTC	Practitioners who are well educated on the condition, and open minded to developing research. I would envisage the team would include a doctor, physio, occupational therapist, dietician/nutrition support and psychological

		support. I should emphasise that the psychological involvement should be around coping with the condition, including managing loss and grief, but not as a treatment in itself.
S1204	HCP_LC, HCP_LTC	A holistic self-assessment , which is triaged so the patient receives appropriate self-management advice and input from the right service. They should have rapid access to necessary diagnostics and a management plan should be developed that is shared with their GP. They should have access to good self management support (digital tools useful for some) and peer support . Where possible multimorbidity should be addressed in a joined up approach and physical and psychological health should be addressed
S184	HCP_LTC, HCP_LC	This concept is slightly odd as even with people with 'explained' symptoms such as breathlessness in COPD - the breathlessness is typically multifactorial and weak correlation between symptom experienced and degree of organ impairment so focus on managing anxiety, deconditioning, symptom management approaches - can use these whether there is 'organ impairment or not'. Symptom-based approaches avoid this type of largely unhelpful dichotomising.
S1293	HCP_LC, HCP_LTC	holistic service addressing pt issues with various expertise
S138	P_LC, HCP_LTC	Physical care should predominate, psychological support should be part of wraparound ancillary service
Ensure good communication between healthcare providers		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1_4	P_LTC, HCP_LTC	Good communication between specialists and GPs
S161	HCP_LC, HCP_LTC	communication with secondary care
S1151	P_LC, P_LTC, HCP_LTC	Communication between primary and secondary care
S1236	HCP_LC, HCP_LTC	Information sharing
S1245	HCP_LC, HCP_LTC	sharing information between teams
S1317	P_LC, P_LTC, HCP_LTC	Communication
S1273	P_LC, HCP_LTC	Communication between professionals IT systems
S1150	P_LC, P_LTC, HCP_LTC	Improved communication between services
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Better communication with GPs and specialists
S1204	HCP_LC, HCP_LTC	good communication with GPs
S1233	HCP_LTC	Better GP support

S1206	P_LC, HCP_LTC	Team working
S1296	HCP_LTC, HCP_LC	Passion of team, skill set and morals
S1266	P_LTC, P_LC, HCP_LTC, HCP_LC	Every health professional wants to do their best
Provide consistency in care provision (care-manager), ongoing support and monitoring		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1206	P_LC, HCP_LTC	Long term named support
S1273	P_LC, HCP_LTC	Continuity of care - not seeing too many different staff.
S1266	P_LTC, HCP_LC, HCP_LTC	Continuity of relationship care
S1269	P_LC, P_LTC, HCP_LTC	Consistency in follow up - combination of the above, rather than seeing different clinicians every time
S1187	LC_P, HCP_LC, HCP_LTC	long appointments to deal with all systems in one go, rather than multiple short appointments
S1_4	LTC-P, HCP_LTC	Keeping two tracks i.e. diagnosis and support at the same time
S1109	LC_P, HCP_LC, HCP_LTC	Difficult follow up of the patients
S1142	LC_P, LTC_P, HCP_LTC	Regular reviews
S1211	LC_P, LTC_P, HCP_LTC	Rationalising medications if there is polypharmacy
S1157	LC_P, LTC_P, HCP_LTC	Regular follow up and containment, often can't fix condition but ongoing support is often valued
S1269	LC_P, LTC_P, HCP_LTC	Offers of long term follow up - acceptance that long term conditions don't go away and it's not appropriate for GPs to take on the clinical burden
S1245	HCP_LC, HCP_LTC	monitoring patient outcomes at a service level
S138	LC_P, HCP_LTC	Overall health and wellbeing including physical health, mental health and function
S1122	P_LC, HCP_LTC	Physical health checks
S1179	LC_P, LTC_P, HCP_LC, HCP_LTC	Use of unsuitable outcome measures
S1296	HCP_CP, HCP_LTC	Long term support (no discharge but episodes of care and easy contact with team)
S161	HCP_LTC, HCP_LC	polypharmacy

S165	HCP_LTC	Stopping unneeded/harmful medication
S1122	P_LC, HCP_LTC,	Medication reviews
Offer easy access to specialist support for multi-system problems with collaborative care approach		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S165	HCP_LTC	Single point of contact for patients
S1150	LC_P, LCT_P, HCP_LCT	self-referral/simplify referral process
S161	HCP_LC, HCP_LCT	access to therapists
S1233	HCP_LTC	All under one roof
S1325	LC_P, HCP_LTC	Clinics for people with multiple symptoms affecting more than one body system
S169	LC_P, HCP_LTC	Ideally, I would like a dedicated clinic for complex phase disease. I anticipate that this would reduce hospital admissions, as seen in a gold standard clinic in the North East.
S1325	LC_P, HCP_LTC	Clinics for people with multiple symptoms affecting more than one body system
S1195	LTC_P, HCP_LTC	Waiting times
S134	LC_P, LTC_P, HCP_LTC	Swift treatment
S161	HCP_LTC, HCP_LC	access to investigations
S165	HCP_LTC	Speedy access to relevant clinician(s)
S169	LC_P, HCP_LTC	Investigations are done centrally (DaTscan) and so there can be a long waiting list.
S1187	LC_P, HCP_LC, HCP_LTC	long appointments to deal with all systems in one go, rather than multiple short appointments
S1211	LC_P, LTC_P, HCP_LTC	Minimising appts at hospital if people are under several services, or trying to coordinate so they are on the same day
S1287	HCP_LTC	Mental health specialists, social care workers and physical health services working truly together - in the same organisation with systems set up so they can liaise with each other. The patient being able to see more than one member of the MDT, and thsi MDT being able to discuss their care regularly together
S1296	HCP_LC, HCP_LTC	Genuine multidisciplinary work
S1_4	P_LTC, HCP_LTC	Consultation possibilities between specialists and GPs
S1325	P_LTC, HCP_LTC	Multidisciplinary care in one location, ideally within the community
S1211	LC_P, LTC_P, HCP_LTC	Generalist overview - not many medical generalists left (GP, geriatrics, paediatrics are probably the only ones left)
S1312	HCP_LTC	Combined clinics with multiple people

S184	HCP_LC, HCP_LTC	inter-speciality referrals
S1242	P_LC, HCP_LTC, HCP_LC	Referrals when required or re-directing to GP
S1296	HCP_LTC, HCP_LC	Expertise of team including a team leader with experience in complexity theory (rehabilitation specialists are good at that)
S1299	HCP_LTC, P_LC	Mental health
S1299	HCP_LTC, P_LC	Social and occupational therapy
S1299	HCP_LTC, P_LC	IBD nurse support
S1122	P_LC, HCP_LTC	Accessing a broad variety of holistic mental health treatments.
S1312	HCP_LTC	Access to clinical services
S1294	P_LC, P_LTC HCP_LTC, HCP_LC	Access to all relevant support at diagnosis-often having long waiting lists results in diminished patient motivation by time they get to top making engagement harder
S134	P_LTC, P_LC, HCP_LTC	Time to get through appointment
S1157	P_LTC, P_LC, HCP_LTC	Adequate amount of time
S1266	P_LTC, P_LC, HCP_LTC, HCP_LC	Plan for each with time
S1289	P_LTC, P_LC, HCP_LTC, HCP_LC	Longer appointments- we have 10 minutes only
S1289	P_LTC, P_LC, HCP_LTC, HCP_LC	If multiple conditions, then appt time to reflect this
S1187	P_LC, HCP_LTC, HCP_LC	time to care (long appointments)
S169	P_LC, HCP_LTC	It would be extremely helpful to have all the appropriate specialists in a dedicated one-stop clinic. E.g. in complex phase PD, patients are likely to have swallowing problems, psychiatric disturbance alongside their movement disorder. There is often a long delay waiting for referrals to be processed, and so this could avoid this.
S1179	P_LC, P_LTC, HCP_LTC, HCP_LC	Therapist with good knowledge and experience in both physical and mental health problems
S165	HCP_LTC	Access to specialists with knowledge of the condition
S1293	HCP_LC, HCP_LTC	support group
S1236	HCP_LC, HCP_LTC	Coordination of care - optimising access to effective treatment and avoiding duplication)

S1109	LC_P, LTC_P, HCP_LTC	Limited time for consultations
S1_4	P_LTC, HCP_LTC	Structural communication between GPs and specialists, both acute hospital and psychiatric trusts
S134	P_LC, P_LTC, HCP_LTC	Timely and responsive but with treatment
S161	HCP_LC, HCP_LTC	multidisciplinary team working, access to all relevant information, sharing of electronic health records, clear divisions of responsibility
S162	HCP_LC, HCP_LTC	all in one place or at least same IT system
S184	HCP_LC, HCP_LTC	Lead clinician for any one patient with other expertise available, complex interventions delivered by a team with the relevant expertise, which can flex depending on patient need
S1122	P_LC, HCP_LTC	Each clinic forming the integrated care pathway must be aware of all of the different clinics forming parts of that pathway. It must be made clear where to refer to and how to continue communicating with the different clinics after the referral has been made. There needs to be two-way communication so that everyone is updated regarding the different progress being made by each specialist service. Otherwise, services run separately rather than in tandem or working with each other.
S1150	P_LC, P_LTC, HCP_LTC	Care for patients that is seamless across the healthcare divide
S1151	P_LC, P_LTC, HCP_LTC	We have CRTs in development with primary care, social services, OT, physio etc but no mental health or links to secondary care. Perhaps link people between secondary care and community would bridge that gap at meetings or virtual mdt?
S1157	P_LC, P_LTC, HCP_LTC	Multi-disciplinary involving primary and secondary care and other AHPs
S1179	P_LC, P_LTC, HCP_LTC	Rather like the MDT teams you see in CMHTs with many professionals liaising around different aspects of care in order to improve patient experience. This includes working with relevant community groups and peer support
S1206	P_LC, HCP_LTC	Mixture of professionals working together with regular mdt
S1195	P_LTC, HCP_LTC	The current models for multiple sclerosis, cancer or HIV/aids are good.
Provide evidence-based treatment and recommendations		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1147	P_LTC, HCP_LTC	Get some evidence before recommending things that probably do not work.
S1147	P_LTC, HCP_LTC	Get some evidence that is based on reliable controlled intervention.
S1147	P_LTC, HCP_LTC	Just get some decent evidence rather than wasting time on surveys

S165	HCP_LTC	It should be focused on providing evidence-based care. If there is no evidence base, then it should be focused on trying to develop that evidence base.
S1294	LC_P, LTC_P, HCP_LC, HCP_LTC	Think beyond EBM for treatment options if appropriate
S1266	P_LTC, HCP_LC, HCP_LTC	Latest evidence and advice
S1157	P_LC, P_LTC, HCP_LTC	Keep up to date on latest guidance for investigation and treatment
S134	LC_P, LTC_P, HCP_LTC	Treatment options
S163	HCP_LTC	Provision of therapies
S1236	HCP_LC, HCP_LTC	Elements to 1. optimise treatment and preserve health and 2. rapidly respond to acute exacerbations
S1273	LC_P, HCP_LTC	Better treatments
S1147	P_LTC, HCP_LTC	It should be evidence based.
Take a patient-centred approach		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S138	P_LC, HCP_LTC	Patient preferences and goals
S1245	HCP_LC, HCP_LTC	realistic patient-centred goals.
S1294	LC_P, LTC_P, HCP_LC, HCP_LTC	Understand patient experience and expectations
S1299	LC_P, HCP_LTC	Patient's view
S1157	LC_P, LTC_P, HCP_LTC	Patient centred approach including social and psychological impact
S138	LC_P, HCP_LTC	Social and emotional support, formal and informal care
S1122	LC_P, HCP_LTC	Physical health inequalities due to their mental illness.
S1312	HCP_LTC	Compliance and adherence with treatments
S1293	HCP_LTC, HCP_LC	future expectations
S163	HCP_LTC	Shared decision
S1245	HCP_LTC, HCP_LC	keep in mind holistic, patient-related goals
S1266	P_LTC, P_LC, HCP_LTC, HCP_LC	Their personal goals

S1142	P_LC, HCP_LTC, HCP_LC	Listen to the patient & negotiate what happens next
S169	P_LC, HCP_LTC	Multiple appointments may be exhausting and challenging for the patient. Video consultation may reduce this.
S1_4	P_LTC, HCP_LTC	Remote consultation for disabled patients possible
S1266	P_LTC, P_LC, HCP_LTC, HCP_LC	Better online resources for patient and GPs tailored to individual
S1317	P_LTC, P_LC HCP_LTC	Caring
S1151	P_LTC, P_LC, HCP_LTC	Compassion and genuine interest in supporting patients as best they can
Ensure services have appropriate resources		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1269	LC_P, LTC_P, HCP_LTC	More staff - better recruitment, retention, skill mix
S1195	LTC_P, HCP_LTC	Funding
S1206	P_LC, HCP_LTC	Adequate funding
S1109	P_LTC, P_LC HCP_LTC	1:1/1:2care on ICU
S1296	HCP_LTC, HCP_LC	Capacity
S1266	P_LTC, P_LC, HCP_LTC, HCP_LC	Improved resources to share probability of illness and treatment effect. Cate charts of smily face for complex situations
S1296	HCP_LTC, HCP_LC	capacity
S1296	HCP_LTC, HCP_LC	capacity
Support self-management		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S184	HCP_LC, HCP_LTC	self-management
S1204	HCP_LC, HCP_LTC	symptom management and good self-management and rehab advice
S158	HCP_LTC, HCP_LC	Symptom management
S1293	HCP_LC, HCP_LTC	self help
S1151	LC_P, LTC_P, HCP_LTC	Sharing knowledge and awareness of what is available and lacking in order to plan to meet those gaps

S1294	LC_P, LTC_P, HCP_LC, HCP_LTC	Support and acknowledge patient education
S163	HCP_LTC	Provision of good quality information
S1293	HCP_LTC, HCP_LC	day to day management
S1233	HCP_LTC	app for self-care
Offer social and community support		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1269	P_LTC, P_LC HCP_LTC	Social support - social isolation / financial problems / occupational support - that kind of thing
S1122	P_LC, HCP_LTC,	Social care related issues.
S1325	HCP_LTC, P_LTC	Eligibility for financial support, benefits and support services
S1266	P_LTC, P_LC, HCP_LTC, HCP_LC	Support from family and friends
S1294	P_LC, P_LTC HCP_LTC, HCP_LC	Support groups not just for those with same disease but at same stage of life/in same occupation where challenges more likely to be similar
S1293	HCP_LTC, HCP_LC	community support
S1312	HCP_LTC	Social support
Use unified electronic healthcare records		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S184	HCP_LTC, HCP_LC	unified electronic healthcare records
S1236	HCP_LC, HCP_LTC	Coordinated assessment with shared access to health records across systems. Multidisciplinary input into development of a care plan with unified record keeping and information sharing to avoid duplication. System in place to review response to interventions with opportunity to revise the care plan etc.
S1266	P_LTC, HCP_LC, HCP_LTC	Seamless but clear when each part has been covered and how each issue or problem has been addressed
Offer relevant screening and diagnostic tests and investigations, rule out other problems		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1236	HCP_LTC, HCP_LC	Timely access to investigations and treatment
S1236	HCP_LTC, HCP_LC	Access to investigations and management
S1109	P_LTC, P_LC	Easy access to urgent investigations most of the time

	HCP_LTC	
S1237	P_LTC, P_LC HCP_LTC, HCP_LC	Investigations
S1179	P_LC, P_LTC HCP_LTC, HCP_LC	Sometimes they're not actually unexplained! Eg patients with hyperthyroidism referred due to anxiety, patients with PMDD or menopause that hasn't been recognised
S1204	HCP_LTC, HCP_LC	to have a broad differential and ensure causes adequately investigated
S1289	P_LTC, P_LC, HCP_LTC, HCP_LC	Basic investigations
S161	HCP_LTC, HCP_LC	exclude serious pathology such as cancer
S161	HCP_LTC, HCP_LC	consider disorders of function
S158	HCP_LTC, HCP_LC	Exclusion of any underlying medical condition

Summary statements about ICP for LC Patients group review

Statements with associated original survey responses for group comments:

Provide diagnostic assessment		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S189	P_LC	Acknowledged as post Covid symptoms
S1132	P_LC, P_LTC	Acknowledged it was real and believed me
S1150	P_LC, P_LTC, HCP_LTC	They had seen other people with the condition
S1153	P_LC, P_LTC	Acknowledge the problem
S1184	P_LC, P_LTC	Diagnosis
S1193	P_LC	Care and compassion (recognition of the problem)
S1203	P_LC	Happy to admit I had long covid.
S1235	P_LC	Validated my experience of symptoms and their cyclical and unpredictable nature, drew comparisons that were anecdotal as well as study-based, legitimising my experience after having been dismissed by other medical professionals.
S1250	P_LC	Diagnosed the symptom
S114	P_LC	Believed my symptoms, sent me for adequate testing, did not spout psychosomatic nonsense.
S146	P_LC	Resp cons gave me time listened and verified my illness
S1121	P_LC, P_LTC	Healthcare workers cannot continue to say that long covid symptoms are physyco logical or functional
S133	P_LC, P_LTC	Neurologist listened to me, offered exam to rule out MS.
S148	P_LC, HCP_LC, HCP_LTC	Offer differential diagnosis
S198	P_LC, P_LTC	Look for POTs or other dysautonomia
S1150	P_LC, HCP_LC, HCP_LTC	They could have ruled out a differential diagnosis
S1218	P_LC	testing to rule out other conditions
S1255	P_LC, P_LTC	Scans should have been ordered to ensure that there was no organic damage (I was hospitalised with double pneumonia, pulmonary embolism, atelectasis and on oxygen.
S1273	P_LC, HCP_LTC	They ruled out other health problems e.g. heart problems.
S1282	P_LC	Ruling out damage other conditions

S1272	P-LC	Tests first, rule out organ related issues. Treatment and counseling side by side
S1306	P_LC	Ruled out other causes via tests
S1_3	P_LC	Blood tests by GP
S1_3	P_LC	No scans or tests offered by Long Covid Service
S1_3	P_LC	Only self-care offered, cannot get hormones properly investigated or possibility of micro-clots or stress-MRI or tilt-table test
S1_3	P_LC	Screening for micro clots
S1_3	P_LC	Full investigation of hormones
S1_3	P_LC	MRI of brain, heart and lungs
S1_6	P_LC	Failure to perform tests specifically relevant to Long Covid pathophysiology
S1_6	P_LC	Be ambitious and try biomedical interventions based on emerging research, case studies and reasonable hypotheses of underlying disease mechanisms
S1_9	P_LC	More comprehensive testing
S114	P_LC	Found the biological cause behind my symptoms.
S114	P_LC	Believed my symptoms, sent me for adequate testing, did not spout psychosomatic nonsense.
S115	P_LC	diagnostics
S117	P_LC	Further testing
S117	P_LC	Appropriate tests
S120	P_LC	Better investigation
S128	P_LC	Did lots of blood tests
S128	P_LC	More testing other than standard blood tests (e.g. imaging, tilt table, skin biopsies for small fibre neuropathy etc)
S128	P_LC	Tests! Including bloods but also imaging, cardiology, and neurological work ups.
S131	P_LC	Getting tests quick and easily
S132	P_LC	Actual effort into testing, and finding out what's wrong, not just saying anxiety when they can't figure it out
S134	P_LC, P_LTC, HCP_LTC	Effective testing and Investigations
S138	P_LC, P_LTC	Listened and undertook investigations
S138	P_LC, P_LTC	More physical and functional assessment and investigations
S138	P_LC, P_LTC	Physical investigations, it is a physical illness primarily with psychosocial impacts
S139	P_LC	Testing and blood screening
S144	P_LC	Offer tests for all symptoms, however minor
S146	P_LC	Ordered tests

S146	P_LC	Order tests, as are symptoms such as pots are very real
S149	P_LC	offered tests
S149	P_LC	proper tests
S150	P_LC	Tests ordered
S150	P_LC	Offer more tests, rare tests
S151	P_LC	Keep testing any possible cause
S155	P_LC	Access to Timely tests
S157	P_LC	Diagnostics
S168	P_LC, HCP_LC	relevant investigations
S172	P_LC, P_LTC	Offering investigations
S174	P_LC	Diagnostic testing to determine any reversible conditions
S174	P_LC	Look at different thresholds for blood work, my doctor at royal Brompton (who I found myself) has a different level for bloods such as b12, iron etc to ensure they're at higher levels to help with fatigue etc. This should be looked into, so supplements can be prescribed
S187	P_LC	tests for blood micro clots
S187	P_LC	tests for auto antibodies
S187	P_LC	test patients for microclots, and autoantibodies
S189	P_LC	Sent me for some tests
S189	P_LC	More thorough tests although I appreciate I was an early case
S189	P_LC	Tests based on current research regarding blood clots (VQ scans), neurological scans, rheumatology
S1109	P_LC, P_LTC, HCP_LTC	Investigated and tried to identify if any organic cause is present
S1109	P_LC, P_LTC, HCP_LTC	Investigating the pathology behind their symptoms and creating trials to see what kind of treatments work for Long Covid. The fact that a chest Xray is normal doesn't mean that PE, asthma or other pathologies don't exist. It just means we have to learn what tools we need to use to investigate
S1124	P_LC, P_LTC	offer full testing
S1132	P_LC, P_LTC	More in depth investigation to diagnose and treat
S1138	P_LC	To offer medical investigations. To offer appropriate blood tests eg immune screening, cytokines etc
S1138	P_LC	Multisystem medical investigations
S1142	P_LC, HCP_LTC, HCP_LC	Basic tests to rule out other possible causes
S1143	P_LC	MRI and echocardiogram

S1149	P_LC, P_LTC	Early tests
S1149	P_LC, P_LTC	Using existing tests to exclude and treat underlying pathology
S1149	P_LC, P_LTC	Establishing baseline tests and getting GP to repeat bloods etc if clinic wants to focus on phone follow-ups
S1152	P_LC	Ruling out anything else by doing tests.
S1159	P_LC, P_LTC	Offer advanced diagnostics.
S1161	P_LC	Blood tests ruled out other problems
S1172	P_LC, P_LTC	Blood tests
S1179	P_LC, P_LTC, HCP_LTC, HCP_LC	Offered tests
S1187	P_LC, HCP_LTC, HCP_LC	Investigations close to home that do not need a referral to a hospital or clinic
S1191	P_LC	Blood tests done quickly
S1191	P_LC	MRI SCAN not made early enough
S1191	P_LC	Appropriate tests done by gp before seeing specialist
S1192	P_LC	A&E carried out basic emergency tests.
S1192	P_LC	Diagnostic tests & access to research info and trials
S1202	P_LC, HCP_LTC, HCP_LC	Microclot testing
S1202	P_LC, HCP_LTC, HCP_LC	Testing/diagnostics
S1211	P_LC, P_LTC, HCP_LTC	Biological investigation & treatment
S1212	P_LC	ECG
S1212	P_LC	Cognitive Dysfunction test
S1220	P_LC	Full on testing I've had to make formal complaints and fight for every test and everyone came back with anomalies
S1224	P_LC, P_LTC	I got lung function tests
S1229	P_LC	Ruled out serious lung & heart damage
S1229	P_LC	Proper in depth testing & analysis. I understand its early days but we are suffering.
S1237	P_LC, P_LTC, HCP_LTC	Investigation
S1237	P_LC, P_LTC, HCP_LTC	Diagnostics

S1238	P_LC	More tests
S1238	P_LC	More in-depth tests
S1244	P_LC	Agree on a full panel of tests that should be offered to long covid sufferers
S1248	P_LC, P_LTC	More heart tests to allay my worries
S1248	P_LC, P_LTC	CT scan
S1248	P_LC, P_LTC	Full medical checks on vital organs
S1250	P_LC	Diagnosis
S1251	P_LC	That all other possibilities were investigated
S1252	P_LC	Offer mote testing to insure no under lying health issues contributing to well being.
S1255	P_LC, P_LTC	Diagnostic tests and scans should be made available to everyone.
S1257	P_LC, P_LTC	Understanding a test coming back normal doesn't mean there's nothing wrong it means the test is not made or good enough to show what is wrong so you need to do another, proably more detailed or in depth test not say "your results were normal, bye"
S1258	P_LC	Investigation such as LFT
S1258	P_LC	Investigation
S1265	P_LC, P_LTC	GP only requested bloods
S1269	P_LC, P_LTC, HCP_LTC	investigations to rule out other possible causes of the symptoms
S1270	P_LC, P_LTC	2nd Dr listened and did tests
S1270	P_LC, P_LTC	Help to look for tests that can help.
S1271	P_LC	More tests
S1271	P_LC, P_LTC	More examinations and tefferals
S1271	P_LC, P_LTC	More tests and medication
S1272	P_LC	Ordering any tests - nothing
S1272	P_LC	Early simple tests
S1279	P_LC	Blood tests
S1279	P_LC	Full investigation of symptoms, not ascribing them to LongCovid so not covered by specialist services in hospital trusts. I had to go private to get an MRI and diagnosis of perimyocarditis
S1279	P_LC	Acceptance of referrals for full diagnostic screening, not being bumped from cardiology because we have LongCovid
S1280	P_LC	More comprehensive testing
S1280	P_LC	Exclude other conditions

S1281	P_LC, P_LTC	Immediate tests and acceptance of diagnosis
S1282	P_LC	More tests
S1282	P_LC	Tests
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Just because the current tests being used are normal does not mean the person hasn't got sx. They should be looking for a cause and treating it. This is a new disease, there is a good chance we don't have the tests for it yet.
S1289	P_LC P_LTC, HCP_LC, HCP_LTC	Access to appropriate tests in a timely manner
S1294	P_LC P_LTC, HCP_LC, HCP_LTC	Investigations
S1294	P_LC P_LTC, HCP_LC, HCP_LTC	Some tests was doing myself at home based on reading eg nasa lean test. Not sure that other patients would have been able to do this which could lead to delays
S1298	P_LC, P_LTC	Ask all LC patients in for a day of tests to establish whether any damage has been done
S1301	P_LC P_LTC	Referred me for tests
S1301	P_LC P_LTC	Giving peace of mind e.g. ruling out urgent issues
S1307	P_LC	Relevant investigations
S1311	P_LC	Get them checked out medically - lungs, etc as this will reassure lots of patients
S1315	P_LC P_LTC	Tested what they could, both in-house and at local hospital
S1318	P_LC	The sent me for tests
S1318	P_LC	More thorough tests
S1318	P_LC	More thorough testing, not just basic bloods and scans
S1321	P_LC	Scans & MRIS and referrals to specialists
S1121	P_LC, P_LTC	He listened attentively, didn't talk down to me and then explained in great detail how he thought my symptoms were due to long covid as well as Crohn's and inflammatory arthritis
S1_6	P_LC	Acknowledge that Long Covid is a multisystem disease characterised by immune, endothelial, autonomic and metabolic dysfunction, cerebral hypoperfusion, brain hypometabolism, microclotting, organ damage and much more, and that is is not just 'respiratory' in nature or a bit of fatigue
S167	P_LC	a clear statement that they understand I have longCovid
S1152	P_LC	Clinically definitive diagnosis
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Gave clear diagnosis
S1234	P_LC	Recognition it exists

S1276	P_LC	Recognise Long covid as a medical condition and support patients when they need help managing work challenges or when they need to claim benefits
S1280	P_LC	Clear diagnosis
S1311	P_LC	Acknowledge of my condition early on as there was a felt a bit of medical gaslighting going on
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	They were a non-diagnostic service. So whatever questions you had about your symptoms, they were no help.
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Early diagnosis
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Comprehensive assessment of multiple systems is vital.
S114	P_LC	Do not push for rehabilitation without actually having the patient evaluated for cardiovascular issues and for post-exertional malaise. Otherwise you will just harm patients.
S132	P_LC	Actually take time to understand all symptoms not just one then they send you away, don't give me time to say every symptom
S136	P_LC, P_LTC	Holistic assessment
S139	P_LC	Discussing physical symptoms, possible causes,
S146	P_LC	Recognise the symptoms sooner
S1224	P_LC, P_LTC	More comprehensive symptom/contributing factors/Information gathering
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Presenting complaints
S1311	P_LC	Physical examination and tests, like lung capacity etc
S1317	P_LC, P_LTC, HCP_LTC	Breathlessness is not explored i just get told its my asthma i know it isnt as there is no wheeze
S133	P_LC, P_LTC	Listening to ALL their symptoms
S135	P_LC	holistic approach to the whole body
S136	P_LC, P_LTC	Holistic assessment
S169	P_LC, HCP_LTC	Comprehensive physical assessment, including screening for common associated syndromes e.g. POTS, MCAS, PESE/PEM.
S189	P_LC	Multidisciplinary assessments
S114	P_LC	Listen and believe the patients. Start investigations early on, and check up on patients. Stop the nonsense about stress and not getting out of the house as cause of long covid! Fever, pain, blood clots, myocarditis are not going to solve themselves with meditation and yoga.

S1109	P_LC, P_LTC, HCP_LTC	Holistic care-identifying all the symptoms that they are experiencing
S1288	P_LC	Focussed care and assessment
S1109	P_LC, P_LTC, HCP_LTC	Holistic care-identifying all the symptoms that they are experiencing
S1128	P_LC	Listening and accurate history
S1263	P-LC	Multidisciplinary
S139	P_LC	Tests, diagnosis of things like POTS etc. Oh and treatments
S133	P_LC, P_LTC	Offer exams
S172	P_LC, P_LTC	Sent me for different investigations
S198	P_LC, P_LTC	Appropriate tests
S1138	P_LC	To screen for cardiac, neuro, pulmonary function, MCAS, cognitive function eg. Executive function etc
S164	P-LC	An in-depth conversation should be the first step to finding out what kind of care is necessary. Questions about symptoms alongside those about how symptoms are affecting life and relationships. From there, the patient can be directed to the right support. Ideally this support can be provided in the same place and would run concurrently
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Access to testing and expertise.
S1157	P_LC, HCP_LC, HCP_LTC	Problem easily identified on tests and defined treatment
S1224	P_LC, P_LTC	Skilled interpretation of tests
S1281	P_LC, P_LTC	Diagnostic Tests (instead of "let's put you on this drug and see what happens)
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Routine bloods and correcting deficits eg vit D, hba1c etc
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Performing relevant investigations and acknowledge their limitations
S1280	P-LC	Comprehensive testing and specialist appointments, offers to explain condition to loved ones, a disability informed coach to learn to live with condition
S1279	P-LC	Start with a full suite of diagnostic tests to identify organ damage instead of screening out with a chest x-ray or blood tests. Combined treatment for damaged organs with advice and support for managing symptoms. Anxiety caused by medical symptoms not the other way round. That needs to be acknowledged
Offer easy access to specialist support for multi-system LC problems with collaborative approach		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>

S1232	P_LC, P_LTC	Easily accessible, specialised health centres
S1315	P_LC, P_LTC	Scope for face-to-face consultation should be standard, now that lockdown is long past.
S1331	P_LC	Appointments by phone so no travelling
S136	P_LC, P_LTC	One-stop service, care co-ordinator, care plan and referrals to specialists from the clinic or specialists attached to
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Long covid clinic run by respiratory with referral to other services. Resp had no actual expertise in covid or long covid. Just referred to other specialties in a fragmented way if you had for example cardiac sx
S1170	P_LC	In-person support.
S167	P-LC	needs to be close to home or online, medication delivered to house, compassion and respect, less forms and more listening
S173	P-LC	Local where possible so that sufferers can travel locally. Long covid patients to be part of team. May need volunteer support groups. Need to collect data on all patients so that they have an idea of extent of need. Short term and long-term care needs recorded and planned
S1252	P-LC	Holistic approach from one person not from different various clinics..a one stop shop.
S186	P-LC	Named individual contact to coordinate care and reduce risk of over exertion in trying to communicate with new individual. Flexibility for severely ill patients who might be housebound including home visits, online appointments, telephone appointments and integrated care involving family carers where relevant. Appropriate diagnostics and treatments for anything that can be treated, and ability to prescribe, recommend/provide mobility aids and other support. Support with practical elements of managing life with long covid.
S1131	P_LC, P_LTC	See patients face to face and listen
S1272	P_LC	A plan if you hit 12 wks early on
S1109	P_LC, P_LTC, HCP_LTC	Being offered the time and the place to address and talk about all the symptoms not one by one and be offered symptomatic treatment while waiting for refferals/investigations
S1150	P_LC, P_LTC, HCP_LTC	They conducted virtual appointments to prevent symptom exacerbation
S1175	P_LC, P_LTC	Home treatment
S1187	P_LC, HCP_LC, HCP_LTC	Rehabilitation close to home and not in a hospital
S1177	P_LC	a dedicated long covid session since I could only discuss one symptom at a time which makes everything take longer
S1212	P_LC	All tests in one place
S1271	P_LC, P_LTC	Face to face appointments
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Single point of access, not referral to several different uncoordinated specialties

S1315	P_LC, P_LTC	Psychological services should not assume that all patients can cope with video consultation.
S1192	P-LC	Initial tests and assessments at centres of excellence, opportunities for a combination of treatments in different formats eg groups, online appointments, in person physio, as local as possible without losing expertise. Use patient stories. Share research and trials.
S117	P-LC	All in one place and easy to get in touch if problems
S1282	P-LC	One point of contact which refers as necessary
S169	P_LC, HCP_LTC	Multiple appointments may be exhausting and challenging for the patient. Video consultation may reduce this.
S1128	P-LC	Should be led by medical clinician screening for sepsis coagulation and organ compromise. Remote monitoring if breathlessness and low O2 present
S136	P_LC, P_LTC	Dedicated GP at GP practice
S182	P_LC, P_LTC	Designated lead practitioner
S1269	P_LC, P_LTC, HCP_LCT	Consistency in follow up - combination of the above, rather than seeing different clinicians every time
S1273	P_LC, HCP_LTC	Continuity of care - not seeing too many different staff.
S1173	P-LC	regular sessions with relevant specialists (e.g. physio), therapy sessions, treatment
S135	P_LC	need a specialist respiratory physio
S136	P_LC, P_LTC	Long Covid Clinics with specialists attached for quicker referral and appts
S117	P_LC	Referral to specialist tests such as cardiology, neurology and rheumatology
S146	P_LC	Seen each specialist, rather than just a neurologist.
S146	P_LC	I have cardiac issues so why can't I speak to a cardiologist?
S153	P_LC	Referral to cardiologist
S153	P_LC	Referral to immunologist
S153	P_LC	Referral to gastro-enterologist
S155	P_LC	Access to testing for heart problems on the NHS
S167	P_LC	Referral to a specialist might have helped, think Im outside the target demographic
S183	P_LC	The long Covid clinics in general to quit to suggest things like physio and psychology when really they should be offering proper treatment and proper testing He's long Covid clinics and Doctors need to stop psychologising it and realised that it is a problem of physical one at that and a vascular one
S1109	P_LC, P_LTC, HCP_LTC	Unable to get any support/therapy for my brain fog symptoms. Being investigated and have main pathologies ruled out for brain fog together with a cognitive assessment should have been offered to all the patients with brain fog.I m an anaesthetist so the brain fog affected me so bad that I felt it wasn't safe to practice and that I could endanger the patients. I went privately and had head MRI, HBOT and saw a psychologist, both in Romania as I couldn't afford it in

		UK due to absent sick leave, reduced hrs pay and horrible Income protection cover who wouldn't offer any support. With these I saw some improvement from 50-70% functionality
S1122	P_LC, HCP_LTC	More helpful support with improving sleep quality.
S1191	P_LC	Website info only relates to some long covid symptoms and needs to give treatment advice on them all, never referred to tinnitus specialist, nerve conduction studies and MRI scan not done before seeing specialist neurologist, should have been referred to correct neurological clinic not to an MS clinic who won't see me again, should not have been prescribed nortriptyline for tingling when from what I can tell it may help pain in peripheral system when I do not have that symptom
S1247	P_LC	Ability for them to refer to other specialities
S1252	P_LC	G.P should provide more information about help out there.
S1255	P_LC, P_LTC	The clinic was respiratory only and Long Covid symptoms are systemic
S1271	P_LC, P_LTC	More referrals
S1276	P_LC	Specialist appointments
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Access to all relevant support at diagnosis-often having long waiting lists results in diminished patient motivation by time they get to top making engagement harder
S1298	P_LC, P_LTC	Referrals to specialist service should have been done straight away and not 6 months later after we had attended a Long Covid Management Programme which consisted of watching some videos about certain topics and then being able to ask some questions. Most of us had been struggling with LC for a very long time and those videos really did not offer much new information.
S1155	P-LC	local support
S1138	P-LC	An initial & thorough multisystem assessment should be completed by a doctor. Referrals to specialist Doctors eg. Neurology, cardiology etc should be done where needed & all appropriate investigations done. The staff involved should be fully trained in long covid research & not just consider existing conditions. The need for physio, OT, psychology support is over estimated & really not necessary for most of us.
S189	P-LC	A series of appointments at a clinic that was integrated, not too long in duration, broken down into manageable sessions with thorough blood tests, scans and follow ups
S126	P-LC	It should focus on lifestyle changes that can help reduce suffering, and also factor in the impact of our illness on our supper networks
S186	P_LC	Often unable to contact GP as too ill to visit or talk on phone, more flexible options would have been helpful
S1269	P_LC, P_LTC, HCP_LCT	easy means of contact if problems arise
S1272	P_LC	Help me book in future appointments. I now can't get through to my doctor

S1299	P_LC, HCP_LTC	Offering contact details to patient in case of worsening of symptoms
S1301	P_LC, P_LTC	Ease of contact to get advice/appts when issues arise
S1138	P_LC	Services should be consultant led. And all staff should be up to date on research about LC. This is not my experience.
S135	P_LC	specialists all in one place or at least communicate with each other as each of my health problems has been treated separately and they are interlinked so a more holistic approach would really help
S144	P_LC	Integrated service with access to various health professionals
S152	P_LC	True multidisciplinary team (with clinicians, not just OT plus physio)
S182	P_LC, P_LTC	Better integrated service, it's way to fragmented
S182	P_LC, P_LTC	More integrated ice by Health Care Trust
S182	P_LC, P_LTC	More of a one stop shop instead of multiple referrals
S1121	P_LC, P_LTC	A more joined up approach between specialists, nursing hotlines to centralise a point of contact as opposed to busy GPs
S1144	P_LC	Integrated support means proper joined up thinking. Everything I have had has been so disparate. No one appears to know what the last person did and no information is passed on
S1151	P_LC, P_LTC, HCP_LTC	Joined up approach at secondary care level. So many overlaps to other conditions, autoimmune and rare. Need to have joint mdts discussing patients.
S1151	P_LC, P_LTC, HCP_LTC	To have clear pathways between primary and secondary care
S1151	P_LC, P_LTC, HCP_LTC	For primary and secondary care to have more seamless service and increase communication and share learning. And for secondary care to communicate more closely with other specialities, sharing learning, awareness of overlaps and discuss patients jointly in an mdt.
S1170	P_LC	Treating all the symptoms together instead of being seen by multiple consultants and healthcare professionals.
S1217	P_LC	'Joined up' care pathway. My GP has not wanted to support in any way & this has been very hard at a difficult time
S1224	P_LC, P_LTC	Joined-up not silo thinking
S1255	P_LC, P_LTC	Not to concentrate on one area of the body. Long Covid is systemic do an holistic approach is essential. The current medical approach of going from specialist to specialist does not work, yet specialists are necessary to diagnose what is going on. Therefore, they need to work together.
S1257	P_LC, P_LTC	Treat people wholistically and have specialists come together to discuss a patient not do it all separately
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	A medical doctor to co-ordinate care with some knowledge of all the systems eg cardio, resp, neuro etc to put everything together and stop care being so fragmented
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Coordinated care

S1298	P_LC, P_LTC	A lot more tests need to be offered by the LC clinic to ensure that e.g. lungs, heart, nervous system work well! It's horrible having to wait months or even a year to see a specialist who then doesn't know anything about LC and the visit was a complete waste of time.
S1304	P-LC	Ideally a one stop clinic that took away the worry of departments not speaking to each other.
S1244	P-LC	All tests, diagnoses, treatment and support from one place
S1235	P-LC	Ideally these would operate simultaneously and feed into one another. There would be consistent follow up to at least update patients on the status of certain types of support. What is particularly challenging is knowing who as a patient you should even ask to follow up on these kinds of things as the operation feels very decentralised. Timing these different support methods to coincide temporally would also help patients feed back on those experiences between one and the other, for example discussing frustrations in treatment with a trained therapist.
S1250	P-LC	Primary could triage symptoms and refer to as many specialist and rehab services as necessary, but from what I understand these would need to be synchronised so all symptoms are treated concurrently.
S1231	P-LC	It needs to be a clear integrated pathway, communication between all parties needs to take place so this is a more joined pathway
S1229	P-LC	There should be consultants available at clinic for all aspects of the illness. They should work together on each body as a whole, rather than separate in individual departments. They should be able to communicate and troubleshoot symptoms in a shared environment, with access to all patients records. They should be open to new treatments which are providing current relief, such as acupuncture & hyperbaric oxygen therapy
S1218	P-LC	specialists from different domains communicating frequently about patient care, coordinating testing and diagnosis accordingly
S1217	P-LC	Someone should be a singular point of contact so there is an overview of treatment & progress
S1160	P-LC	1 PROJECT MANAGER TO BE THE PATIENT CONTACT AND THAT PROJECT MANAGER TO ORGANISE MULTI-DISCIPLINARY TESTING AND TREATMENT
S1144	P-LC	Integrated support means proper joined up thinking.
S1143	P-LC	One named person coordinating referrals and collating information
S157	P-LC	Starts with a single point of contact
S155	P-LC	Have a clinic that has Functional Doctors who look at all the person not just the heart or the lungs. Not sure why psychological. I would have physiotherapy, acupuncture, meditation, yoga as offerings.
S144	P-LC	Be properly integrated; provide access to all three all the time
S149	P-LC	I would like a one stop shop, where people with multi-systemic syndromes come to one place and see a variety of specialists in one location

S151	P-LC	A rehabilitation centre where you stay for an appropriate length of time, that offers specialised support for people to learn to live with their condition. As well as weekly programs, support groups and specialists in those fields that seem to be most affected. Plus additional support for family members to help them learn to cope with the impact of their loved ones disabling condition.
S1191	P-LC	Leaving all this to small local clinics is ineffective. National approach is required to allow appropriate resources
S1220	P-LC	You turn up for an appointment they run all the tests and you see the consultant at the end of the appointment to discuss the results etc
S110	P_LC	Less waiting time will be at 9mths with long covid before I go to my initial appointment
S117	P_LC	Waiting time
S119	P_LC	Wait times
S120	P_LC	Waiting times
S120	P_LC	Reduced waiting times
S131	P_LC	Referral time limits
S132	P_LC	Quicker referrals
S133	P_LC, P_LTC	Referral to a specialist much faster
S134	P_LC, P_LTC, HCP_LTC	Swift treatment
S135	P_LC	timely appointments
S136	P_LC, P_LTC	Waiting lists for specialists (such as cardio, neurology, gastro etc) being far, far shorter!
S136	P_LC, P_LTC	Speedy appts - 25mths in and I'm still not back at work full-time but going through rehab while also having a phased return to work - phased return as work is pressurising me into returning to full-time. It's the wrong way around?
S136	P_LC, P_LTC	Speedy referrals, appts and support
S144	P_LC	Lessen waiting times
S148	P_LC, HCP_LC, HCP_LTC	Access to service, long waiting list
S169	P_LC, HCP_LTC	Investigations are done centrally (DaTscan) and so there can be a long waiting list.
S176	P_LC	Length of wait for long Covid clinic
S182	P_LC, P_LTC	Speeding up of any subsequent referrals
S1109	P_LC, P_LTC, HCP_LTC	Decrease waiting times- I was tachycardic and SOB for 5 months before being started on an antiarhythmic. When I was given amlodipine by A&E doctor, my GP wouldn't continue prescribing it and referred me to cardiology . I had Covid on 12th of March 2020 and started diltiazem in mid august 2020

S1142	P_LC, HCP_LC, HCP_LTC	Swift assessment
S1150	P_LC, P_LTC, HCP_LTC	NHS waiting list. I decided to use private insurance
S1152	P_LC	Waiting times
S1153	P_LC, P_LTC	Speed of treatment
S1153	P_LC, P_LTC	Speed
S1161	P_LC	Very long waiting times
S1170	P_LC	Reduced waiting times.
S1177	P_LC	Faster appointments
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Timely assessment and treatment
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Waiting times for therapy are too long
S1184	P_LC, P_LTC	Timing
S1191	P_LC	Unnecessary delay going to pointless long covid clinic when neurologist referral could have been made quicker, why was I forced to wait for 3 months before being allowed to be referred to the long covid clinic, studies and surveys I've seen often give too much focus on fatigue and respiratory symptoms when there are many different symptoms as well that seem to be forgotten about and sometimes not even mentioned
S1191	P_LC	Quicker triage tailored for your own symptoms
S1193	P_LC	Time/ ease of access in the first instance
S1217	P_LC	Faster, easier referral
S1218	P_LC	more timely access to NHS long covid clinic appointments
S1223	P_LC	Give appointments to people within a fair order
S1223	P_LC	Prioritise appointments to people who've had symptoms for over a year
S1226	P_LC, P_LTC	GP said there would be no help for 2 months
S1226	P_LC, P_LTC	Fast access
S1229	P_LC	Referral process and wait time is too long. My original referral wouldn't be accepted back in 2020 because of not having a positive test when no tests were available in March 2020 during my original infection. Then the referral was lost in 2021, my gp is still pushing for me to be seen 2 years after my infection.
S1232	P_LC, P_LTC	Time between being referred & having available appointments
S1238	P_LC	Timeframe

S1239	P_LC, P_LTC	Less wait for Ling Covid clinic would be good. Very relieved to know you are conducting a therapeutic trial. Sorry it will be such a wait
S1248	P_LC, P_LTC	Speed of NHS services
S1258	P_LC	Waiting time
S1269	P_LC, P_LTC, HCP_LCT	they could have bloody well got in touch earlier than 7 months after referral
S1274	P_LC	I waited too long
S1279	P_LC	Referrals took too long, were rebuffed or were superficial examination.
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	I saw a private consultant very quickly so this worked well
S1298	P_LC, P_LTC	Greatly reduce the waiting times to be seen. Having to wait months or even a year just to see one specialist is horrible. Your entire life gets put on hold.
S1301	P_LC, P_LTC	Speed of tests/referrals
S1306	P_LC	Wait time...still no appointment with long covid clinic
S1307	P_LC	Speed of referral
S1311	P_LC	A quicker referral to a specialist clinic
S1321	P_LC	Speed of services.
S1331	P_LC	Not have to wait months to talk to anyone
S170	P_LC, P_LTC	Too many appointments
S1_7	P_LC	Referral to proper specialists
S1_8	P_LC	Help the patient I have been left on my own with no help nor support from GP
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Referral pathways should make sure patients can be referred to the right service for their needs.
S174	P_LC	Offer respiratory physio ASAP
S1121	P_LC, P_LTC	Mobility, more access to mobility aids and pain clinics
S1122	P_LC, HCP_LTC	Accessing a broad variety of holistic mental health treatments.
S1142	P_LC, HCP_LC, HCP_LTC	Referrals when required or re-directing to GP
S1144	P_LC	To actually offer support
S1152	P_LC	Financial support
S1153	P_LC, P_LTC	Refer me to a specialist
S1158	P_LC, P_LTC	Referral to specialist

S1172	P_LC, P_LTC	Support groups
S1173	P_LC	symptom management
S1211	P_LC, P_LTC, HCP_LTC	Rheumatology has very good set up for inflammatory arthritides - phone helpline, specialist nurses etc
S1224	P_LC, P_LTC	signposting to other helping organisations
S1234	P_LC	Practical help
S1248	P_LC, P_LTC	Develop a group network as helps to talk to others
S1250	P_LC	Referral to specialist services and reassurance that there are options to try
S1251	P_LC	A plan of support rather than medication for life
S1269	P_LC, P_LTC, HCP_LCT	easy to contact if problems
S1299	P_LC, HCP_LTC	More symptomatic attitude to improve their symptoms, not to rushed to discharge them from clinic
S1311	P_LC	Encourage them to network with others with long covid, eg on Facebook as there is more information there
S1315	P_LC, P_LTC	Referring to specialist services wherever practicable.
S1193	P_LC	Giving patients the option to speak to advisors freely instead of having to wait. Its alienating and depressing living with the condition.
S1315	P_LC, P_LTC	they were able to do all the hospital referrals together
S1298	P_LC, P_LTC	Put in contact with other Long Covid patients
S1157	P_LC, HCP_LC, HCP_LTC	Appropriate length appointments
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Recognising limitations of current models of working, eg 10min Gp appointments for patients with multiple problems
S1187	P_LC, HCP_LC, HCP_LTC	single appointments to cover all of the health issues in one place. But these must be long enough! e.g., 1 hour per patient
S1187	P_LC, HCP_LC, HCP_LTC	long appointments to deal with all systems in one go, rather than multiple short appointments
S1187	P_LC, HCP_LC, HCP_LTC	time to care (long appointments)
S1228	P_LC	Give enough time
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Longer appointments- we have 10 minutes only

S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	If multiple conditions, then appt time to reflect this
S136	P_LC, P_LTC	Care co-ordinator, care plan with regular reviews - service being able to make referrals to specialists
S1301	P_LC, P_LTC,	Doctors managing different aspects communicate with each other, and not just for the most seriously ill patients.
Provide patient centred approach		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S148	P_LC, HCP_LC, HCP_LTC	Treatment plan agreed with patient
S1142	P_LC, HCP_LC, HCP_LTC	Agreed to prescribe what I asked for but with some reluctance
S1142	P_LC, HCP_LC, HCP_LTC	Write requested referrals
S1151	P_LC, P_LTC, HCP_LTC	Gp very compassionate and did her best to help and listen to a way to access secondary care services.
S1211	P_LC, P_LTC, HCP_LTC	Believed my opinion on research & agreed to prescribe medications that were reasonable
S1229	P_LC	Pushed for long covid clinic referral
S1237	P_LC	While not well versed in long covid himself, my GP was very responsive and willing to request tests that had been recommended by other professionals, studies, and other resources that I brought him
S1279	P_LC	Adapted approach to my goals- I have high level job and want to get back to that. They didn't assume that because I can walk and talk, I was ok
S1294	P_LC, P_LTC, HCP_LC HCP_LTC	Collaborative approach acknowledging fact that as a doctor I was reading available information too and making my own suggestions
S1270	P_LC, P_LTC	Don't dismiss as mental or anxiety.
S1257	P_LC, P_LTC	Didn't say long covid isn't real or in your head
S1203	P_LC	Did not try to persuade me it was anxiety etc.
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Listen and try and understand
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Important to build rapport and have empathy
S1224	P_LC, P_LTC	How far a little kindness goes
S1142	P_LC, P_LTC,	Empathy & understanding

	HCP_LTC	
S114	P_LC	Behaved professionally and showed modesty. Accepted that symptoms unexplained by known conditions are important to investigate, rather than discard as psychological.
S115	P_LC	listening
S117	P_LC	Listened to
S126	P_LC	Believe them that this is real
S134	P_LC, P_LTC, HCP_LTC	Listening holistically
S134	P_LC, P_LTC, HCP_LTC	listening
S138	P_LC, HCP_LTC	Believe and listen to people
S149	P_LC	Listened
S151	P_LC	Listen and explain more about my symptoms
S151	P_LC	listen
S154	P_LC	Listened
S164	P_LC	Listening to the patient
S168	P_LC, HCP_LC	Listened to me
S172	P_LC, P_LTC	To listen to the patient
S182	P_LC, P_LTC	Listening not assuming
S182	P_LC, P_LTC	Listening active GP
S183	P_LC	Listening to the patient is the most important thing and not dismissing the symptoms or levelling up with a mental health issue
S186	P_LC	Believed me
S198	P_LC, P_LTC	One GP really listened
S198	P_LC, P_LTC	Listened
S198	P_LC, P_LTC	Not all doctors listen or believe
S198	P_LC, P_LTC	GPs who don't listen gate keep care
S198	P_LC, P_LTC	Listen and believe
S1109	P_LC, P_LTC, HCP_LTC	A dressed my main symptoms
S1122	P_LC, HCP_LTC	Listened and validated my symptoms.
S1144	LC_P	To talk to people with LC so they can learn

S1150	P_LC, P_LTC, HCP_LTC	listen
S1150	P_LC, P_LTC, HCP_LTC	They listened to the patient
S1151	P_LC, P_LTC, HCP_LTC	The psychologist valued what I was saying, listened and gave me the time I needed to explain my symptoms.
S1151	P_LC, P_LTC, HCP_LTC	To listen to patients, give them time to explain complex symptoms that could be attributed to a few things/symptoms from medication/ symptoms developed from lack of support or treatment
S1151	P_LC, P_LTC, HCP_LTC	Ensure patients know they are being listened to and valued and ask them what they feel they need. Explain things to them in a way they can understand and check understanding.
S1153	P_LC, P_LTC	Understanding of the impact symptoms have on life
S1156	LC_P	Listen to patients
S1157	P_LC, P_LTC, HCP_LTC	Patient centred
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Listen to patients. If they have a long term condition, they will know a lot about it so avoid patronising them
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Respect patient experience
S1187	P_LC, HCP_LC, HCP_LTC	Time to explore symptoms and effect on life
S1193	P_LC	Listened and weren't dismissive
S1193	P_LC	Listen to patients and acknowledge the seriousness of the issue, and the impacts it might be having on their lives
S1217	P_LC	Understanding
S1218	P_LC	neurologist: willing to consider symptoms collectively
S1221	P_LC	Careful listening of symptoms
S1224	P_LC, P_LTC	Active listening and responding to the individual
S1228	P_LC	Listened
S1231	P_LC	Listen to all symptoms
S1231	P_LC	Believe patients and the impact long covid has on their lives
S1234	P_LC	Listening to all symptoms
S1234	P_LC	Understanding it is not one constant state

S1235	P_LC	Learning from patient experience, centring in discussions. Offering low stakes anecdotal suggestions based on patient feedback to other patients.
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	No apps
S1247	P_LC	Listened to me
S1251	P_LC	A recognition that it can cause difficulties in such a range of areas. So many doctors still only think it's the respiratory symptoms
S1252	P_LC	Being listened to.
S1255	P_LC, P_LTC	Make sure people are coping but do NOT psychologise everything, as has been done with Long Covid
S1257	P_LC, P_LTC	Listen to all the people with Long Covid self-treating and listen to what is working for a lot of them (low histamine, low sugar, yeast free diet, H1 and H2 blocker antihistamines, things that help people with MCAS (mast cell activation syndrome), rest.
S1257	P_LC, P_LTC	Listened
S1257	P_LC, P_LTC	Listen - not hear; listen and absorb what is being said
S1274	P_LC	Listened
S1274	P_LC	believed me
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Learning from patient experience and taking this on board
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Patients understanding and what they are hoping to gain from input
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Understand the specific individual's situation and therefore the impact of problems
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Understand patient experience and expectations
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Try and do the above and understand where they want to try and get to. Explore all possible underlying contributing factors
S1311	P_LC	Listening
S1317	P_LC, P_LTC, HCP_LC, HCP_LTC	Understand the problems
S1318	P_LC	They listened
S1332	P_LC	Listened
S1332	P_LC	Tried to provide some hope

S1228	P-LC	Listen before talk
S183	P-LC	Well run Service that's fully staffed, fully funded, has a full MDT specialise in all different regions, and more importantly that they listen to the patients
S1193	P-LC	I am keen to work with professionals to develop this. Form someone with lived experience, i'd like to support this.
S115	P_LC	admitting when they didn't know
S1118	P_LC, P_LTC	Transparency when they genuinely don't know how to treat.
S1122	P_LC, HCP_LTC	Being honest when they don't know something, and not deciding that their lack of knowledge means that the symptoms must be caused by a mental health problem.
S1235	P_LC	Acknowledging unknowns rather than being defensive about uncertain areas of knowledge/research,
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Be prepared to say 'I don't know'
S117	P_LC	Believed
S154	P_LC	Understood
S1132	P_LC, P_LTC	Were supportive
S1251	P-LC	A dedicated team with a named support worker
S1_9	P_LC	Not assuming that fatigue was due to deconditioning
S115	P_LC	More innovation and out of the box thinking
S182	P_LC, P_LTC	More open initial assessment
S198	P_LC, P_LTC	All other GPs don't listen properly
S1150	P_LC, P_LTC, HCP_LTC	They could have listened
S1157	P_LC, HCP_LC, HCP_LTC	Stop treating it like a functional illness. I arrived at the clinic to be presented with questionnaires about anxiety, depression and trauma
S1313	P_LC	Recognition of ongoing deterioration.
S135	P_LC	the package they put together was like one size fits all sadly it didn't work for me and was dismissed and told to learn to live with it
S138	P_LC, HCP_LTC	Some irrelevant theory e.g., a suggestion of deconditioning, if unhelpful thinking doubt activity restriction, it wasn't true and isn't relevant to me
S186	P_LC	No treatment offers or support with managing disabling symptoms
S154	P_LC	Listening & hearing patients, personalised support and treatment plans
S1122	P_LC, HCP_LTC	Validation of the patient's symptoms and using the the patient's experiences to develop a care plan.

S1150	P_LC, P_LTC, HCP_LTC	Agree on a plan with patient input
S1228	P_LC	Plan and listen
S1230	P_LC	Develop a personal action plan which is realistic and recognises good and bad days
S1274	P_LC	Trying lots of things out and not waiting for evidence. My quality of life is being lost now- I can't wait Years for a study
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	There are no evidence-based treatments so if things make sense be prepared to consider it whilst evidence is collected. This is a new problem so can leave people feeling helpless when sensible safe trials of things suggested but refused because 'there's no evidence base'
S1317	P_LC, P_LTC, HCP_LTC	Improved care plans so the service user knows what the plan is
S1321	P_LC	Treatment management - NOT mental health management
S1234	P-LC	It should flex to the needs of the patient, if it could at its essence look to provide treatment that would be a start
S154	P-LC	Personalised, truly patient-centred & needs led. A consistent support team who knows the patient, a fully holistic approach that understands & educates patient about the mind/body connection of LC & the importance of the nervous system.
S1221	P-LC	Advice concerning initially managing the symptoms both physically medically and psychologically and this should be about each individual's condition rather than a generalised response. Fully understanding that there are many patients suffering possibly more severe or critical illnesses but sidestepping this something that is investigative and provides remedies to symptoms rather than the unsympathetic response of managing the conditions
S1247	P-LC	Where those HCP can refer and liaise with other specialists providing individualised care!!! Including social care and advice re benefits etc.
S1274	P-LC	Needs to be completely flexible and personalised - Based on what matters to me
S117	P_LC	Communication
S182	P_LC, P_LTC	More feedback from symptoms that went to MDT, no real feedback given for months
S1101	P_LC	Co-ordination - I have had no oversight of my care
S1151	P_LC, P_LTC, HCP_LTC	Communication.
S146	P_LC	Tell them what to expect and when rather than leaving ppl in limbo, regular contact
S169	P_LC, HCP_LTC	All patients receive a copy of their clinic letter and are included in decision making.
S1151	P_LC, P_LTC, HCP_LTC	Have a clear plan and communicate that plan with patients. Have someone in place that can follow up after specialist appointments. Someone who has time and can coordinate care.
S1221	P_LC	I clear directive which was conspicuously absent

S133	P_LC, P_LTC	Being taken seriously first time. Especially when not someone who used the GP a lot beforehand.
S172	P_LC, P_LTC	Not dismissing symptoms as normal woman's problem
S192	P_LC, P_LTC	Take me seriously
S1224	P_LC, P_LTC	If I had been believed, diagnosed, referred to Long Covid clinic (physio said she'd done the same as I would have had in the Long Covid clinic)
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Being taken seriously as a serious illness
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Taken seriously
S1270	P_LC, P_LTC	Needs to be taken more seriously.
S1279	P_LC	Referrals took too long, were rebuffed or were superficial examination.
S1281	P_LC, P_LTC	They listened and took me seriously
S1299	P_LC, HCP_LTC	Believe your patient
S1315	P_LC, P_LTC	Listening to and taking patients' concerns seriously.
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	More time is needed than just 10 mins.
S134	P_LC, P_LTC, HCP_LTC	Time to get through appointment
S168	P_LC, HCP_LC	we have time to listen
S1151	P_LC, P_LTC, HCP_LTC	Someone who has time to give to patients and ensure patients feel they are able to fully explain/communicate their issues
S116	P_LC	No gaslighting/ no dx FND
S131	P_LC	Stop gaslighting us saying it's anxiety just because they don't know what's wrong.
S133	P_LC, P_LTC	Told me that despite being "Just migraines", it was a very real debilitating conditions that necessitated to be treated properly
S133	P_LC, P_LTC	Acknowledge symptoms
S136	P_LC, P_LTC	Acknowledgement
S149	P_LC	not tell you it's related to anxiety and fob you off with CBT
S150	P_LC	Do not psychologize symptoms!
S155	P_LC	Be believed- Covid can cause gut problems
S156	P_LC	Recognition
S167	P_LC	Believe their symptoms are real, even when the tests are 'normal'

S167	P_LC	Believe what they tell you, it is sensible to have an awareness of a deadly disease which is running loose through our community, it doesn't make us headcases
S186	P_LC	Validation of symptoms and experiences
S192	P_LC, P_LTC	DO NOT psychologize physical symptoms
S1101	P_LC	Acknowledgment of real, physical condition - do not palm off onto psychology (although this can be a useful supportive service)
S1128	P_LC	Belief and curiosity
S1131	P_LC, P_LTC	Believe the patient and do not gaslight base on results. Absence of evidence does not mean evidence of absence.
S1132	P_LC, P_LTC	Not blaming psychological reasons
S1150	P_LC, P_LTC, HCP_LTC	Validate
S1151	P_LC, P_LTC, HCP_LTC	To listen to the patient and value what they are saying. To acknowledge long Covid is complex, and the evidence is emerging. To acknowledge the patient's frustration and keep abreast of developments.
S1153	P_LC, P_LTC	Acknowledging the problem
S1158	P_LC, P_LTC	Reassurance that it's a physical disease
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Believe patient experience of symptoms
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Ongoing recognition of the condition which can course many symptoms but is never acknowledged
S1211	P_LC, P_LTC, HCP_LTC	Belief in symptoms/experience, do not say it's all caused by anxiety or depression
S1223	P_LC	Stop people feeling despair. We aren't making this up!
S1226	P_LC, P_LTC	Recognised the problem
S1247	P_LC	Believe in our symptoms
S1257	P_LC, P_LTC	Acknowledged there were things wrong with me
S1307	P_LC	Acceptance symptoms real
S1311	P_LC	Believe in their symptoms without question
S146	P_LC	Believing them!
S153	P_LC	Believing patients
S172	P_LC, P_LTC	Listening to symptoms and believing patient
S1124	P_LC, P_LTC	no gaslighting
S1132	P_LC, P_LTC	Believing them

S1226	P_LC, P_LTC	Believe the patient
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Belief
S1_9	P_LC	Be open minded and inquisitive into the conditions
S133	P_LC, P_LTC	Offer to try treatments
S198	P_LC, P_LTC	Willingness to try treatments
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Offer symptomatic treatment and be prepared to take qualified risks with that
S1269	P_LC, P_LTC, HCP_LCT	greater willingness to try other treatments with less robust evidence bases- once you've tried NICE-recommended treatments there are still other options!
S1269	P_LC, P_LTC, HCP_LCT	options to try different treatments - evidence-based ones first, then other options if appropriate and the first ones haven't tried
Offer reviews of care and provide ongoing support		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S136	P_LC, P_LTC	Covid Rehab - supporting recovery after being medically stable
S1223	P_LC	Make sure that cases of long covid are Logged and recorded, against vaccines too
S186	P_LC	Short appointments hard to discuss long term condition
S1225	P-LC	Longer appointment times to discuss multiple symptoms. Someone with responsibility for coordinating your overall care
S138	P_LC, HCP_LTC	Continuity of care
S170	P_LC, P_LTC	Continued support, especially when there is new research
S172	P_LC, P_LTC	Not discharging just because they haven't yet found out what's wrong
S1157	P_LC, HCP_LC, HCP_LTC	Regular follow up and containment, often can't fix condition but ongoing support is often valued
S1158	P_LC, P_LTC	Continued care
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Unsuitability of short-term therapy
S1187	P_LC, HCP_LC, HCP_LTC	Time to ensure the patient is seen for long enough to ensure all issues are resolved
S1191	P_LC	Don't give up trying to find out what is physically wrong - I've effectively been told that there is nothing else they can do and I'll just have to learn to live with it. I don't find that acceptable and am going to try acupuncture
S1206	P_LC, HCP_LTC	Long term care for patients

S1220	P_LC	They just discharge or lose you in system as they don't know what to do with you and are snowed under
S1232	P_LC, P_LTC	Ongoing support
S1269	P_LC, P_LTC, HCP_LCT	Offers of long term follow up - acceptance that long term conditions don't go away and it's not appropriate for GPs to take on the clinical burden
S1280	P_LC	Continuity of care
S133	P_LC	Did check up to see how treatment was going
S134	P_LC, P_LTC, HCP_LTC	Forcing medical review and tests
S144	P_LC	Have follow-up appointments to review symptoms as they frequently change
S144	P_LC	Keep seeing people periodically to discuss if things have changed
S152	P_LC	Good virtual Comms through video sessions and in app messaging
S157	P_LC	Follow ups
S167	P_LC	doctor contacted a week later to see how I was doing on the sertraline and upped the dose from 50 to 100 so I was more balanced
S168	P_LC, HCP_LC	check up after a few month
S169	P_LC, HCP_LTC	Regular follow up appointments
S172	P_LC, P_LTC	Poor follow up
S173	P_LC	Followed up on my wellbeing
S173	P_LC	Offer a clinic appointment to follow up
S189	P_LC	Follow up by my GP
S1109	P_LC, P_LTC, HCP_LTC	Difficult follow up of the patients
S1142	P_LC, HCP_LTC, HCP_LC	They did get in contact
S1149	P_LC, P_LTC	Follow-up appointments with junior doctors who couldn't make decisions on treatment/referrals without speaking to consultants, meaning it was easy for follow-up actions to be missed or treatment options to be forgotten
S1149	P_LC, P_LTC	More frequent repeat tests eg bloods/ 6 min walk test to track any improvement / deterioration
S1150	P_LC, P_LTC, HCP_LTC	Follow up
S1151	P_LC, P_LTC, HCP_LTC	Regular reviews

S1152	P_LC	Regular well-being checks
S1157	P_LC, P_LTC, HCP_LTC	Regular follow up
S1157	P_LC, P_LTC, HCP_LTC	Regular follow up and containment, often can't fix condition but ongoing support is often valued
S1187	P_LC, HCP_LC, HCP_LTC	Follow up, ensuring there is capacity in the system to review patients
S1192	P_LC	Format of follow up
S1211	P_LC, P_LTC, HCP_LTC	Rapid review - slotted me into clinic as emergency
S1224	P_LC, P_LTC	Follow-up
S1231	P_LC	Don't just send for tests and discharge patients
S1248	P_LC	Regular phonecalls
S1248	P_LC	Telephone consultation/chat
S1255	P_LC, P_LTC	I was given blood tests for various conditions and received absolutely no feedback, even after contacting the clinic to remind them. The nurse asked if I was better, to which I replied in the negative. She then told me that I should go to the GP as it is better to be treated in the community. As GPs are as much as, or more, in the dark as patients, this is patently ridiculous! GPs are waiting for answers from Long Covid clinics. I have not been back to the GP.
S1255	P_LC, P_LTC	Follow up tests and advice to ensure that condition has not worsened
S1255	P_LC, P_LTC	Review medications annually at least
S1269	P_LC, P_LTC, HCP_LTC	regular follow up
S1269	P_LC, P_LTC, HCP_LTC	Regular follow up with an appropriate skilled and compassionate clinician
S1270	P_LC	It's been managed well.
S1272	P_LC	Change my nasal spray
S1274	P_LC	Enough resource for regular follow up and setting up peer support- I feel completely alone with this
S1280	P_LC	Follow up appointments with the same doctor
S1281	P_LC, P_LTC	Regular contact
S1288	P_LC	Follow up
S1288	P_LC	Follow up as information and knowledge is changing

S1294	P_LC, HCP_LC, P_LTC, HCP_LTC	Follow up review
S1294	P_LC, HCP_LC, P_LTC, HCP_LTC	Regular review to address subtle changes that may have occurred and provide opportunity for discussion of new approaches to treatment and management of applicable
S1294	P_LC, HCP_LC, P_LTC, HCP_LTC	Planned reviews
S1298	P_LC, P_LTC,	ONE doctor who keeps an eye on things LONGTERM!!!
S1299	P_LC, HCP_LTC	Keeping people under follow up as very little is known about long covid yet
S1299	P_LC, HCP_LTC	Regular follow ups
S1301	P_LC, P_LTC	Arranged follow up appointments to discuss results
S1301	P_LC, P_LTC	No ongoing supervision by NHS specialist
S1311	P_LC	Regular Contact
S1315	P_LC, P_LTC	Repeat blood tests (for abnormal thyroid results) not automatically scheduled
S1317	P_LC, P_LTC, HCP_LTC	No allocated person different each time, no follow up relying on GPs
S1317	P_LC, P_LTC, HCP_LTC	Review if interventions are working
S1214	P-LC	Easy to treat, not confusing, continuity of care, not dismissive
S119	P-LC	Check ins and support groups where you could then be offered what is needed.
S1206	P_LC, HCP_LTC	Long term named support
S1152	P_LC	Having an MDT approach that follows how symptoms change. Reinfection gave me more problems.
S1153	P_LC, P_LTC	Something combining therapeutics with support group counseling
Provide evidence-based treatment and recommendations		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1_3	P_LC	Only self-care offered, cannot get hormones properly investigated or possibility of micro-clots or stress-MRI or tilt-table test
S126	P_LC	If there were actual effective treatments for post viral conditions like POTS/ dysautonomia that factored in the CFS/ME element of the disease
S132	P_LC	CBT did nothing, this illness isn't anxiety or depression
S134	P_LC, P_LTC, HCP_LTC	Give me actual treatment so I can get better

S1122	P_LC, HCP_LTC	More treatments and understanding if the pathophysiology of the illness.
S1153	P_LC, P_LTC	Offer any sort of treatment or hope
S1157	P_LC, HCP_LC, HCP_LTC	Stop treating it like a functional/psychological condition
S1211	P_LC, P_LTC, HCP_LTC	Minimising appts at hospital if people are under several services, or trying to coordinate so they are on the same day
S1270	P_LC, P_LTC	Help with treatment.
S1273	P_LC, HCP_LTC	Better treatments
S1306	P_LC	Taking a functional approach to find most effective leverage points for intervention, including close attention to symptoms that may be significant
S1332	P_LC	Having actual treatments that work
S1332	P_LC	We need actual treatments
S1_6	P-LC	Psychology should not form a central part of this support. CBT or any other psychological intervention should not be offered as 'treatment' for Long Covid. If psychology must have a role in Long Covid services, it should be a minor, secondary, ancillary role at most - and this should be made clear.
S116	P-LC	Physical should be main focus, the rest is "management of disease".
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	They were poorly informed about the condition they saw.
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	The right expertise should be within the team to meet the needs of the patients being seen.
S1150	P_LC, P_LTC, HCP_LTC	They knew the condition and how to diagnose
S1151	P_LC, P_LTC, HCP_LTC	More education around overlapping conditions that might have a contributing factor
S1151	P_LC, P_LTC, HCP_LTC	Ongoing education and shared learning to ensure patients are getting the best from the service
S1157	P_LC, HCP_LC, HCP_LTC	Access to up-to-date information about treatment
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Recognise the way in which many problems the person presents with may relate to the LTC
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Acknowledgement of own knowledge and understanding

S1315	P_LC, P_LTC	Learning constantly about new developments and research in relevant fields.
S1170	P-LC	Senior healthcare professionals should be trained to recognise and treat the multiple symptoms together.
S1152	P-LC	MDT team, that have in-depth knowledge of the condition. Good communication between HCPs.
S1131	P_LC, P_LTC	Remember science backs up knowledge but for new conditions there us no knowledge so science needs time to catch up. And whilst this happens antidepressants are not the solution to all patient problems. At one point people thought the world was flat!
Provide employment support and sick note		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S134	P_LC, P_LTC, HCP_LTC	Support for employment
S1318	P_LC	The wrote me Drs letter for not being at work for months
S1262	P-LC	As long as support and understanding are there and help to get through it. Also, the help employer's understand
S187	P-LC	You should never be given a mental health questionnaire on arrival. The patient should then be tested straight away for the presence of microclots and auto antibodies. They should then be prescribed antivirals (paxlovid) and anticoagulants. They should be shown how to PACE using a heart rate monitor to keep the HR within the levels advised by ME groups. They should be given a sick not that staes they have long covid and financial support to rest until they are 100% fit and able to return to work. Treatment should start at 4 weeks.
S173	P_LC	Consider a diagnosis to help with benefits etc
S1112	P_LC, P_LTC	support in access to benefits
S1230	P_LC	Signing people off work so they don't have to try to work when too tired to do anything
S1149	P_LC, P_LTC	paid time off to recuperate if struggling with energy and/or cognitive function, treatment trials, and support with activities of daily living.
Provide access to research		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S132	P_LC	Biomedical research not exercise, CBT, diet
S138	P_LC, HCP_LTC	More options e.g research options, biomedical trials, access to treatments
S169	P_LC, HCP_LTC	Opportunity to be involved in biomedical research. The Long Covid clinic network would be a great opportunity to do this. We do the same within the Parkinson's Service that I work in.
S170	P_LC, P_LTC	I had hoped to be part of clinical trial
S170	P_LC, P_LTC	Campaign for more clinical trials
S173	P_LC	Record symptoms and long-term effects on health as evidence
S198	P_LC, P_LTC	More research into treatment for ME/chronic fatigue so that there are actual treatments

S1101	P_LC	Access to treatments from current biomedical research - even if not fully evidenced. More harm is done by doing nothing.
S1112	P_LC, P_LTC	research into the condition
S1121	P_LC, P_LTC	More research and drug trials are needed
S1122	P_LC, HCP_LTC	Being forthright are offering enrolment into clinical research to enable access to new treatments.
S1128	P_LC	Current research and possible treatments
S1149	P_LC, P_LTC	More unofficial trials of new theories e.g. micro clots/ antivirals
S1153	P_LC, P_LTC	Recommend clinical trials and studies
S1153	P_LC, P_LTC	Enrol me in a study or trial
S1192	P_LC	Diagnostic tests & access to research info and trials
S1225	P_LC	Trials of potential treatments
S1248	P_LC, P_LTC	More information on studies and how to get involved as a volunteer to help others
S1274	P_LC	I'm the absence of treatments I would like to be offered experimental ones eg aspirin for micro clots, antihistamine for mast cell activation, etc. Hyoerbaric oxygen therapy?
S1304	P_LC	New study advice
S1306	P_LC	Trialling or referring to trials of basic medications like antihistamines or low dose aspirin
S1318	P_LC	Research into treatments
S1320	P_LC	Biochemical research and drug trials
S1332	P_LC	Advocate for research project and funding
Encourage early intervention		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S110	P_LC	Referred straight away not after the 12 weeks mark
S182	P_LC, P_LTC	Quickly referred by GP
S1238	P_LC	Early intervention
S1315	P_LC, P_LTC	Pro-active support following initial infection, to monitor development of long Covid
S1317	P_LC, P_LTC, HCP_LTC	Early intervention
S1317	P_LC, P_LTC, HCP_LTC	Supporting me to see someone about breathlessness earlier
S1331	P_LC	Prompt help on symptoms
Ensure services have appropriate resources		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>

S1244	P_LC	Maximise funding and manpower for research and clinical trials to treat PEM, fatigue, cognitive dysfunction
S149	P_LC	they were not properly funded to provide a complete service, they could only offer some advice and a referral on to other services
S149	P_LC	They need money to provide a proper service, they wanted to help but were limited in what they were allowed to provide
S1234	P_LC	Resources to be referred to
Provide no psychological treatment		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S150	P-LC	I just need biological.
S128	P-LC	The social and psychological pathways should be scrapped. The disease is physical.
S152	P-LC	Should be 95%+ focused on biological system. Any psychological support should only form if treatment of it is a symptom and not included by default. Unclear what is meant by social, eg support for benefit applications may be helpful for some?
S1152	P_LC	Greater emphasis on pathophysiology, less on psychology
S1320	P_LC	NOT CBT THATS INSANE !
S187	P-LC	You should never be given a mental health questionnaire on arrival. The patient should then be tested straight away for the presence of microclots and auto antibodies. They should then be prescribed antivirals (paxlovid) and anticoagulants. They should be shown how to PACE using a heart rate monitor to keep the HR within the levels advised by ME groups. They should be given a sick not that states they have long covid and financial support to rest until they are 100% fit and able to return to work. Treatment should start at 4 weeks.
Avoid (graded) exercise as a treatment in case of PEM		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1_7	P_LC	To read up to date NICE guidelines and do not tell me to exercise
S115	P_LC	don't focus on exercise or psychology as that isn't going to help people with very real damage to their bodies.
S1_9	P_LC	Not to consider exercise/weight loss etc at a treatment
S139	P_LC	No graded exercise therapy!
S183	P_LC	Be aware that physical exercise is not a treatment for long Covid and can make you worse
S198	P_LC, P_LTC	One GP told me more exercise was the answer

S1125	P_LC, P_LTC	Doctors should not tell patients that this is psychosomatic, or that exercise and antidepressants will help. Exercise made me 10x worse!
S1143	P_LC	GP said to do graded exercise when I was still suffering PEM
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Should not have advised gradually increased exercise. This made symptoms worse
S1229	P_LC	Stop advising exercise! It makes symptoms worse for those of us with pem
S1244	P_LC	exercise sessions via video call (discontinued - worsened my symptoms)
S1321	P_LC	Consistency - one nurse told me to exercise which is a total no go with long covid PEM
S1327	P_LC	The vast majority thought I was post-Covid and would get better with time and/or increase of exercise (despite PEM). In reality, like most patients, my body is adding to the stack of autoimmune conditions- mostly chronic as time goes on. I imagine that this is mainly to do with the untreated vascular issues I have.
S114	P_LC	Do not push for rehabilitation without actually having the patient evaluated for cardiovascular issues and for post-exertional malaise. Otherwise you will just harm patients.
S169	P_LC, P_LTC	The healthcare providers need education around PEM/PESE, pacing, and that GET is not appropriate.
S1143	P_LC	GP said to do graded exercise when I was still suffering PEM
S1_3	P_LC	In a long covid group, the service tried to push the discredited GET approach
S153	P_LC	GET made me worse
S1131	P_LC, P_LTC	GET should not be offered as a solution
S153	P_LC	No cbt and get as cure-alls. Proper investigations and testing. Address treatable symptoms
S137	P_LTC	It should under no circumstances have an 'integrated pathways'. Rehab services focus on exertion. Long covid with PEM/PESE (getting much iller 24hrs after exertion) needs to never be treated with this.
Offer advice on pacing		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S153	P-LC	No cbt and get as cure-alls. Proper investigations and testing. Address treatable symptoms. Advice on pacing (LongCovid.physio). OT could offer energy saving tips. DON'T immediately jump to psychological-social conclusions for symptoms. Only offer support if there are real indications (not assumed) that this is needed in these areas.
S164	P_LC	Pacing strategies
S170	P_LC, P_LTC	Explain what pacing is (6 months late)
S1143	P_LC	Customised pacing advice
S1247	P_LC	Pacing advice
S1_9	P_LC	Recommended pacing

S1271	P_LC, P_LTC	Pace and rest
S1282	P_LC	Advice on pacing
S1143	P_LC	Advice on managing heart rate
S164	P_LC	Pacing strategies
S1247	P_LC	Pacing advice
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Occupational therapy - help with pacing
S151	P_LC	Offer some sort of rehabilitation programme which involves therapy to learn to pace myself.
S187	P_LC	tell them to rest and PACE using a heart rate monitor
S192	P_LC, P_LTC	Advise to rest, pace
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Teach people how to pace and actively rest. This is vital as most people think they should try to push through and get back to normal life asap.
S1203	P_LC	Understanding of palliative techniques including breathing, diet, how to pace, etc.
S1157	P_LC, P_LTC, HCP_LTC	Telephone consultation with nurse discussed pacing which was helpful
S169	P_LC, HCP_LTC	Advice on pacing. Many people living with Long Covid are likely to be chronically pushing beyond their energy envelope.
S170	P_LC, P_LTC	Explain pacing
S1112	P_LC, P_LTC	offered advice re Pacing
S1143	P_LC	Custom pacing and heart rate advice
S1157	P_LC, HCP_LC, HCP_LTC	Telephone consultation with nurse discussed pacing which was helpful
S1157	P_LC, HCP_LC, HCP_LTC	Tailored advice on lifestyle such as nutrition, sleep (including medication to help sleep if needed), advice about pacing which actually is really hard to do properly
S1214	P_LC	Told me about pacing
S1247	P_LC	Pacing advice
S1269	P_LC, P_LTC, HCP_LCT	practical advice e.g. re breathing exercises and pacing
S153	P_LC	Support with pacing (see LongCovid.physio)
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	General healthy living advice, rest, pacing, diet etc

S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Support with pacing and return to work being aware of the specific considerations of the individuals situation and role
S187	P-LC	You should never be given a mental health questionnaire on arrival. The patient should then be tested straight away for the presence of microclots and auto antibodies. They should then be prescribed antivirals (paxlovid) and anticoagulants. They should be shown how to PACE using a heart rate monitor to keep the HR within the levels advised by ME groups. They should be given a sick not that staes they have long covid and financial support to rest until they are 100% fit and able to return to work. Treatment should start at 4 weeks.
S1149	P_LC, P_LTC	Respiratory Physio assessment and advice on breathing dysfunction and pacing
Provide fatigue management		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1122	P_LC, P_LTC	Fatigue management programme was helpful, delivered by the Long Covid Clinic.
S1244	P_LC	no real help for fatigue
S144	P_LC	Chronic fatigue management gave good advice about managing fatigue
S1217	P_LC	They made me more aware of the strategies for coping with fatigue
S1232	P_LC, P_LTC	Fatigue management workshop
Provide breathing exercise		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1143	P_LC	Breathing exercises to fix disordered breathing
S1203	P-LC	Good understanding of basic ways of dealing with symptoms that are well known in patient groups but not known by doctors. Eg, breathing techniques such as Statis.life in the US. Offer psychological help without us having to ask for it as dealing wiht the illness is very hard.
S1244	P_LC	was told for months that if I engaged with the active breathing course and exercise sessions I could expect to get better. This was not true and the long covid physio clinic have now discharged me saying there's nothing more they can do and I should just expect to have to live with this chronic condition permanently
S1271	P_LC, P_LTC	Breathing exercises
S1220	P_LC	Told to breathe in and out through my nose
S1232	P_LC, P_LTC	Breathlessness workshop
S1149	P_LC, P_LTC	Respiratory Physio assessment and advice on breathing dysfunction and pacing
S1132	P_LC, P_LTC	Breathing rehab
S1143	P_LC	Breathing exercises and assessment

Provide care manager		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1101	P-LC	Care co-ordination with access to relevant specialists, OT, physiotherapy, all of whom are knowledgeable about Long Covid. Take account of current research and listen to patients.
S1318	P-LC	I'm thinking one person who could oversee all aspects, otherwise it's super fragmentary.
S186	P_LC	Named individual contact to coordinate care and reduce risk of over exertion in trying to communicate with new individual. Flexibility for severely ill patients who might be housebound including home visits, online appointments, telephone appointments and integrated care involving family carers where relevant. Appropriate diagnostics and treatments for anything that can be treated, and ability to prescribe, recommend/provide mobility aids and other support. Support with practical elements of managing life with long covid.
S169	P_LC, HCP_LTC	Close working relationship with dedicated specialist nurses. Means the patient has a point of contact who is responsive. Challenging clinical issues can then be referred onto the relevant Consultant for timely action.
S1280	P_LC	Follow up appointments with the same doctor
S1265	P_LC, P_LTC	One lead practitioner to co-ordinate the different support options
S1298	P_LC, P_LTC	You need one designated doctor who coordinates all the different aspects of your care and all the help and tests offered need to take place within a few weeks. As symptoms change with LC you really need a doctor who keeps an eye on things long term and not just one assessment.
S1301	P_LC, P_LTC	Easy point of contact for patient to arrange appointment, get test results, seek urgent advice.
S1317	P_LC, P_LTC, HCP_LTC	A care co-ordinator taking responsibility and having a relationship with the individual or sole understanding
S1325	P_LTC, HCP_LTC	If needs an inquisitive general physician at its heart, probably a specialist nurse, PT, OT, pharmacist. They shouldn't work to protocols, but have leeway to explore different treatments.
Provide psychological support		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S168	P_LC, HCP_LC	CBT support
S1132	P_LC, P_LTC	Support with coming to terms with the condition
S1160	P_LC	PSYCHOLOGICAL SUPPORT
S1230	P_LC	Mental health support as it's frightening to think you may never get back to normal
S1276	P_LC	Mental health support
S1281	P_LC, P_LTC	Psychological help

Provide biopsychosocial model of care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1311	P-LC	I think incorporating the expertise of occupational health, physios, mental health specialists, as well as vascular and lung specialists.
S114	P-LC	It should look like the core is to do adequate investigation of the physical symptoms, adequate tests informed by the wealth of biomedical research on long covid. Getting up to date with this biomedical research is paramount. Socially, you should make sure people get sickness benefits and get help with daily activities when they cannot perform them. Psychologically, you need to believe the patients and listen to them. Do not gaslight them and tell them thinking positive will get them better. They need support with pacing, with rest, with physical pain that is unmanageable at times. They need professionalism, not dismissiveness.
S115	P-LC	Physical: run all the tests and diagnostics, offer all the treatments available. Social: Get people into support networks so they can talk to others who can relate. Psychological: take a backseat. You can offer support to those who have a hard time processing the loss of their previous life, but don't try to "cure" people.
S1298	P_LC, P_LTC	I did a Long Covid rehab in Germany which was amazing. I spent 4 weeks in a rehab centre just being able to concentrate on being better. They ran lots of tests and discovered e.g. I had a significant Vit B12 deficiency, and the programme was really varied consisting of lots of physio sessions, different types of exercise and relaxation classes, the use of a swimming pool, different treatments to get my nerves working properly again, talks, etc. These rehab centres are a core part of the German health system and whenever you have a bigger health problem such as e.g. cancer, stroke, heart attack, hip replacement, etc., you get to spend 3-5 weeks in one of these centres and they really do a great job in improving your quality of life.
S1142	P_LC, HCP_LC, HCP_LTC	More holistic approach
S1252	P_LC	G.P should take a more holistic approach.
S1276	P_LC	Better mental health treatments offer
S1331	P-LC	Located in an outpatient setting with a contact person such as a CNS equivalent who can refer on as needed
S114	P_LC	Have an integrated approach with many specialists (cardiologists, neurologists, immunologists, etc.) who can give a complex picture, rather than the scattered one received from individual evaluations by a specialist at a time.
S164	P_LC	Taking a holistic approach to treatment and care
S170	P_LC, P_LTC	for people with severe long covid: point towards services that help with household tasks. You can't pace if you need to cook. People with children can't recover
S1101	P_LC	Access to social care - many LC patients cannot look after themselves or family

S1121	P_LC, P_LTC	How symptoms are affecting daily life, what can be done to support this
S1159	P_LC, P_LTC	Try multiple approaches to ease symptoms until more is known about underlying causes.
S1177	P_LC	Holistic long covid symptoms
S1192	P_LC	Listening & believing patients. Treating holistically. Multidisciplinary approach.
S1320	P-LC	Drug treatment priorities - clinical support in investigating all issues - therapy to support burden of awful disease
S168	P_LC, HCP_LC	MDT approach, experience clinicians
Provide self-management advice		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S134	P_LC, P_LTC, HCP_LTC	Advice for self-management
S138	P_LC, HCP_LTC	Self-management advice
S186	P_LC	Support with management of symptoms (i.e. guidance on pacing, provision of mobility aids etc)
S1276	P_LC	Help managing symptoms
Provide no lifestyle interventions		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1_9	P_LC	Not to consider exercise/weight loss etc at a treatment

Summary statements about ICP for LTC Patients group review

Statements with associated original survey responses for group comments:

Provide patient centred care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1153	P_LC, P_LTC	Acknowledging the problem
S1226	P_LC, P_LTC	Recognised the problem
S1257	P_LC, P_LTC	Acknowledged there were things wrong with me
S133	P_LC, P_LTC	Told me that despite being "Just migraines", it was a very real debilitating conditions that necessitated to be treated properly
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Ongoing recognition of the condition which can course many symptoms but is never acknowledged
S133	P_LC, P_LTC	Acknowledge symptoms
S136	P_LC, P_LTC	Acknowledgement
S1150	P_LC, P_LTC, HCP_LTC	Validate
S198	P_LC, P_LTC	Believed me
S1285	P_LTC	acceptance and belief in the client about what they say is true
S1132	P_LC, P_LTC	Believing them
S1325	P_LTC, HCP_LTC	Believing patients, no matter how strange their symptoms sound
S172	P_LC, P_LTC	Listening to symptoms and believing patient
S1226	P_LC, P_LTC	Believe the patient
S1275	P_LTC	Don't stigmatise young people as being mentally ill or malingering. If they keep coming back there is clearly something wrong and you may not be looking in the right direction.
S172	P_LC, P_LTC	Not dismissing symptoms as normal woman's problem
S1315	P_LC, P_LTC	Listening to and taking patients' concerns seriously.
S1100	P_LTC	treated me on a level as an equal
S1136	P_LTC	Physicians should believe their patients' symptoms.
S182	P_LC, P_LTC	Listening active GP
S198	P_LC, P_LTC	Listened

S1100	P_LTC	listened and gave me time
S1264	P_LTC	Listened
S1266	P_LTC, HCP_LC, HCP_LTC	Listen and Time
S1300	P_LTC	Listened
S1325	P_LTC, HCP_LTC	Listened to me
S145	P_LTC, HCP_LTC	I felt listened to
S1151	P_LC, P_LTC, HCP_LTC	The psychologist valued what I was saying, listened and gave me the time I needed to explain my symptoms.
S1281	P_LC, P_LTC	They listened and took me seriously
S1325	P_LTC, HCP_LTC	Respected my expertise
S1150	P_LC, P_LTC, HCP_LTC	They listened to the patient
S172	P_LC, P_LTC	Listening to patient
S1257	P_LC, P_LTC	Listened
S1285	P_LTC	Not making assumptions about a person.
S130	P_LTC	Listening
S134	P_LC, P_LTC, HCP_LTC	Listening
S145	P_LTC, HCP_LTC	Ensure the patient feels listened to
S198	P_LC, P_LTC	Listen and believe
S1150	P_LC, P_LTC, HCP_LTC	Listen
S1151	P_LC, P_LTC, HCP_LTC	To listen to patients, give them time to explain complex symptoms that could be attributed to a few things/symptoms from medication/ symptoms developed from lack of support or treatment
S1241	P_LTC	Listen and dont assume that they know it all from s book because fnd is not a one size fits all.
S1257	P_LC, P_LTC	Listen - not hear; listen and absorb what is being said
S1317	P_LC, P_LTC, HCP_LTC	Understand the problems
S159	P_LTC	the ability to listen and respect the patient view
S1151	P_LC, P_LTC, HCP_LTC	Ensure patients know they are being listened to and valued and ask them what they feel they need. Explain things to them in a way they can understand and check understanding.

S1157	P_LC, P_LTC, HCP_LTC	Patient centred
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Listen to patients. If they have a long term Condition they will know a lot about it so avoid patronising them
S1224	P_LC, P_LTC	Active listening and responding to the individual
S171	P_LTC	Listening
S1255	P_LC, P_LTC	Make sure people are coping but do NOT psychologise everything, as has been done with Long Covid
S1_5	P_LTC	an app for patients sharing our experiences
S1100	P_LTC	reassured me that I was not at risk of hospitalisation
S1224	P_LC, P_LTC	How far a little kindness goes
S171	P_LTC	Empathy
S1_4	P-LTC, HCP_LTC	Accessible
S1315	P_LC, P_LTC	When I expressed concern at not being heard about inability to use video, the service director (whom I know) was supportive.
S1315	P_LC, P_LTC	Psychological services should not assume that all patients can cope with video consultation.
S1315	P_LC, P_LTC	Scope for face-to-face consultation should be standard, now that lockdown is long past.
S1325	P_LTC, HCP_LTC	Working together with patients towards THEIR goals
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Acknowledgement of own knowledge and understanding
S172	P_LC, P_LTC	It should look to be supportive to the patient, adapted to their individual needs and to include them in any planning.
S1224	P_LC, P_LTC	its important to listen, believe me, discuss a plan, and follow-up (a phone or video call appreciated). Records by/to pathway partners, with patient copied in. Contact clarity and key worker identified.
S1270	P_LC, P_LTC	Understanding the issues people face and what can be done to mitigate those problems. More awareness and testing needs to be done.
S1271	P_LC, P_LTC	In person tailored support
S1268	P_LTC	Patient groups should have an equal role with HCPs in service design. Individual patients should be respected and listened to. Psychological support should not be prescribed unless requested by the patient. Very sick patients, including those with energy-limiting illnesses limiting capacity for exertion such as listening and talking, will be too ill for psychological interventions; medical and social support are more important. Home visits will be required for patients with severe energy-limiting illness.
S1_5	P_LTC	letting me know how severe my symptoms need to be to ask for the next level of treatment

S1151	P_LC, P_LTC, HCP_LTC	Have a clear plan and communicate that plan with patients. Have someone in place that can follow up after specialist appointments. Someone who has time and can coordinate care.
S1266	P-LTC, HCP_LC, HCP_LTC	Tailored to individual
S1157	P_LC, P_LTC, HCP_LTC	Access to up to date information about treatment
Provide evidence-based treatment		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1275	P_LTC	Followed NICE guidelines but also thought outside the box
S1151	P_LC, P_LTC, HCP_LTC	More education around overlapping conditions that might have a contributing factor
S1264	P_LTC	Acted on my concerns. Also very little practioners have heard of FND in the NHS and alot of people with FND have been treated appalling..As they think we are making it up .(why would we?)and have never heard of it.More education is needed .
S1317	P_LC, P_LTC, HCP_LTC	Not comparing me to their sister saying that my breathlessness is all related to asthma
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	They were poorly informed about the condition they saw.
S159	P_LTC	removing GET
S1259	P_LTC	Drs need to do their research and learn about FND
S1285	P_LTC	Looking outside the box in relation to various known conditions.
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Recognise the way In which many problems the person presents with may relate to the LTC
S1264	P_LTC	Understand the condition and believe it is real .More education is needed in the NHS regarding certain conditions.
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	The right expertise should be within the team to meet the needs of the patients being seen.
S1285	P_LTC	Providing someone who has not only knowledge but also be able to provide client with psychological support
S1300	P_LTC	understanding differences in presentation of same condition in different people
S1315	P_LC, P_LTC	Learning constantly about new developments and research in relevant fields.
S124	P_LTC	Don't be afraid to say "I don't know, but I'll try to find out"
S134	P_LC, P_LTC,	Medication

	HCP_LTC	
S1271	P_LC, P_LTC	Medication
S1150	P_LC, P_LTC, HCP_LTC	They knew how to treat the condition
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Offered effective treatment
S1285	P_LTC	gave tablets for tremor but no thorough investigation took place
S1317	P_LC, P_LTC, HCP_LTC	Trialling a preventer inhaler although it made no difference it could have worked
S1_4	P_LTC, HCP_LTC	treatment
S145	P_LTC, HCP_LTC	I was treated
S1269	P_LC, P_LTC, HCP_LTC	tried various treatment options
S1325	P_LTC, HCP_LTC	Were prepared to trial treatments beyond any guidelines
S1132	P_LC, P_LTC	No treatment options offered
S1153	P_LC, P_LTC	Offer any sort of treatment or hope
S124	P_LTC	Offer safe, effective treatments
S1264	P_LTC	More treatment such as physio, and understanding of the condition
S1158	P_LC, P_LTC	Treatment
S1270	P_LC, P_LTC	Help with treatment.
S1271	P_LC, P_LTC	Medication
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	Patients should be listened to and supported, with treatment as per evidence - not dismissed and told they'll be all right.
S1132	P_LC, P_LTC	Treatment options
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Treatment
S1264	P_LTC	Offer treatments that may help improve things . Moving forward .Such as physio. It is still a postcode lottery .

S1269	P_LC, P_LTC, HCP_LTC	greater willingness to try other treatments with less robust evidence bases- once you've tried NICE-recommended treatments there are still other options!
S1325	P_LTC, HCP_LTC	The UK medical community needs to be less risk averse and once standard treatments are exhausted, be prepared to try alternative options.
S1269	P_LC, P_LTC, HCP_LTC	options to try different treatments - evidence-based ones first, then other options if appropriate and the first ones haven't tried
S133	P_LC, P_LTC	Offer to try treatments
S159	P_LTC	a willingness to experiment with treatments off license if necessary
S198	P_LC, P_LTC	Willingness to try treatments
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Offer symptomatic treatment and be prepared to take qualified risks with that
S124	P_LTC	Patient safety
S143	P_LTC	Any treatment offered should be properly evidenced.
S1_4	P_LTC, HCP_LTC	Good info
S1317	P_LC, P_LTC, HCP_LTC	Recent information about proper inhaler use
S124	P_LTC	Offer scientifically based facts and information
S1172	P_LC, P_LTC	Proper Information
S1239	P_LC, P_LTC	Information.
S1_4	P_LTC, HCP_LTC	Inform the patient well
S124	P_LTC	Truthful and realistic information based on science and the actual lived experience of the patient group as a whole (never false hope!)
S1301	P_LC, P_LTC	Information about the condition and how it will be managed
S1241	P_LTC	Patient needs answers not a fb site to join in order to find out what fnd is
S159	P_LTC	encourage pacing
S170	P_LC, P_LTC	Encourage any exercise (can't do that with long covid)
S1112	P_LC, P_LTC	Advice re symptom management or treatment if applicable
S1301	P_LC, P_LTC	Guidance on self care
S1147	P_LTC, HCP_LTC	A better evidence base
S1112	P_LC, P_LTC	research into the condition

S1153	P_LC, P_LTC	Enroll me in a study or trial
S1147	P_LTC, HCP_LTC	Get a reliable evidence base. The evidence base for managing long term conditions is in general valueless, based on inadequate trial methodology.
S1112	P_LC, P_LTC	research into the condition
S1259	P_LTC	Specialised FND clinics
Take a Biopsychosocial approach to care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1157	P_LC, P_LTC, HCP_LTC	Holistic approach
S1275	P_LTC	Listened and took holistic approach
S1257	P_LTC	Treat me wholistically - I am not just a womb or just a piece of skin - it's all connected
S1157	P_LC, P_LTC, HCP_LTC	Holistic approach
S1275	P_LTC	Holistic approach, ask the patient their story and what brought them to this point. What their journey has been
S1224	P_LC, P_LTC	More comprehensive symptom/contributing factors/Information gathering
S130	P_LTC	Noting all symptoms
S1281	P_LC, P_LTC,	Contact with a doctor, nurse, psychologist, physiotherapist, referral to hyperbaric oxygen therapy or other non main- stream treatments
S1275	P_LTC	Guidelines should have been followed.
S1317	P_LC, P_LTC, HCP_LTC	Refer to current recommendations
S1266	P_LTC, HCP_LC, HCP_LTC	Proactive focus on each issue
S1226	P_LC, P_LTC	Look for links
S1275	P_LTC	Didn't use my weight as the cause as i am now overweight but was thin when i first started to get ill ten years ago, and they understood everything combined affects my weight.
S1226	P_LC, P_LTC	Problem only began post covid but Dr don't really link it to covid
S1281	P_LC, P_LTC	Link the chest pains to long covid
S1100	P_LTC	really understand how past trauma effects current presentation
S1211	P_LC, P_LTC	Awareness of other health problems & how they interact
S1100	P_LTC	past diagnosis has an impact on how much to share in the current moment

S1275	P_LTC	A good flow chart or mind map taking the holistic approach and identifying what is best for each patient. It should never be a one box fits all approach. Ideally there would be adequate funding as well to help support an integrated support service
S159	P_LTC	holistic/multi agency support
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	They existed. That was nice.
S1151	P_LC, P_LTC, HCP_LTC	Gp referred to primary care MH practitioner and from there to CMHT it was well run
S1_5	P_LTC	difficulties in transferring medical records from abroad
S1211	P_LC, P_LTC, HCP_LTC	Rheumatology has very good set up for inflammatory arthritides - phone helpline, specialist nurses etc
S1153	P_LC, P_LTC	Refer me to a specialist
S1241	P_LTC	Neuro offering help
S1259	P_LTC	Mental health support
S1132	P_LC, P_LTC	Support with coming to terms with the condition
S1275	P_LTC	Support for the patient mentally and physically and also some support for family and care givers.
S1285	P_LTC	full mental health service including counsellors
S111	P_LTC	Heavy on the B (biological), s (social) and p (psychological) only if there's a real need. Not as a sop (standard operating procedure).
S121	P_LTC	Social and psychological support should be unequivocally the servants of biological medicine, never a substitute, never a leader, notwithstanding the that those delivering social and psychological care may be dedicated and very able professionals
S122	P_LTC	Proper medical treatment and support for social issues, eg disability benefits. Psychological support should be of the form: take patients seriously, offer pain/sleep meds etc if needed, support to achieve okay living conditions, empathy
S124	P_LTC	It's fine to offer counseling for coping etc at a later stage, but all the medical stuff needs to get done first.
S127	P_LTC	If it is a physical illness put the physical first! Provide clear signposting for social support. Offer mental health support to those who need it but beware misinterpreting mental health questionnaire results of chronically ill patients.
S147	P_LTC	Support offered should primarily involve biomedical investigations and support, with social support looking like help with accessing benefits if unable to work, help with accessible housing issues etc. Psychological support should only

		be from the point of view of how living with these conditions (and often losing everything from your former life and your ability to do the things that bring you purpose and joy) can obviously affect a person's mental health.
S160	P_LTC	Psychology and social input should be secondary and adjunctive only. Some people will require no input from this area
S1113	P_LTC	Psychological support should only be seen as an additional service for someone who needs support adjusting to living with energy limiting conditions. Medical issues should be fully explored rather than defaulting to anti depressants and CBT. Thorough testing for issues like orthostatic intolerance should be carried out. Discussions should include whether aids would help, including support with blue badge, considering whether a wheelchair might help the person do more with limited energy. Support should be patient centered not pushing one size fit all mentality.
S1241	P_LTC	Appealing. It should be outlined as a group of professional individuals all working together on the patient and making sure patient gets the most beneficial help
S197	P_LC, P_LTC	Focus should be on physical care. I want a medical model approach as the priority. Social model second - discussions on mobility aids, referrals to have a safe return to work assessment, guidance on claiming benefits, disability rights etc. Psychological support offered only in the context of this being a debilitating illness with no treatment - I have never been offered anything to help me deal with the burden of society having deemed me unworthy of medical care.
S198	P_LC, P_LTC	Equal importance of physical not just assuming I'm "anxious". Multi-disciplinary doctor led services
S1239	P_LC, P_LTC	Actual pharmacological treatments, as appropriate. Time to discuss symptoms, and difficulties with dealing with the condition. Advice, support including possibility of group support or therapy
S1315	P_LC, P_LTC,	It should be holistic. Patients need a full initial assessment, then immediate provision of information/access to relevant information resources, followed by referral for specifically relevant forms of treatment and to be kept updated on time-scales for that, where not immediately available.
Offer appropriate screening/diagnostic tests and investigations and confirm a diagnosis		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S145	P_LTC, HCP_LTC	I was investigated
S172	P_LC, P_LTC	Sent me for different investigations
S1132	P_LC, P_LTC	Investigated
S1301	P_LC, P_LTC	Extensive tests
S1157	P_LC, P_LTC, HCP_LTC	Problem easily identified on tests and defined treatment
S1300	P_LTC	identified areas of muscle weakness

S159	P_LTC	testing for related conditions (POTS etc)
S1224	P_LC, P_LTC	Skilled interpretation of tests
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Diagnostica
S133	P_LC, P_LTC	Offer exams
S198	P_LC, P_LTC	Appropriate tests
S1158	P_LC, P_LTC	Investigation
S1237	P_LC, P_LTC, HCP_LC, HCP_LTC	Investigation
S1281	P_LC, P_LTC	Diagnostic Tests (instead of “let’s put you on this drug and see what happens)
S172	P_LC, P_LTC	Investigations
S133	P_LC, P_LTC	Neurologist listened to me, offered exam to rule out MS.
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Gave clear diagnosis
S113	P_LC, P_LTC, HCP_LC, HCP_LTC	They were a non-diagnostic service. So whatever questions you had about your symptoms, they were no help.
S1179	P_LC, P_LTC, HCP_LC, HCP_LTC	Early diagnosis
S125	P_LTC	Diagnostic tests are a must to rule out co morbidities. There was out of date and non scientific treatments and advice (evidence-based treatments and advice). The doctors did not know the latest research or basic things about my condition (Clinicians aware of condition and up to date on relevant research).
S1150	P_LC, P_LTC, HCP_LTC	They knew the condition and how to diagnose
Offer ongoing support with reviews of care		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1269	P_LC, P_LTC, HCP_LTC	regular follow up
S1270	P_LC, P_LTC	It’s been managed well.
S1211	P_LC, P_LTC, HCP_LTC	Rapid review - slotted me into clinic as emergency
S133	P_LC, P_LTC	Did check up to see how treatment was going

S1151	P_LC, P_LTC, HCP_LTC	Regular reviews
S1157	P_LC, P_LTC, HCP_LTC	Regular follow up
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Follow up review
S1300	P_LTC	patient initiated follow up
S145	P_LTC, HCP_LTC	I got lost to follow up taking a specialist medication that was not reviewed
S1301	P_LC, P_LTC	No ongoing supervision by NHS specialist
S124	P_LTC	Offer regular follow-ups long term including tests when new symptoms appear
S1255	P_LC, P_LTC	Follow up tests and advice to ensure that condition has not worsened
S1269	P_LC, P_LTC, HCP_LTC	Regular follow up with an appropriate skilled and compassionate clinician
S1281	P_LC, P_LTC	Regular contact
S1241	P_LTC	Give follow up appointment
S1255	P_LC, P_LTC	Review medications annually at least
S1264	P_LTC	Have a clinic to assess that person every six months so they are not left completely alone and left for years without help.
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Regular review to address subtle changes that may have occurred and provide opportunity for discussion of new approaches to treatment and management of applicable
S1317	P_LC, P_LTC, HCP_LTC	Review if interventions are working
S1150	P_LC, P_LTC, HCP_LTC	Follow up
S1300	P_LTC	ensuring long term follow up is planned
S170	P_LC, P_LTC	Continued support, especially when there is new research
S1232	P_LC, P_LTC	Ongoing support
S1158	P_LC, P_LTC	Continued care
S1264	P_LTC	A clinic that you could attend then have follow ups (maybe in the area most needed once assessed) and not just to go once .There maybe better outcomes if there was regular treatment and follow ups. .Not to go once and then be forgotten about ,as if doing a tick box exercise. Also clinics dotted around the country.and not just in one area.

S1149	P_LC, P_LTC	Patients need regular biological/medical testing, Psychological support may be needed to help patients deal with the life changes that long-term illness brings, but not to treat any psychological symptoms as causative.
Provide consistent support which is easy to access and offered by a consistent care provider/care-manager		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S182	P_LC, P_LTC	Designated lead professional
S1264	P_LTC	Not left me with no after care .For me to just accept to get on alone.It is a postcode lottery and I cannot access any care now .Much to my neurologist frustration.He has discharged me now as he cannot offer any more treatment as I don't live near the hospital where he works .But had to see him as he is one of a handful of specialists in the country.
S171	P_LTC	Availability
S172	P_LC, P_LTC	Support
S182	P_LC, P_LTC	Designated lead professional
S1301	P_LC, P_LTC	Ease of contact to get advice/appts when issues arise
S136	P_LC, P_LTC	Dedicated GP at GP practice
S1269	P_LC, P_LTC, HCP_LTC	easy means of contact if problems arise
S1239	P_LC, P_LTC	Acknowledgement of referral
S1239	P_LC, P_LTC	Less wait for Ling Covid clinic would be good. Very relieved to know you are conducting a therapeutic trial. Sorry it will be such a wait
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	I saw a private consultant very quickly so this worked well
S1150	P_LC, P_LTC, HCP_LTC	NHS waiting list. I decided to use private insurance
S1153	P_LC, P_LTC	Speed
S1226	P_LC, P_LTC	Fast access
S1300	P_LTC	Ensuring prompt referral to treatment
S136	P_LC, P_LTC	Speedy referrals, appts and support
S182	P_LC, P_LTC	Quickly referred by GP
S1300	P_LTC	Not being referred at initial point of diagnosis
S1317	P_LC, P_LTC,	Supporting me to see someone about breathlessness earlier

	HCP_LTC	
S1285	P_LTC	ideally be provided from specific building or area not necessarily within the main hospital
S1300	P_LTC	Access to all support in one place to minimise travel. Providing support that reflects everyday scenarios.
S182	P_LC, P_LTC	One setting
S1184	P_LC, P_LTC	1 multidisciplinary clinic
S1187	P_LC, HCP_LC, HCP_LTC	The Nhs needs to change its approach and give timely access to patient, not have patients referred to secondary care to wait to be seen.
S1226	P_LC, P_LTC	Local service
S1232	P_LC, P_LTC	Video/remote
S1257	P_LC, P_LTC	It should contain multidisciplinary teams. There should be continuity of care (patient sees same person for e.g. physio)
S1259	P_LTC	There should be nurses attached to neurology who deal only with FND to help support
S1315	P_LC, P_LTC	Referring to specialist services wherever practicable.
S159	P_LTC	They need to talk to each other and understand the whole - not pull in different directions
S1269	P_LC, P_LTC, HCP_LTC	i want to see a specialist who knows a LOT about my long term condition, not a generalist who knows a LITTLE about lots of them
S1109	P_LC, P_LTC, HCP_LTC	Ait should be like a one stop clinic, with a pre appointment triage /telephone consultation were the main issues can be discussed and appointments can be made so the patient can attend during one day, at the end of day having an appointment with one person who summarises the findings, and comes up with a plan together with the patient. It may be impossible to achieve but may be helping people recover quicker, getting back to work wuicker
S1259	P_LTC	Specialised centres with all the help you need
S142	P_LTC	Specialist nurse like MS or cancer patients have
S1269	P_LC, P_LTC, HCP_LTC	easy to contact if problems
S1224	P_LC, P_LTC	referred me on
S1285	P_LTC	nothing apart from saying i could contact the specialist nurse.
S130	P_LTC	Extended appointments length
S1281	P_LC, P_LTC	Appointment with asthma nurse
S1100	P_LTC	more time maybe
Provide collaborative care linking services between primary care, hospital and mental health settings		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>

S1_5	P_LTC	information transfer between GP and hospital
S1_5	P_LTC	sharing info between specialist hospital team and GP
S1315	P_LC, P_LTC	Newly-involved therapists should review records of previous treatment etc in their own service.
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Collaborative approach facilitating appropriate requests for assistance/medication
S1294	P_LC, P_LTC, HCP_LC, HCP_LTC	Collaborative approach acknowledging patients understanding having checked it is correct and appropriate
S182	P_LC, P_LTC	More integrated ice by Health Care Trust
S1224	P_LC, P_LTC	Joined-up not silo thinking
S1289	P_LC, P_LTC, HCP_LC, HCP_LTC	Coordinated care
S182	P_LC, P_LTC	More of a one stop shop instead of multiple referrals
S1257	P_LC, P_LTC	Treat people wholistically and have specialists come together to discuss a patient not do it all separately
S1325	P_LTC, HCP_LTC	Multidisciplinary care in one place
Provide support with employment, sick notes, access to benefits		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1112	P_LC, P_LTC	support with access to benefits
S1100	P_LTC	the economic status of service user
S1224	P_LC, P_LTC	signposting to other helping organisations
S1224	LC_P, P_LTC	I had to leave my job - I didn't get the support I needed. With no income I could have had my home repossessed, I lost my professional qualification by not being able to revalidate. I was misdiagnosed with a significant illness and had to stop driving. I was treated with drugs which affected me profoundly. I live alone, so had to cope with safety issues. I asked for a second opinion and was taken off all the drugs. I have not yet had confidence to reapply for my license, and in anycase cannot afford to get my car back on the road. I was obliged to apply for Universal Credit and have a fitness for work assessment. I am dependant on friends for lifts and cheap social opportunities to join in when I have paced. I am out of action for 1 - 2 days after any exertion - mental or physical. My life is significantly diminished, but I'm determined to be content and enjoy everything I CAN do. These last few years I've had to adapt (what a difference getting a shower stool made to me - enabling me to wash my hair etc. I have worked out how to do things (cut the grass in short phases, accept sitting for longer than anticipated rests - no self judgement. Give u).
Provide self-management guidance		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1285	P_LTC	helping people to be as self-sufficient as much as possible within the perimeters of their symptoms

The service should be properly funded/have access to resources		
<i>Ps ID</i>	<i>Role</i>	<i>Original survey response</i>
S1301	P_LC, P_LTC	No NHS service so had to pay privately
S1266	P_LTC, HCP_LC, HCP_LTC	More time for GP

Original statements associated with combined LC or LTC statements

List of statements: Integrated care should ...

Original grouping	Original Statement (reviewed by small groups)	Contributes to combined LC statement
LC_HCP	Take a collaborative approach including a range of specialist support (MDT) and agreed criteria for support	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC_HCP	Provide consistent, comprehensive care which is easy to access and minimises the burden for patients	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC_HCP	Ensure patients and clinicians have/share knowledge and understanding of symptoms, self-management and services available	Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients
LC_HCP	Provide opportunities for community support	Provide opportunities for patient-led support
LC_HCP	Offer support relating to employment and sick notes	Provide vocational rehabilitation with employment and welfare support
LC_HCP	Offer relevant screening and diagnostic tests and investigations, rule out other problems	Provide appropriate diagnostic assessment which is person centred to rule out other conditions
LC_HCP	Ensure team skills and resources are appropriate to provide a multi-service approach	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC_HCP	Offer patient-centred care	Validating the patients experience and knowledge to provide a person-centred care plan
LC_HCP	Include long-term care with reviews of health, care provision and personalised care plans	Include long-term care with reviews of health, care provision and personalised care plans
LC_HCP	Provide evidence-based care	Provide evidence-based treatment and recommendations Provide easy access to research studies where possible
LC_HCP	Share information between services	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC_HCP	Provide care manager	Provide a care coordinator
LC_HCP	Provide self-management advice	Provide self-management advice and support in line with individual needs and abilities
LC_HCP	Offer supervision/managerial support/sufficient resources/funding	Ensure services have sufficient and appropriate resources, including funding

LC-P	Provide diagnostic assessment	Provide appropriate diagnostic assessment which is person centred to rule out other conditions
LC-P	Offer easy access to specialist support for multi-system LC problems with collaborative approach	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC-P	Provide patient centred approach	Ensure the person is listened to, acknowledged, supported and believed
LC-P	Offer reviews of care and provide ongoing support	Offer personalised continuity of care
LC-P	Provide evidence-based treatment and recommendations	Provide evidence-based treatment and recommendations
LC-P	Provide employment support and sick note	Provide vocational rehabilitation with employment and welfare support
LC-P	Provide access to research	Provide easy access to research studies where possible
LC-P	Encourage early intervention	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC-P	Ensure services have appropriate resources	Ensure services have sufficient and appropriate resources, including funding
LC-P	Provide no psychological treatment	Ensure all services offer a full biopsychosocial model of care
LC-P	Avoid (graded) exercise as a treatment in case of PEM	Provide evidence-based fatigue management which should not include graded exercise regimes as defined by the NICE guidance
LC-P	Offer advice on pacing	Provide evidence-based fatigue management which should not include graded exercise regimes as defined by the NICE guidance
LC-P	Provide fatigue management	Provide evidence-based fatigue management which should not include graded exercise regimes as defined by the NICE guidance
LC-P	Provide breathing exercise	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LC-P	Provide a care manager	Provide a care coordinator
LC-P	Provide psychological support	Ensure all services offer a full biopsychosocial model of care
LC-P	Provide biopsychosocial model of care	Ensure all services offer a full biopsychosocial model of care
LC-P	Provide self-management advice	Provide self-management advice and support in line with individual needs and abilities
LC-P	Provide no lifestyle interventions	Provide evidence-based fatigue management which should not include graded exercise regimes as defined by the NICE guidance

Original grouping	Original Statement (reviewed by small groups)	Contributes to combined LTC statement
LTC_HCP	Take a Biopsychosocial approach to care	Ensure all services offer a comprehensive biopsychosocial model of care
LTC_HCP	Ensure good communication between healthcare providers	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LTC_HCP	Provide consistency in care provision (care-manager), ongoing support and monitoring	Include long-term care with reviews of health, care provision and personalised care plans
LTC_HCP	Offer easy access to specialist support for multi-system problems with collaborative care approach	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LTC_HCP	Provide evidence-based treatment and recommendations	Provide evidence-based treatment and recommendations
LTC_HCP	Take a patient-centred approach	Listen and validate patients experience and provide patient centred care
LTC_HCP	Ensure services have appropriate resources	Ensure services have sufficient and appropriate resources, including funding
LTC_HCP	Support self-management	Provide self-management advice and support in line with individual needs and abilities
LTC_HCP	Offer social and community support	Provide opportunities for patient-led support and social prescribing
LTC_HCP	Use unified electronic healthcare records	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LTC_HCP	Offer relevant screening and diagnostic tests and investigations, rule out other problems	Provide appropriate diagnostic assessment which is person centred to rule out other conditions
LTC_P	Provide patient centred care	Ensure the person is listened to, acknowledged, supported and believed
LTC_P	Provide evidence-based treatment	Provide evidence-based treatment and recommendations
LTC_P	Take a Biopsychosocial approach to care	Ensure all services offer a comprehensive biopsychosocial model of care
LTC_P	Offer appropriate screening/diagnostic tests and investigations and confirm a diagnosis	Provide appropriate diagnostic assessment which is person centred to rule out other conditions
LTC_P	Offer ongoing support with reviews of care	Include long-term care with reviews of health, care provision and personalised care plans
LTC_P	Provide consistent support which is easy to access and offered by a consistent care provider/care-manager	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services

LTC_P	Provide collaborative care linking services between primary care, hospital and mental health settings	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
LTC_P	Provide support with employment, sick notes, access to benefits	Provide vocational rehabilitation with employment and welfare support
LTC_P	Provide self-management guidance	Provide self-management advice and support in line with individual needs and abilities
LTC_P	The service should be properly funded/have access to resources	Ensure services have sufficient and appropriate resources, including funding

LC or LTC statements associated with combined statements used in Survey 2

LC Statement (incorporating Patient and healthcare professional views)	LTC Statement (incorporating Patient and healthcare professional views)	Combined Statement (Included in Survey 2)
Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services	Offer timely, consistent and easy access to patient centred multi-system support using a multi-disciplinary and integrated approach with shared information between services
Ensure the person is listened to, acknowledged, supported and believed		Ensure the person is listened to, acknowledged, supported and believed
Provide appropriate diagnostic assessment which is person centred to rule out other conditions	Provide appropriate diagnostic assessment which is person centred to rule out other conditions	Provide appropriate diagnostic assessment which is person centred to rule out other conditions
Offer personalised continuity of care		Offer personalised continuity of care
Provide evidence-based fatigue management which should not include graded exercise regimes as defined by the NICE guidance		Provide evidence-based fatigue management which should not include graded exercise regimes as defined by the NICE guidance
Provide evidence-based treatment and recommendations	Provide evidence-based treatment and recommendations	Provide evidence-based treatment and recommendations
Ensure all services offer a comprehensive biopsychosocial model of care	Ensure all services offer a comprehensive biopsychosocial model of care	Ensure all services offer a comprehensive biopsychosocial model of care
Provide a care coordinator		Provide a care coordinator
Provide vocational rehabilitation with employment and welfare support	Provide vocational rehabilitation with employment and welfare support	Provide vocational rehabilitation with employment and welfare support
Ensure services have sufficient and appropriate resources, including funding	Ensure services have sufficient and appropriate resources, including funding	Ensure services have sufficient and appropriate resources, including funding

Provide self-management advice and support in line with individual needs and abilities	Provide self-management advice and support in line with individual needs and abilities	Provide self-management advice and support in line with individual needs and abilities
Include long-term care with reviews of health, care provision and personalised care plans	Include long-term care with reviews of health, care provision and personalised care plans	Include long-term care with reviews of health, care provision and personalised care plans
Validating the patients experience and knowledge to provide a person-centred care plan	Listen and validate patients experience and provide patient centred care	Validating the patients experience and knowledge to provide a person-centred care plan
Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients		Ensure clinicians and services provide knowledge and understanding of symptoms and services available to patients
Provide opportunities for patient-led support	Provide opportunities for patient-led support and social prescribing	Provide opportunities for patient-led support and social prescribing
Provide easy access to research studies where possible		Provide easy access to research studies where possible