# RightCare cystic fibrosis toolkit: Self-assessment questionnaire

The aim of the questions below is to assist your service or team to reflect on their current service provision and to identify where there are opportunities to improve across the pathway.

Completing this questionnaire will identify which priority areas within the [main cystic fibrosis toolkit](https://www.england.nhs.uk/publication/rightcare-cystic-fibrosis-toolkit) you should focus on.

These questions should be used alongside other resources to facilitate discussion and identify improvement opportunities or exemplars of good practice. The self-assessment questions have been developed in partnership with our stakeholders.

Specifically these questions are designed to:

* assess the existing system provision of services and quality care for people along the pathway
* identify any current gaps in service provision and/or current opportunities to enhance or develop services/systems at a local level
* consider future demand, using local intelligence alongside projected data to ensure accuracy and consistency
* assess the progress of any system improvements over time

For each question, please select the response which best describes your current cystic fibrosis service provision.

Response options are: Yes = Met, Partly = Partly met, No = Not met, N/A = Not applicable. A page for notes and comments is included at the end.

This Word version includes checkboxes to mark the answers if completing digitally. An interactive version of the self-assessment can also be found on the [RightCare FutureNHS site](https://future.nhs.uk/NationalRightCare/browseFolder?fid=53959536&sort=name&dir=asc&viewMode=S&done=CONDeleted). Please note that you will need to be a member of FutureNHS to access this site.

1. Optimal management and personalised care
   1. Supporting self-management (risk management)
2. Is your risk management and identification approach well-embedded within all aspects of cystic fibrosis services that consider a person's specific needs and circumstances?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Outpatient care

1. Is outpatient care accessible for people with cystic fibrosis when needed, without delay and are they seen by healthcare staff with experience in cystic fibrosis?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do commissioners and adult centres plan for growth in-line with increased numbers of people with cystic fibrosis, with regards to both capacity and resources?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Enhanced treatment at home

1. Do you have the infrastructure and resources to provide virtual consultations as appropriate, including IT tools and virtual monitoring capability?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Screening

1. Do your services provide screening for conditions associated with increased risk for people with cystic fibrosis, dependent on age and cystic fibrosis-specific risk factors, and adapt accordingly?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is genetic carrier testing for partners provided as part of the fertility/pregnancy support for people with cystic fibrosis?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are people with cystic fibrosis encouraged and informed to engage with other relevant healthcare providers and sectors to attend routine health checks which are not available in cystic fibrosis centres?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services have a robust process in place for annual screening of all patients for mental health, emotional wellbeing and social factors?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Cystic fibrosis transmembrane conductance regulator (CFTR) modulators

1. Have your cystic fibrosis services adapted to the evolving challenges for those patients on CFTR modulators, including excess weight gain and the need for body composition measurements?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Have your cystic fibrosis services adapted to the evolving challenges for those patients on CFTR modulators, including the increased challenges for obtaining lower respiratory tract samples from patients with reduced sputum load, such as use of induced sputum?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services assess patients who are not responding to CFTR modulators to understand the cause?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is a person's eligibility for CFTR modulators regularly assessed, including their willingness or decision on whether to take CFTR modulators (or their ability to adhere to treatment) at least annually?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Does your cystic fibrosis services monitor for the potential for psychological/ psychiatric/cognitive impacts of CFTR modulators?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are your cystic fibrosis services aware that if an expectant mother is taking Kaftrio during pregnancy and/or during lactation, the newborn screening may deliver false/negative result?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Inpatient care

1. Do people with cystic fibrosis have access to inpatient care when needed and without delay?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are people with cystic fibrosis looked after on a ward by doctors and multidisciplinary team (MDT) staff with experience in cystic fibrosis?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Treating emergencies and exacerbations

1. Are your cystic fibrosis services able to provide for urgent and specialist care needs and advice 24 hours a day, seven days a week?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are beds on a ward suitable for cystic fibrosis care available within 24 hours for an emergency admission, as well as capacity to ensure elective and non-urgent admissions can be managed appropriately?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Where intravenous antibiotic therapy is administered at home, is the quality and standard of care equal to that of inpatient services with support from the cystic fibrosis MDT as appropriate?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. End of life care

1. Is a standard model of end of life care followed such as the [Gold Standard Framework for End of Life Care](https://www.goldstandardsframework.org.uk/)?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is specific guidance on the management of advanced disease and palliative care – complexity of care and co-morbidities – followed, and do your cystic fibrosis teams work with other involved specialties, as required?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Supporting specific patient groups
   1. Late diagnosis in adults
2. Is a sweat test and genotyping arranged for everyone with clinical features suggestive of cystic fibrosis (irrespective of newborn screening test result), and results interpreted in line with the latest diagnostic guidelines for cystic fibrosis and CFTR-related disorder?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. If indicated, is psychosocial support offered for the individual throughout the diagnostic process and following confirmation of the diagnosis?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Ageing population and retirement planning

1. Have the members of your cystic fibrosis MDT extended their scope to manage the evolving needs of the population (for example, non-medical prescribing) and additional clinical input by other non-cystic fibrosis specialist clinical teams that may be required to care for a more complex ageing population?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are good, clear processes of communication embedded between the cystic fibrosis MDT and other teams involved in the care of people with cystic fibrosis to provide joined up, holistic care for the ageing population?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do you plan for increased demand on social work and psychology support to help patients through the emotional burden of changing health status, increased life expectancy and associated impacts on their life plans – such as education, employment, family planning, menopause, pension, retirement and benefits, including at diagnosis and transition?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Adolescents

1. Do your cystic fibrosis services forward plan for young people and families who need additional support at the stage of adolescence?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services have early and ongoing conversations with young people and their families, which are tailored to the young person's developmental age and stage, to help them understand the changes and potential challenges that come with growing up having cystic fibrosis, and the importance of maintaining treatment and avoiding risk-taking behaviours?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is education and skills in working with young people during adolescence provided for cystic fibrosis paediatric and adult services so that the needs of this age group are met?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services have robust, multidisciplinary processes in place locally to support adolescents specifically (and their caregivers) with adherence to treatment issues, in both paediatric and adult services and throughout the potentially difficult time of transition between services?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do services create and use their own screening tools locally to identify adolescent health-compromising behaviours and provide appropriate interventions, such as referral to educational resources or local substance misuse, weight management or physical activity services?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Fertility, pregnancy and parenting

1. Is education on male and female sexual and reproductive health started by the age of 10-12 years and continued through transition to adult services and beyond?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is family planning counselling provided for patients and their families so they are fully informed about how health and parenting can intersect? And does adequate screening take place to address any psychosocial concerns such as discussing cystic fibrosis care with their child and/or the need for increased support during periods of acute illness and/or as a parent's health declines?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is genetic screening for partners provided as part of the fertility and pregnancy support for people with cystic fibrosis, with a referral to genetic counsellors if required?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are medication reviews carried out when women with cystic fibrosis are planning to conceive and during pregnancy, with adjustments being made as appropriate?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Lung transplantation and post-transplant care

1. Do you ensure equity of access to specialist cystic fibrosis care for management of cystic fibrosis-related complications for those in receipt of a solid organ transplant?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Neurodiversity

1. Are your cystic fibrosis teams alert to the possibility of undiagnosed neurodivergence and do they implement screening and referral for specialist assessment as appropriate?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do you have clear pathways and processes in place to support people with cystic fibrosis who receive a diagnosis of neurodivergence?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Learning disability

1. Are reasonable adjustments made according to individual patient need, and is information provided in an accessible and easy read format?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are your cystic fibrosis services provided with education and training to ensure medications are taken appropriately and avoid the over-medication of autistic people, people with a learning disability, or both (STOMP), if appropriate?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Diversity and inclusion

1. Do your cystic fibrosis services have an appointed equality, diversity and inclusion lead to drive work forward in this area and identify solutions?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services proactively understand the diversity within their population and the barriers which prevent people accessing care?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Future demand considerations
   1. Cystic fibrosis adults living longer
2. Do you plan for growth in line with increased numbers of people with cystic fibrosis, with regards to capacity and resources; taking into account the likely increased prevalence of age dependent cystic fibrosis and non-cystic fibrosis complications within the population?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your paediatric and adult centres continue to adapt the education and psychosocial support provided to people with cystic fibrosis and their families, to reflect the change in expectations of both life expectancy and future complications associated with living longer?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Future models of care

1. Do your cystic fibrosis centres and services provide virtual consultations and remote monitoring technology as part of a personalised care approach?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Feeback on quality of service

1. Do your cystic fibrosis services actively seek feedback on quality of service and use this to inform and implement improvements?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Research and clinical trials

1. Are your cystic fibrosis services and teams supported to work with local research and development departments and research networks to facilitate and engage with research and registry-based trials?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Psychosocial wellbeing and mental health
   1. Emotional wellbeing and mental health
2. Do your services plan for increased access to consultation with cystic fibrosis psychosocial professionals so they can provide psychologically and socially informed care to increasing numbers of people in adult care?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Is access to liaison psychiatry services available to people with cystic fibrosis as needed; preferably on both an inpatient and outpatient basis?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Psychosocial impacts of modulators

1. Are your cystic fibrosis services aware of the psychological impacts of modulators and do they provide monitoring, support and interventions, as appropriate?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Equity of access to cystic fibrosis psychology and social work

1. Is access to cystic fibrosis psychosocial support equitable and offered to all patients, as appropriate?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. NHS staff wellbeing

1. Is the wellbeing of the cystic fibrosis MDT considered by the service and actions put into place to support this?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Medicines optimisation
   1. Medicine routine
2. Do your cystic fibrosis services work in partnership with people with cystic fibrosis and their families to ensure that the medicines routine is suitable and appropriate for individual's needs?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do you ensure that care is taken to avoid drug interactions from prescribed medicines?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are the regular medication reviews standardised to ensure they are normalised, accepted and expected?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Does a specialist cystic fibrosis pharmacist undertake a comprehensive medicines review at least annually in all patients?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do you ensure inhaled medication technique is reviewed regularly, including equipment cleaning/sterilisation routines?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Treatment burden

1. Are the regular medication reviews collaborative and do they incorporate shared decision making where patients are supported to understand the medication and treatment options?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Where needed, do you implement regular standardised home visits by members of the cystic fibrosis MDT, to allow a holistic review of patients in their living environment (looking at medications usage, equipment, techniques and sterilisation routine)?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Medicine taking behaviour

1. Have you adopted a shared decision making approach to support and encourage correct medicine taking behaviour? Is appropriate NICE guideline ([NG197](https://www.nice.org.uk/guidance/ng197)) followed?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Supply of medicines

1. Do you have clearly defined medicines supply routes with communicated escalation processes for when there are issues, and emergency contact details to access support in a timely manner?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Health inequalities
   1. Social determinates of health
2. In the absence of a national consensus social risk screening tool, have your cystic fibrosis services developed and implemented their own social screening tools?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are specialist cystic fibrosis social workers included as essential members of the cystic fibrosis MDT across your service?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis teams consider indoor and outdoor environmental risks and triggers, and consider how to support the patient (such as signposting to council and housing services)?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Ethnicity

1. Do your cystic fibrosis services collect and monitor data about ethnicity in addition to social risk to help identify areas of inequality and improvement within the cystic fibrosis pathway?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services ensure that there is representation of patients from ethnic minority backgrounds in the development of cystic fibrosis pathways and services to ensure the requirements of patients are fully understood and met?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Poverty

1. Do you ensure that cystic fibrosis services implement social risk screening to identify any issues that patients and their families have relating to food, fuel, digital and appliance insecurity, and access to transport?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Digital poverty and exclusion

1. Are your cystic fibrosis services aware of digital exclusion and do they implement actions to mitigate against this?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Equity of access

1. Do your cystic fibrosis services ensure aspects of identity – such as race, language spoken, gender, or sexual orientation – are not overlooked, to ensure health care services are provided in line with cultural, social, communication and personal needs?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services identify individual's barriers that may impact on access to services, such as transport, digital poverty, or lack of childcare, and refer to the specialist social worker for support?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Are interventions and support targeted to address and overcome barriers to care implemented to mitigate and reduce risks?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

* 1. Health behaviours

1. Do you refer patients and their families (people they live with) to local stop smoking services if commissioned and available in your local area, for help to stop smoking or provide alternative methods of stop smoking support if no local services are available?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services consider creating and using their own screening tools locally to identify areas of concern and provide appropriate interventions?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Do your cystic fibrosis services ensure they are aware of any environmental risks that could impact on health or wellbeing and are they able to advise patients on strategies to minimise these?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |

1. Where environmental risks relate to poor living conditions, does the specialist cystic fibrosis social worker liaise with the patients’ local community services such as housing, environment health, social care and local child care support services where appropriate to resolve issues?

|  |  |  |  |
| --- | --- | --- | --- |
| Yes | Partly | No | not applicable |