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**Indicator Supporting Documentation**

**IAP00610 Adherence to nebulised therapy in Cystic Fibrosis**

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| FIELD | CONTENTS |
| IAP Code | IAP00610 |
| Title | Adherence to nebulised therapy in Cystic Fibrosis |
| Published by | CFHealthHub |
| Reporting period | Annually, real time |
| Geographical Coverage | Currently all UK adult CF centres have been invited to take part; 19 out of 26 (73%) have indicated participation by the end of 2020. Currently, 3 centres have been collecting data. |
| Reporting level(s) | Clinician, CF Centre |
| Based on data from | CFHealthHub (CFHH) |
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| Rating | Assured |
| Assurance date | 7/11/19 |
| Review date | 7/11/22 |
| Indicator set | N/A |
| Brief Description [This appears as a blurb in search results] | Cystic Fibrosis is an inherited life-limiting illness in which the commonest reason for premature death is respiratory failure due to uncontrolled lung infections. People with Cystic Fibrosis (PWCF) find it difficult to establish sustained habits of self-care and median adherence to inhaled therapy in adults is less than 40%. Correspondingly, it can be difficult for clinicians to determine in an appointment whether worsening clinical symptoms are due to low adherence, or another medical reason such as an infection. Lung health of people with Cystic Fibrosis (CF) can be preserved and life expectancy extended by the daily use of inhaled therapy in the form of antibiotics and mucolytics. Adherence to inhaled therapy is therefore an important process measure to enable People with Cystic Fibrosis (PWCF) and their clinical teams to understand the success of care.  |
| Purpose | CFHealthHub (CFHH) is a digital information technology platform that automatically collects adherence data, and makes time and date stamped data describing daily and weekly adherence to inhaled therapy (mucolytics and antibiotics) data available to PWCF and their clinical teams. This creates a learning health system that transforms CF care through behaviour change interventions that create clinician and patient activation. The data in CFHH has 3 purposes/audiences (hereafter referred to as ‘levels’);1. **PWCF:** There is considerable evidence (reviewed below) that making feedback of time and date stamped data about a desirable behaviour (taking medication) supports behaviour change (increased adherence). The CFHH enables ‘patient activation’ whereby patients have the knowledge, skills and motivation to contribute to the management of their own care.
2. **Clinician:** Providing clinicians with accurate data on a PWCF’s adherence to their prescribed medication provides more complete information, which helps them interpret the clinical picture when a PWCF attends clinic. CFHH removes the invisibility of patient’s self-care behaviours and facilitates ‘clinician activation’ whereby clinicians are equipped with the knowledge, skills and motivation to support patients in building habits of self-care
3. **Centre:** Making the aggregate of this data available at a centre level will allow centre to track their performance over time, as well as centres with lower performance to seek support to improve adherence rates.

This indicator is at the centre level as it is this data which is made available beyond the PWCF and immediate clinical team as well as used to compare the performance of CF centres. |
| Definition | Adherence to inhaled therapy for people with Cystic Fibrosis as a percentage of daily inhalations /daily prescriptions at patient & client level, and the median average of the same at centre level |
| Data Source | **Data Source 1: Cystic Fibrosis Registry**<https://www.cysticfibrosis.org.uk/the-work-we-do/uk-cf-registry>**Data source 2: Nebuliser devices uploading data to CFHealthHub**CFHealthHub receives date and time stamped data on the use of preventative inhaled therapies delivered via the chipped E-track.CFHealthHub is developed and maintained by the School of Health Sciences | Division of Informatics, Imaging & Data Science | Faculty of Biology, Medicine and Health | The University of Manchester which has extensive expertise in maintaining data observatories |
| Numerator | **PWCF level**: Number of doses taken in a day is found from CFHealthHub inhalation data. This is capped at 100% based on the PWCF prescription. Adjusted for nebulised antibiotics require multiple accentuations for a complete dose (this is relevant for data from the Ineb) . **Centre level:** Mean adherence of each PWCF at each CF centre over a time period identified |
| Denominator | **PWCF level**: Prescription (number of doses) per day as defined within CFHealthHub. **Centre level:** Number of PWCF using CFHH at each CF centre over a time period identified |
| Calculation | **The time period over which the indicator can be calculated is flexible.** **Patient/Clinician level**1. Daily prescriptions (due to prescription dates) for a PWCF are entered into CFHH by clinical team. For example, PWCF should take 4 medication doses per day
2. Daily inhalations (due to time stamp) identified for PWCF. For example, PWCF takes 3 doses of medication on a day (this figure is capped at 100% of daily prescription)
3. Daily adherence per PWCF is calculated.

For the above example, the patient would achieve 75% adherence (3/4=0.75\*100)**Centre level**1. For each time period identified, each PWCF at a centre has the mean adherence calculated. This is the mean of their daily adherence over this period.
2. The median of the mean adherences of each PWCF is calculated at each centre.

For example, at a centre with 5 patients using CFHH with mean adherences over a time period identified of 30%, 90%, 75%, 20% and 60%, the median adherence at the centre would be 60%. |
| Interpretation Guidelines | **Patient level** * PWCF prescription (denominator number) based on agreed target between PWCF and clinician
* Patients are empowered to look at their own data over time to see how their adherence has changed. These plots also can be used alongside hospital admissions, lung function and weight to allow patients to develop insights into possible relationships between patterns of self-care around lung health and the need for rescue therapy.

**Clinician level*** PWCF prescription (denominator number) based on agreed target between PWCF and clinician
* Clinicians can use patient level data in consultations to optimise the diagnostic process i.e., unstable clinical status and zero adherence support adherence, unstable clinical status and 100% adherence review medication regimen, revise diagnosis and look for new problems e.g. acquisition of resistant pathogens, new diabetes etc.

**Centre level*** Figure 1 provides information regarding how many patients in each CF centre are using CFHH, which provides important contextual information regarding the % of patients reached. Centres with only a small proportion of patients providing data are likely to “over-estimate” adherence by only including the best adherers. Centres with the higher coverage of people on nebulised treatment is also more likely to be providing better quality care, given that almost everyone with CF will benefit from nebulised DNase.
* The number of patients at each centre is provided by the CF registry, which operates at an 8 month time lag in comparison to the real time data presented on CFHH. Therefore, it is possible there may be some inaccuracies in this data, as PWCF may have joined or left each centre. This affects only the contextual information provided with the indicator regarding the number of patients at each CF centre using CFHH, rather than the patient adherence indicator itself.

It will be clarified that the denominator reflects agreed target between the PWCF and their clinician, rather than a normative prescription based on the PWCF’s characteristics. |
| Caveats | * 19 out of 26 CF Centres (73%) have been recruited to take part by the end of 2020. However at present only 3 centres have been collecting data.

Public access to the data is currently unavailable, and is being investigated for future iterations |

**Application Form**

**Section 1: Introduction and Overview**

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| **1.1 Indicator title** | Adherence to nebulised therapy in CysticFibrosis  | **1.8 Application type** | New indicator |
| **1.2 Reference number***(if unsure, please leave for IMAS team)* | IAP00610 | **1.9 Requestingorganisation** | University of Sheffield School of Health andRelated Research (ScHARR)  |
| **1.3 Topic area** | Cystic Fibrosis within specialised commissioning | **1.10 Applicant details** | Name: Dr Martin WildmanTitle: Consultant in Adult Cystic Fibrosis / Reader in Health Services Research Email: Martin.Wildman@sth.nhs.uk / Martin.Wildman3@nhs.net |
| **1.4 Domain (if applicable)** | N/A |  |  |
| **1.5 Set** | Cystic fibrosis adherence | **1.11 Alternate contact details**  | Name: N/AEmail: N/A |
| **1.6 Please explain if ‘Set’ is ‘Other’ or ‘N/A’** | N/A | **1.12 SRO/ sponsor / policy owner details** | Name: NHS England specialised commissioningTitle: Reader In Health Services Research School Health & Related Research University of SheffieldEmail: martin.wildman3@nhs.net |

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| **1.7 Brief Summary of indicator (max 100 words)** | Lung health of people with Cystic Fibrosis (CF) can be preserved and life expectancy extended by the daily use of inhaled therapy in the form of antibiotics and mucolytics. Adherence to inhaled therapy is therefore an important process measure to enable People with Cystic Fibrosis (PWCF) and their clinical teams to understand the success of care. The CFHealthHub platform makes data available to patients and clinicians for use in care at a centre level. This patient adherence indicator at CF centre level is used to promote a learning culture. |

This application form should cover one indicator. Each indicator in a set will require its own application. Wherever you’re unsure about answering any section please contact indicator.assurance@nhs.net

Sections 2 and 3 cover policy and presentation which will be reviewed and approved by the Indicator Governance Board (IGB).

Sections 4 and 5 cover the data, construction and testing of the indicator and will be reviewed and approved by the Methodology Review Group (MRG). MRG will also advise IGB of their thoughts on policy and presentation as appropriate.

The final section is an overall view of the application by the Indicator and Methodology Assurance Service (IMAS) and will be completed by IMAS in conjunction with the applicant to advise both MRG and IGB.

Applications should be updated to take on board comments from IGB and MRG'; once approved, the finalised application and the Appraisal Log will form the basis of for its entry into the National Library of Quality Assured Indicators

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| **Section 2: Rationale and Policy Basis (IGB to assess, MRG to advise)** |  |
| **2.1 Why is this indicator needed and why is it important that it be measured?** | Cystic Fibrosis is an inherited life-limiting illness in which the commonest reason for premature death is respiratory failure due to uncontrolled lung infections. Cochrane systematic reviews, which summarise randomised controlled trial evidence, demonstrate the relationship between the process measure of daily treatment with inhaled mucolytics and antibiotics and the outcome of preserved lung health in terms of lung function improvement (FEV1) and reduced respiratory exacerbations (associated with decreased quality of life and loss of lung function which in turn is associated with reduced life expectancy[[1]](#footnote-2) (Cystic fibrosis: diagnosis and management NICE guideline [NG78]Published date: October 2017 (https://www.nice.org.uk/guidance/ng78).). People with Cystic Fibrosis (PWCF) find it difficult to establish sustained habits of self-care and median adherence to inhaled therapy in adults is less than 40% (Daniels et al Chest 2011; 140:425–432). Correspondingly, it can be difficult for clinicians to determine in an appointment whether worsening clinical symptoms are due to low adherence, or another medical reason such as an infection. CFHealthHub (CFHH) is a digital information technology platform that automatically collects adherence data, and makes time and date stamped data describing daily and weekly adherence to inhaled therapy (mucolytics and antibiotics) data available to PWCF and their clinical teams. This creates a learning health system that transforms CF care through behaviour change interventions that create clinician and patient activation. The data in CFHH has 3 purposes/audiences (hereafter referred to as ‘levels’);1)**PWCF:** There is considerable evidence (reviewed below) that making feedback of time and date stamped data about a desirable behaviour (taking medication) supports behaviour change (increased adherence). The CFHH enables ‘patient activation’ whereby patients have the knowledge, skills and motivation to contribute to the management of their own care.2)**Clinician:** Providing clinicians with accurate data on a PWCF’s adherence to their prescribed medication provides more complete information, which helps them interpret the clinical picture when a PWCF attends clinic. CFHH removes the invisibility of patient’s self-care behaviours and facilitates ‘clinician activation’ whereby clinicians are equipped with the knowledge, skills and motivation to support patients in building habits of self-care 3)**Centre:** Making the aggregate of this data available at a centre level will allow centre to track their performance over time, as well as centres with lower performance to seek support to improve adherence rates. This indicator is at the centre level, as it is this data which is made available beyond the PWCF and immediate clinical team, as well as used to compare the performance of CF centres. However, the PWCF and clinician level data sharing are the mechanism through which adherence improves, and therefore the rationale behind these will be provided throughout the form. It should be noted that the data being shared at the PWCF and clinician level is the same, though the purpose differs with the audience. Throughout the application form, it will be signposted when ambiguous which data level is being discussed. **PWCF level**The median adherence to preventative inhaled therapies in people with CF (PWCF) is less than 40% (Daniels et al Chest 2011; 140:425–432). Low adherence is associated with increased exacerbations which leads to a fall in patients’ quality of life and lung function and low lung function is associated with increased mortality. Poor adherence leads to lives that are disrupted and shortened by avoidable hospital admissions for rescue therapy that can be associated with allergic reactions and gradually diminishing renal function. Often patients are poor at self-reporting their adherence (adherence is said to be ‘invisible’), and patients with the poorest adherence are most likely to overestimate adherence. Meta-analysis level data highlights that the feedback of time and date stamped adherence data can support improvement in adherence rates (Demonceau et al Drugs 2013; 73:545–562)[[2]](#footnote-3). Providing data on adherence (making adherence ‘visible’) via CFHealthHub will help PWCF secure outcomes that are important to them. **Clinician level**The availability of adherence data at the point of consultation enables accurate diagnosis and optimises clinical management.Real time data is important in supporting communities of practice to improve care since quality improvement cycles that can engage clinical teams are most effective if results can be easily measured (ie the “metrics that matter” can be measured easily and without the requirement for significant additional resources) and fed back to clinical teams in real time.**Centre level**The CFHealthHub presents median adherence for patients at CF centres using the CFHH system. It is designed to create a data-rich digital environment in which clinicians from participating centres can create a community of practice, and share approaches to adherence support and benchmark against each other. This is able to support system wide improvements in adherence via shared learning and community based improvement.Implementing this indicator will realise benefits to the wider NHS. CF numbers are increasing by around 200 adults per year (equivalent to a new adult unit annually) with rapid cost increases for providers inevitable unless practice changes. A major driver of CF costs is hospital admissions for rescue therapy. Median adherence to the medicines that prevent exacerbations leading to hospital admission is 36% (Daniels et al Chest 2011; 140:425–432). This indicator aims to support changes in clinician and patient behaviour that will transform CF care from an emphasis on clinician led reactive hospital-based rescue to patient led community-based prevention. Health economic modelling suggests that implementing a learning health system supporting an improvement collaborative that moves the system from rescue to prevention could potentially save around £100 million over 5 years across all adults with CF[[3]](#footnote-4).**Justification of adherence as a useful quality indicator in CF**The process measure of medication adherence has been favoured over an outcome measure of lung function, as there are insufficient numbers of patients at UK CF centres to detect a statistically significant change of 5% difference in lung function between centres (Nightingale & Osmond JCF 2017). There is strong randomised controlled trials (RCT) evidence for the relationship between the process measure of adherence to inhaled therapies[[4]](#footnote-5) and outcomes such as lung function and exacerbations. As such, this indicator is well placed to support quality measurement in CF.  |
| **2.2 Is there any clinical evidence or professional opinion that can be cited in the development of this indicator?***.* | Randomised controlled trials (RCTs) of inhaled mucolytics and inhaled antibiotics demonstrate that these treatments can reduce infections and improve lung function. However, though adherence in RCTs is typically around 80%, adherence to inhaled therapies in adults with CF in routine clinical practice is typically around 36% (Daniels et al Chest 2011; 140:425–432). Therefore, the management of PWCF could be greatly improved by increasing adherence to inhaled therapies. Given the central importance of adherence in determining outcomes in CF, adherence has the potential to be an important quality indicator.NICE guidance (NG78) promotes the use of mucolytics and inhaled antibiotics for the treatment of CF, as well as monitoring adherence for these drugs (https://www.nice.org.uk/guidance/ng78).Below we summarise the evidence that suggests providing adherence data through the CFHH could be used to improve adherence.**PWCF level*** Patients who have the knowledge, skills and self-efficacy to self-manage and maintain self-management over time despite the challenge of changing circumstances have been shown to have better outcomes including a reduced need for unscheduled care (Kinney et al Patient Educ Couns 2015; 98:545-552.)
* Meta-analysis has demonstrated that feedback of adherence data alongside cognitive-educational components can increase adherence by around 20% (Demonceau et al Drugs 2013; 73:545–562).
* Habit is important to sustain self-care, with studies suggesting that habit may be a better predictor of long-term medication adherence than conscious motivational factors (Phillips et al J Behav Med 2016; 39:1076–1091).
* Studies among PWCF have shown that high adherers have higher habit scores than low adherers (Hoo et al Thorax 2018;[Epub ahead of print], Hoo et al Health Psychol Behav Med 2017;5:299–316)
* Meta-analysis level data shows implementation plans to be effective in supporting behavioural enactment which is a building block of habit formation. (Gollwitzer, P. M., & Sheeran, P. (2006). Advances in Experimental Social Psychology, 38, 69)
* The Lind alliance identified that simplifying the burden of care was the first priority for people with CF. Since habits are automatic behaviours, this has the consequence that sustained behaviours driven by habit are associated with much less burden than behaviours driven by will power and attention (Lind Alliance Thorax 2017;0:1–3.doi:10.1136/thoraxjnl-2017-210473)
 |
| **2.3 Is there any clinical evidence or professional opinion to support the ongoing need for this indicator?** | **Clinical evidence*** The evidence outlined above such as the Cochrane systematic reviews of randomised controlled trials demonstrate the relationship between the use of inhaled therapies and the outcomes of lung function, exacerbations and quality of life.

**Professional opinion*** A survey of centre directors within the UK demonstrated a consensus among respondents that having real time adherence data available during consultations was considered important[[5]](#footnote-6).
* The fact that 70% of Adult CF units within the UK chose to adopt the 19/20 CF self-care CQUIN and are working to implement the CFHealthHub learning health system and use the clinician facing dashboard is compelling evidence that professional opinion are supportive of the incorporation of real time adherence data in routine clinical care.
 |
| **2.4 Which governmental strategies or policies is supported by the use of this indicator?** | * The 26 UK CF centres have been invited to join the CFHH. So far, 19 of these centres have agreed join. Data is currently available from A, C and B. However, the policy which supports the development of this indicator is England specific. It is recognised that improved Patient activation levels are associated with reduced cost to the NHS in terms of the use of unscheduled care by patients with long term conditions and in 17/18 and 18/19 NHS England established a Patient activation CQUIN as a policy delivery initiative to attempt to increase patient activation. One domain of patient activation is increased adherence to preventative medication and the Cystic Fibrosis indicator is intended to capture data reflecting adherence. In 17/18, 18/19 and 19/20 NHS England specialised commissioning has commissioned a CQUIN specifically designed to increase adherence in CF. As such the National CF self-care Indicator captures the impact of policy initiatives to improve adherence.

 The NHS Long Term plan supports improving medicines adherence, which the CFHH is designed to do (<https://www.england.nhs.uk/long-term-plan/>). Additionally, it seeks to drive the development and integration of digital systems at scale that optimise clinical care by creating integrated services that make care more efficient and humane. The NHS Long Term plan additionally recognises that patient and clinician activation in long term conditions reduces unscheduled care. CFHH is therefore an example of the digital aspirations of the NHS LTP. NHS England have a variety of initiatives which are designed to increase the value from medicines, both by securing more favourable procurement arrangements with pharmaceutical companies, as well as ensuring patients adhere to medicine regimens prescribed to them (<https://www.england.nhs.uk/medicines/>). Ensuring patients are engaged in the process by their clinical team is one of the mechanisms by which adherence is noted to increase. Therefore, the CFHH is aligned with this policy. As a result of the primacy of engaging patients in self-care to increase adherence in CF, there is a CQUIN designed to support this (<https://www.england.nhs.uk/publication/pss3-cystic-fibrosis-self-care-pss-cquin-indicator/>). This indicator is part of this CQUIN. The following patient story highlights the potential of the programme to policy makers and the public. **A patient story in a CF unit without CFHealthHub**Jane turned up for an unscheduled clinic visit with her mum. This was unusual since as an independent 24 year-old Jane usually came to clinic alone. When the doctor entered the clinic room Jane was looking at the floor, her mum on the edge of her seat anxious and scared. Over the previous 12 weeks Jane had become increasingly breathless. After work she was exhausted and went straight to bed. She was losing weight and her lung function was down by 14%. The doctor took a brief history. Jane was using colomycin alternating with tobramycin and not quite sure how much she was taking. The doctor ordered a blood sugar series, sputum culture, chest x-ray and some bloods, admitted her to hospital for 14 days of intravenous antibiotics and swapped twice daily colomycin for three times daily aztreonam.**A Patient story in a centre with CFHealthHub** The graph below shows data which is available in real time to patients’ mobiles and to the clinical team in centres using CFHealthHub. 6 months before the clinic visit Jane had been taking 17 nebulisers a week, but in the 3 months leading up to clinic this had fallen to 5 per week.Chart showing patient nebuliser use before and after clinic visit*\*This is a composite patient story using illustrative data to maintain confidentiality***The power of real time data: patients at home no longer out of sight out of mind**Review of CFHealthHub data for all centre patients at the weekly team meeting in April identified Jane’s change in adherence to preventative therapy. Phone support to Jane followed by a home visit enabled problem solving and supported self-care. Adherence recovered. The crisis out-patient visit was avoided. There was no costly escalation from twice daily colomycin (circa £1.1K per annum) to thrice daily aztreonam (circa £12K per annum) no need for a 14-day hospital admission costing around £2.5K and no month of terror where Jane was sure that her CF had progressed and that her death might be approaching.  |
| **2.5 Who would use this indicator and why?** | **PWCF level*** PWCF can review their data to better understand their adherence, and to help develop habits which increase adherence.
* PWCF can review their data to work with members of the clinical team who have been trained in the use of CFHH data for behaviour change to create sustained habits of self-care

**Clinician level*** With patient consent, clinicians can use adherence data to build a comprehensive picture of the reasons for a patient’s clinical status i.e. as part of making a diagnosis

**Centre level**The CFHealthHub platform enables the sharing of data (with patient consent) at a centre level. This allows the creation of a CF wide improvement collaborative that will drive the necessary change that is already well advanced in the units that have been in the improvement collaborative for the past 2 years (C,A and B) and the extension of CFHealthHub into 70% of adult centres. The CFHealthHub indicators will be used within a community of practice including most of the adult centres in the UK.It is anticipated this indicator will provide insight into the following questions;1. Where we are now: Enable centres to understand the adherence levels in the centre at a given time.
2. Has adherence changed? Enable centres to understand the adherence level today compared to a period in the past and this also allows the impact of improvement interventions to be understood.
3. How does adherence in our centre compare to adherence in other centres? This will be most informative within the collaborative learning health system where reasons for variation can be discussed in an open non-judgmental community of practice

The indicators can be used to inform quality improvement projects. The centre level indicator is not intended to be used for the following1. As a way of identifying failing units as more experience with the indicators needs to be accumulated to understand more about the mediators of success and failure

The indicator is intended as a management tool to prompt further investigation and has the advantage of being explicitly developed within a learning health system within which systematic interviews will be carried out to understand how best to use benchmarking information within a community of practicing sharing the same digital platform.  |
| **2.6 Is there a relationship to other existing indicators?** | IAP00611: Normative adherence to nebulised therapy in Cystic Fibrosis in a subset of patients defined by chronic pseudomonas acquisition at a centre level using the CFHealthHub platform |
| **2.7 Comparability to other existing indicators** | No currently existing comparable indicators exist.  |
| **Section 3: Presentation and interpretation (IGB to assess, MRG to advise)** |  |
| **3.1 How will the indicator be presented?***.* | **Patient level**Patient facing adherence data is based on a treatment schedule (prescription) arrived at after discussions between patient and clinical team. As such, the adherence data reflects adherence to a regimen that is defined by patient and clinician negotiation (concordance) rather than a regime which is normative in terms of being driven by the optimal regime that the evidence suggests will lead to optimum outcomes. Wherever possible the regimen would be “normative” in terms of the patients’ characteristics but this patient-defined target recognises that the prescription which provides the denominator is arrived at by negotiation between the patient and the clinical team rather than defined by normative assumptions of what the optimum regimen would be on the basis of evidence around effectiveness.Therefore, if a PWCF agrees with their clinician they will take their inhaled therapies twice a day the denominator will be 2. The data will be available in real time to the PWCF in an app on their mobile phone or other electronic device. The formats in which the data can be visualised are the results of a 14 month iterative process involving co-production with PWCF. PWCF have the option of choosing to see their data in a wide variety of formats including: * + As a bar graph with a bar running from 0% to over 100% representing each day and colour coded green if they have hit their target, amber if they have taken greater than zero treatment but less than 100% treatment and the day will have red. PWCF can choose to simply look at 1 week’s data on one screen or many weeks or months of data.
	+ Organised by day of the week or time of the day
	+ Organised by monthly average

Clarity and user friendliness has been optimised by the 14 month period of co-production using iterative software sprints in an agile design framework to create the initial data format which was tested using “think aloud” methodology and observed use and then assessed in a feasibility pilot in two new CF centres where qualitative researchers interviewed patients about the data presentation format. See section 2.4 for an example of this interface.**Clinician level**Clinicians will have access to the same data and interface (provided the PWCF has given their consent for this to be viewed by the clinical team) as the PWCF. **Centre level*** CFHH is available to patients in 70% of adult centres in the UK. Here they can view median adherence of patients in other centres.
* Currently CFHH is only available to people with CF (PWCF) aged 16 and older but work is underway to extend to PWCF aged 13 and above.
* There is no ‘publication date’ as with more traditional indicators or official/national statistics. Data is uploaded in real time, and those clinical team members with access to CFHH can view it concurrently. However, it is noted that sometimes there is a delay in uploading all the data, and therefore it is advised that the most stable snapshot is of a 2 month period (to allow for regimens with alternating months of treatment), at 3 months time lag. Additionally, the CF Registry provides the number of patients at each centre which is used to provide information regarding how many patients are accessing CFHH, and this data source operates with a minimum of 8 month time delay.

 Image showing the Learning health system and increase in percentage using shared data to create a community of practice**Figure 1:** CFHH interfaceFor each ‘teacup’;* the large dark blue circle corresponds to the number of patients (as ascertained from CF registry data) at each CF centre.
* the inner light blue circle corresponds to the number of patients at each CF centre who are using CFHH.
* IAP00610 is the % in the centre of the light blue circle. This corresponds to adherence to nebulised therapy using simple numerator adjustment with the denominator defined by agreement between the patient and the clinician. This % is the mean adherence for a 2 month period for all patients using CFHH, and taking the median of all patients in the centre.
* See IAP00611 for a description of the green olive shapes.

To interpret the data from Centre B, we see that a larger proportion of all the patients in Centre B are using CFHealthHub when compared to Centre A and Centre C but that the % adherence in Centre B amongst those using CFHealthHub is the lowest at 31.4% when compared to Centre A at 41.4% and Centre C at 38.2 %. The schematic is helpful since it suggests that in Centre B, the more difficult to reach patients have been reached. However, % adherence falls when compared to Centre A and Centre B where a smaller proportion of all patients in the centre have been reached. It is important to recognise that an important metric that this schematic captures is the proportion of patients where adherence is visible. Visible adherence data makes the diagnostic processes in consultation more effective.  |
| **3.2 What contextual information will be provided alongside the indicator?***.*  | **PWCF level** * PWCF prescription (denominator number) based on agreed target between PWCF and clinician
* Patients are empowered to look at their own data over time to see how their adherence has changed. These plots also can be used alongside hospital admissions, lung function and weight to allow patients to develop insights into possible relationships between patterns of self-care around lung health and the need for rescue therapy.

**Clinician level*** PWCF prescription (denominator number) based on agreed target between PWCF and clinician
* Clinicians can use patient level data in consultations to optimise the diagnostic process i.e., unstable clinical status and zero adherence support adherence, unstable clinical status and 100% adherence review medication regimen, revise diagnosis and look for new problems e.g. acquisition of resistant pathogens, new diabetes etc.

**System level*** Figure 1 provides information regarding how many patients in each CF centre are using CFHH, which provides important contextual information regarding the % of patients reached. Centres with only a small proportion of patients providing data are likely to “over-estimate” adherence by only including the best adherers. Centres with the higher coverage of people on nebulised treatment is also more likely to be providing better quality care, given that almost everyone with CF will benefit from nebulised DNase.
* It will be clarified that the denominator reflects agreed target between the PWCF and their clinician, rather than a normative prescription based on the PWCF’s characteristics.
 |
| **3.3 What is considered “good” performance? What is considered “bad” performance?** | **PWCF and clinician level*** High levels of adherence are considered good. RCT data have suggested that within RCTs patients can achieve 80% adherence. Centre level data show that around 10% of patients within a centre have 80% adherence[[6]](#footnote-7) at a time when systematic adherence is not implemented and so we have suggested that , 80% adherence is what patients can realistically achieve, and which would be considered ‘good’. Poor adherence would be considered to be 50% and below.

**Centre level*** Across all patients, the CF centre would hope to achieve 80% median adherence though this is likely to require considerable learning within the community.

**Improving a ‘bad’ position**Evidence based training in behaviour change to support PWCF to improve adherence has been provided over the past 2 years (2018 and 2019) to at least 1 member of the clinical team in each centre and it is intended that this training will be cascaded to other multi-disciplinary team (MDT) members over the next 12 months. The centre level CF indicator is designed to create an awareness of adherence, to allow this to be benchmarked across the learning health system and for that shared data to support the community of practice to support optimum configurations of centre care to improve adherence. The providers are the MDT team members in individual centres and they will be supported with training in behaviour change and also training in the Dartmouth microsytems approach to quality improvement (<https://www.sheffieldmca.org.uk/>) in order to implement the system change that is required to shift centre CF care from reactive hospital based rescue characterised by low levels of adherence to self-care to community based prevention characterised by high levels of patient led self-management with adherence levels closer to 80% than 30%. |
| **3.4 Is there a target to be achieved?** | **PWCF and clinician level**Data on the CFHH should be used by the PWCF to optimise their self-care. As such the direction of travel will be patient led supported by the clinical team in the context of a long term therapeutic relationship. Within this relationship it will be apparent that treatment works when it is taken and the ability of CFHH to display months and years of data alongside data about the use of rescue therapy and hospital admissions allows a mature conversation about treatment out of which a direction of travel defined by the patient will emerge. **Centre level**It is intended that data will be used within the community of practice created by the CFHH learning health system and we expect that targets will be owned by the community of practice and emerge as the community of practice develop a sense of what is possible. |
| **3.5 How will any interested parties use the information provided by the indicator?** | **PWCF and clinician level**All the clinical teams that have access to the patient data work in learning health system centres which have a CFHealthHub interventionist who has been intensively trained in how to use the patient facing indicator by trainers within the larger CFHH team. (Professor of psychology with expertise in behaviour change and physiotherapist who was involved in co-production of patient facing adherence indicator). The following major themes are emphasised in terms of how the indicator should and should not be used**Should be used*** Data should only be accessed by clinical team with patient consent (this should occur automatically as patients control access within the CFHealthHub digital platform)
* Indicator should only be used to empower self-care within high quality nurturing relationships.
* Indicator should be used by clinical teams to support an understanding of clinical status. This is a diagnostic application of CFHealthHub indicator data which is distinct from the behaviour change function.

**Should NOT be used*** Indicator should not be used as a stick to coerce patients to change behaviour

**Centre level****Should be used for** * Shared insights and learning across community of practice

**Should NOT be used for** * External judgement since much remains to be understood about the use and implications of the data and this will emerge from the use of the indicator through co-production of data use within the learning health system and we would recommend that the use of the data should emerge as consensus outputs from all users within the learning health system including people with CF, clinical teams and the NHS England purchasers.
 |
| **3.6 Consider how the results can be used for benchmarking. If so, what methodology will be used?** | **PWCF and clinician level**The PWCF data will be used by the PWCF and clinician to track their own adherence over time. The patients will be able to see all their data from when they first start using CFHealthHub and will use this to understand progress. **Centre level**Individual centre “teacup” diagrams will be used to compare performance between CF centres. |

|  |  |
| --- | --- |
| **Section 4: Data (MRG to assess)** |  |
| **4.1 What is the source of the data and why should it be used?** | **Data Source 1: CF Registry**Using the CF Registry gives as an unbiased estimate of the total number of PWCF within the UK on an annual basis. Data accessed on 1st September each year provides the previous year’s numbers. The CF Registry will provide the number of PWCF within the whole of the UK as well as split by centre. This will be uploaded into CFHealthHub by the team on an annual basis.**Method of using CF registry and issues around data linkage*** Anonymised data will be used to provide the number of patients in each centre. Anonymised data is aggregated across centres to provide the total number of patients in the learning health system.

CF registry:<https://www.cysticfibrosis.org.uk/the-work-we-do/uk-cf-registry>**Data source 2: Nebuliser devices uploading data to CFHealthHub**CFHealthHub receives date and time stamped data on the use of preventative inhaled therapies delivered via the chipped E-track. It is important to note that this device is the only device that can provide the full range of inhaled nebulised therapies in CF. The Phillips Ineb can also collect date and time stamped data on inhaled therapies but it is unable to transfer data in real time. We are able to take data from the Ineb and display these data in CFHealthHub.CFHealthHub is developed and maintained by the School of Health Sciences | Division of Informatics, Imaging & Data Science | Faculty of Biology, Medicine and Health | The University of Manchester which has extensive expertise in maintaining data observatories.CFHH data will be available on an ongoing basis and CF Registry annually.  |
| **4.2 Was any other data source considered?**  | There are no other data sources with the relevant information available.  |
| **4.3 What is the coverage period of the data?** | PWCF, clinicians and centre level staff can view real time data on the CFHH from when PWCF begin to upload, over any time period they choose including the previous week, month, or since PWCF started to submit data. Section 2.4 provides an example of this interface. **Centre level**There is no ‘publication date’ as with more traditional indicators or official/national statistics. Data is uploaded in real time, and those with access to CFHH can view it concurrently. However, it is noted that sometimes there is a delay in uploading all the data, and therefore it is advised that the most stable snapshot is of a 2 month period (to allow for regimens with alternating months of treatment), at 3 months time lag. Additionally the CF Registry provides the number of patients at each centre which is used to provide contextual information regarding how many patients are accessing CFHH, and this data source operates annually with an 8 month time delay. Section 3.1 provides an example of the interface which makes the indicator available at a centre level.  |
| **4.4 Which geographic area(s) will be covered and reported on by this indicator?** | Currently all UK adult CF centres have been invited to take part and 19 out of 26 (73%) have been recruited to take part by the end of 2020. Currently, 3 centres have been collecting data.  |
| **4.5 How will the data be extracted or collected?** | **Data capture****CFHH**Adherence data is captured by chipped nebulisers. Two currently available devices provide time and date stamped adherence data for inhaled therapies in CF: Pari E-track and Philips I-Neb. These two devices are able to deliver all the inhaled preventative therapies in CF. Data captured by the E-tracks and I-Nebs are transferred to CFHealthHub via internet-hubs. The platform is agnostic and the IP belongs to the NHS so that there would be no barriers to the connection of other devices capable of reliable data capture. Patient’s prescriptions (for denominator data) are inputted into CFHealthHub by their clinical team on an ongoing basis. **CF Registry**Data on patient numbers at each centre for contextual information will be made available through the CF registry. CF centres are required to submit data on all their CF patients annually to the CF registry, otherwise they will not be paid for these patients.  |
| **4.6 Data fields required** | **CFHH*** Doses taken at a given time on a given date.
* Time of dose
* Date of dose
* Patient’s prescription details

**CF Registry*** Lung transplant status
* Contextual information on number of patients treated at that centre
* Patient pseudomonas status
 |
| **4.7 Are any data filters required?** | People with lung transplantation are excluded from the indicator, as these people no longer have lungs that have the Cystic Fibrosis mutation and as such the lungs are not “CF lungs”. Patients who have had a transplant can be identified by a code within the CF registry. |
| **4.8 Are there any linkages to other datasets?** | No. |
| **4.9 Are there any limitations or potential bias?** | **Data limitations*** The number of patients at each centre is provided by the CF registry, which operates at an 8 month time lag in comparison to the real time data presented on CFHH. Therefore, it is possible there may be some inaccuracies in this data, as PWCF may have joined or left each centre. This affects only the contextual information provided with the indicator regarding the number of patients at each CF centre using CFHH, rather than the patient adherence indicator itself.
* There is a possibility of data loss when a patient has used the nebuliser but the data has not been displayed in CFHealthHub. Considerable work has been carried out to understand how data might be lost by CFHealthHub, which would cause the patient facing indicator portal to show zero adherence when the patient had actually taken the treatment. The reasons for data loss are well understood and can only occur under a small number of readily identified circumstances and a paper will shortly be published that will present the work that has been carried out to explore data quality.
* When a patient takes a treatment from day A after midnight, it is counted in the treatment for day B. If the patient then takes all of day B’s treatment later in the day, day B will have treatment capped at 100% and Day A will appear to have missed the target. This is a well understood issue that would be largely resolved if Day A ran from 4 am to 0355 on day B. However, reprogramming the timings within CFHH is labour-intensive and to date there has been insufficient resource to resolve this issue that is currently managed by training clinical teams and informing patients.
* Patients taking dry powders are missed by this system.

**Potential biases*** As the target prescription which is the denominator is agreed between the PWCF and clinician, it is possible that across a centre, lower than optimal prescriptions are consistently agreed in order that adherence appears higher. However, this gaming behaviour will be identified and addressed through communities of practice in the learning health system.
 |
| **4.10 Further notes on data**  | None |
| **Section 5: Construction and Testing (MRG to assess)** |  |
| **5.1 How will the indicator measure be calculated / constructed?** *Please provide explanation of coding where applicable and rationale behind demographic breakdowns* | **The time period over which the indicator can be calculated is flexible. See section 4.3 regarding the coverage period and delays to data being available.** **Patient level**1. Daily prescriptions (due to prescription dates) for a PWCF are entered into CFHH by clinical team.
2. Daily inhalations (due to time stamp) identified for PWCF.
3. Daily adherence per patient is calculated.

**Centre level**1. For each time period identified, each PWCF at a centre has the mean adherence calculated. This is the mean of their daily adherence over this period.
2. The median of the mean adherences of PWCF is calculated at each centre.
 |
| **5.2 Numerator explanation** | **PWCF level**: Number of doses taken in a day is found from CFHealthHub inhalation data. This is capped at 100% based on the PWCF prescription. Adjusted for nebulised antibiotics require multiple accentuations for a complete dose (this is relevant for data from the Ineb) . **Centre level:** Mean adherence of each PWCF at each CF centre over a time period identified |
| **5.3 Denominator explanation** | **PWCF level**: Prescription (number of doses) per day as defined within CFHealthHub. **Centre level:** Number of PWCF using CFHH at each CF centre over a time period identified |
| **5.4 Provide a worked example** | **Patient level**1. Daily prescriptions (due to prescription dates) for a PWCF are entered into CFHH by clinical team. For example, PWCF should take 4 medication doses per day
2. Daily inhalations (due to time stamp) identified for PWCF. For example, PWCF takes 3 doses of medication on a day (this figure is capped at 100% of daily prescription)
3. Daily adherence per PWCF is calculated. For the above example, the patient would achieve 75% adherence (3/4=0.75\*100)

**Centre level**1. For each time period identified, each PWCF at a centre has the mean adherence calculated. This is the mean of their daily adherence over this period.
2. The median of the mean adherences of each PWCF is calculated at each centre. For example, at a centre with 5 patients using CFHH with mean adherences over a time period identified of 30%, 90%, 75%, 20% and 60%, the median adherence at the centre would be 60%.
 |
| **5.5 Could any risks be associated with the use of this indicator?** | PWCF and clinicians agreeing a sub-optimal target for the prescription, either because the patient does not want to be confronted with low adherence, or there is a desire to make centre level adherence appear better may harm the long term health of the PWCF. Similarly, PWCF could be moved to dry powders, so they are not part of the indicator at all. The contextual information provided on CFHH and learning community of practice should ameliorate this risk. Viewing this indicator alongside IAP00611 will provide a more standardised comparison, which will better gauge the extent of adherence at different CF centres. This should dissuade sub-optimal target setting in order to make adherence appear better. PWCF may feel that data on CFHH is used by the clinical team in a ‘big brother’ way, which may harm the therapeutic relationship. Patients can choose not to share the data if they feel this is the case. Additionally, there will be MDT members at each CF centre using CFHH, who have been trained in behaviour change interventions, and will be able to handle challenges sensitively.  |
| **5.6 Risk adjustment or standardisation type and methodology** | No risk adjustment or standardisation methodologies have been used.The rationale for this is that if a certain CF centre has a large number of patients that have low adherence due for example to socio-demographic factors it is important from an improvement perspective that the low adherence is visible since this allows the community of practice to provide support to explore whether the centre could be using different methods to provide the required care for these patients and by adjusting, it will artificially inflate the engagement with the patient group who might be difficult to engage.The CFHH aims to provide data for learning within the community of practice to allow variation to be made as obvious as possible rather than adjusted away. The community of practice should work together to develop different approaches to support different patients.  |
| **5.7 What are the confidence intervals and control limits and why have they been used?** | No confidence intervals have been used at present. The rationale for this decision is that at present the aim is to provide the indicator data back to the community of practice, in order that they can best discern how to work with the data, rather than creating too much focus on centres which appear to be under or over performing. As the denominator for the indicator is agreed between PWCF and the clinician, this indicator is not a ‘like for like’ comparison between centres.  |
| **5.8 Could the indicator be manipulated to influence the outcome?** | Centres could move low adherence patients onto dry powders, as data from these prescriptions is not recorded (therefore they would not be considered as part of the indicator) which would have the effect of making centre adherence appear higher. However, contextual information is provided regarding how many patients per CF centre use CFHH, so this gaming behaviour would become apparent. At an individual level, if a patient is struggling to take 3 nebulisers per day, it would be possible to reduce the patient’s prescription. This would result in a higher daily adherence but a less effective regimen. This why it is important to consider the indicator along with IAP00611, which will provide information on PWCF adherence against a normative prescription.  |

**Indicator Assurance Report**

**IAP00610**

**What do the Assurance Ratings mean?**

|  |  |
| --- | --- |
| **Rating** | Description |
| **Fit for use** | This indicator can be used with confidence that it is constructed in a sound manner that is fit for purpose. |
| **Fit for use with caveats** | The indicator is fit for use, however users should be aware of caveats and/or recommendations for improvement that have been identified during the assurance process. |
| **Use with caution – data quality issue** | The indicator is based on a sound methodology for which the assurance process endorse the use, however issues have been identified with the national data source which have implications for its use as an indicator. |
| **Not fit for use** | Issues have been identified with the indicator which have resulted in the assurance process currently not endorsing its use as a quality indicator. |
| **Not enough information provided** | There has not been enough information supplied to the assurance process to be able to accurately give the indicator a level of assurance. |

**Final Assurance Rating from the Indicator Governance Board - 07/11/2019**

|  |  |
| --- | --- |
| **Reason for assessment** | Initial assurance |
| **Iteration** | 1st IGB meeting |

|  |  |
| --- | --- |
| **Ratings Against Assessment Criteria** |  |
| Clarity  | **Fit for use** |
| Rationale  | **Fit for use** |
| Data  | **Use with caution – data quality issue** |
| Construction  | **Fit for use** |
| Presentation and Interpretation  | **Use with caution – data quality issue** |
| Risks and Usefulness  | **Use with caution – data quality issue** |

**Overall Rating – Use with caution – data quality issue**

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| --- | --- |
| **Outcome** | **This indicator has been approved for inclusion in the National Library of Quality Assured Indicators** |

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| --- | --- |
| **Approval date** | 07/11/2019 |
| **Review date** | 07/11/2024 |

**Details of Methodology Appraisal – 22/08/2019**

|  |  |
| --- | --- |
| **Methodology appraisal body** | IMAS Methodology Review Group (MRG) |
| **Reason for assessment** | Initial assurance |
| **Iteration** | 1st MRG meeting |

***Suggested Assurance Rating by Methodology Appraisal Body***

|  |  |
| --- | --- |
| **Ratings Against Assessment Criteria** |  |
| Introduction and Overview  | Fit for use |
| Rationale and Policy Basis  | Fit for use |
| Presentation and Interpretation  | Fit for use |
| Data | Use with caution – data quality issue |
| Construction and Testing | Use with caution – data quality issue |
| IMAS provided Information | Fit for use |

**Overall Appraisal Rating – Use with caution – data quality issue**

**Summary Recommendation to Applicant:**

MRG thanks the applicant for the extensive work that they have put in to the application. While there are some concerns over the data quality due to the present low participation rate of CF centres, there is nothing stopping this progressing to IGB.

**Summary Recommendation to IGB:**

After review of the responses to the queries raised by MRG, it has been determined that the application can progress to IGB, recommending that it is approved with the following caveats. However, the low participation rate of CF Centres requires a classification of ‘use with caution, data quality issue’

• 19 out of 26 CF Centres (73%) have been recruited to take part by the end of 2020. However at present only 3 centres have been collecting data.

• Public access to the data is currently unavailable, and is being investigated for future iterations

**Please see the appraisal log below for detailed description of recommendations, issues and actions that explain the above rating(s).**

**1. Introduction and Overview**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
|  | N/A |  |  |  |  |  |

**2. Rationale and Policy Basis**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
|  | N/A |  |  |  |  |  |

**3. Presentation and Interpretation**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
|  | N/A |  |  |  |  |  |

**4. Data**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
|  | N/A |  |  |  |  |  |

**5. Construction and Testing**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| ***Section*** | ***Issue or recommendation*** | ***Raised*** ***by / Date*** | ***Response or Action taken by applicant*** | ***Response by / Date*** | ***Resolved*** | ***Sign off by / Date*** |
|  | N/A |  |  |  |  |  |

**Any feedback should be made to Data Standards Assurance Service (DSAS) Team at NHS Digital. Likewise, if you are unclear regarding any of the recommendations in this report or have any queries about the assurance process in general, please contact the DSAS team.**

**Data Standards Assurance Service**

**NHS Digital**

**1 Trevelyan Square, Boar Lane,**

**LEEDS**

**LS1 6AE.**

**Email:** **Standards.assurance@nhs.net**

**Website: https://digital.nhs.uk/systems-and-services/all-a-z/indicator-methodology-and-assurance-service**

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• Susannah Sadler1 • Martin Wildman2 [↑](#footnote-ref-4)
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Zhe Hui Hoo,1,2 Benjamin Gardner,3 Madelynne A Arden,4 Simon Waterhouse,5 Stephen J Walters,1 Michael J Campbell,1 Daniel Hind,5 Chin Maguire,5 Jane Dewar,6 Martin J Wildman1,2 [↑](#footnote-ref-7)