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Adherence in Respiratory Disease



DR HELEN WHITE

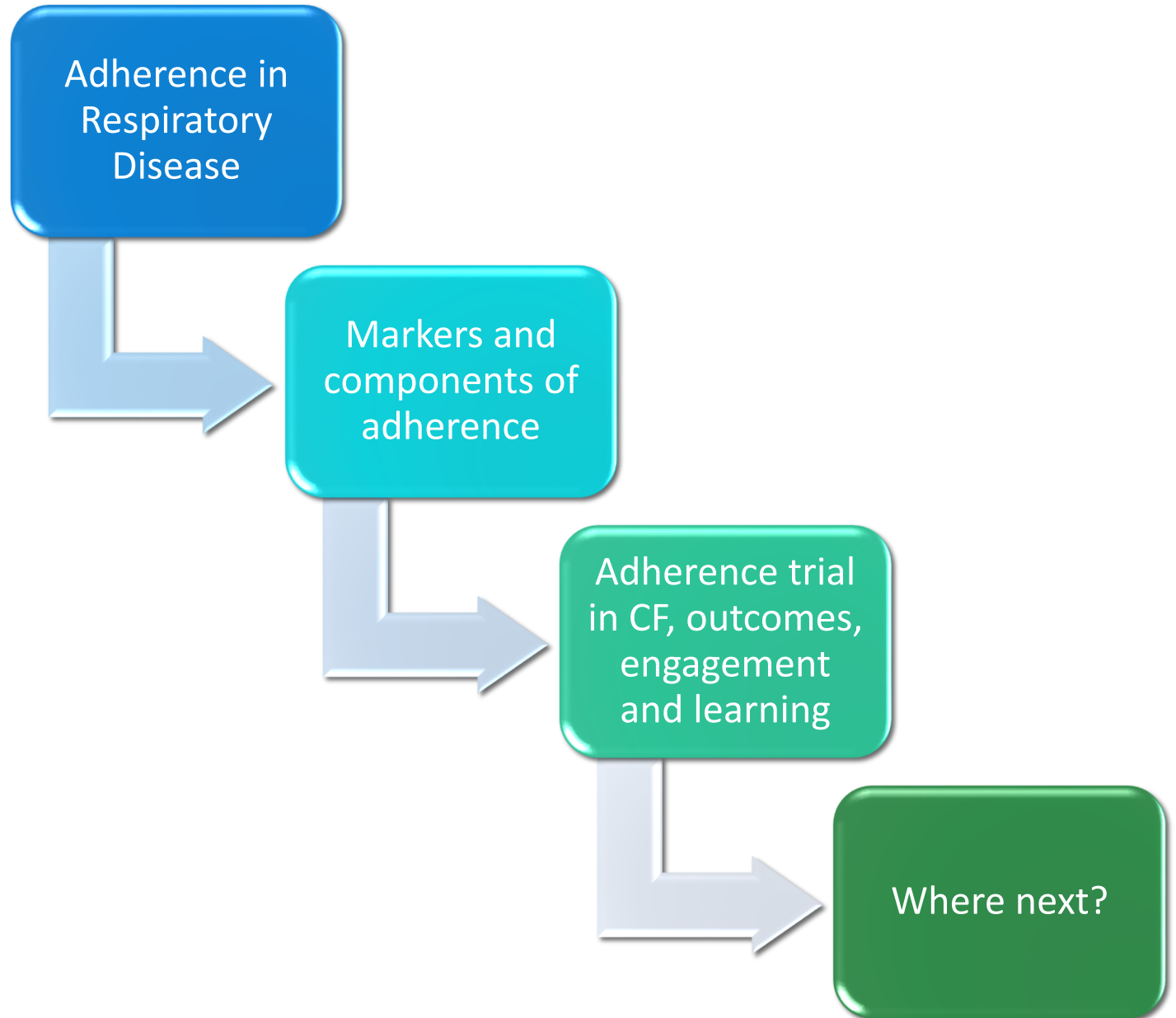
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Overview



Adherence....?

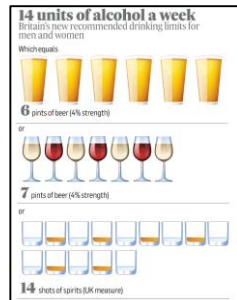
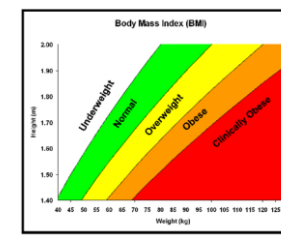
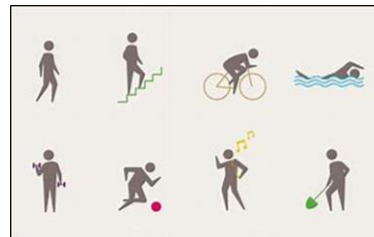
DEFINITION

‘The extent to which a person’s behaviour corresponds with the agreed recommendations from a healthcare provider’

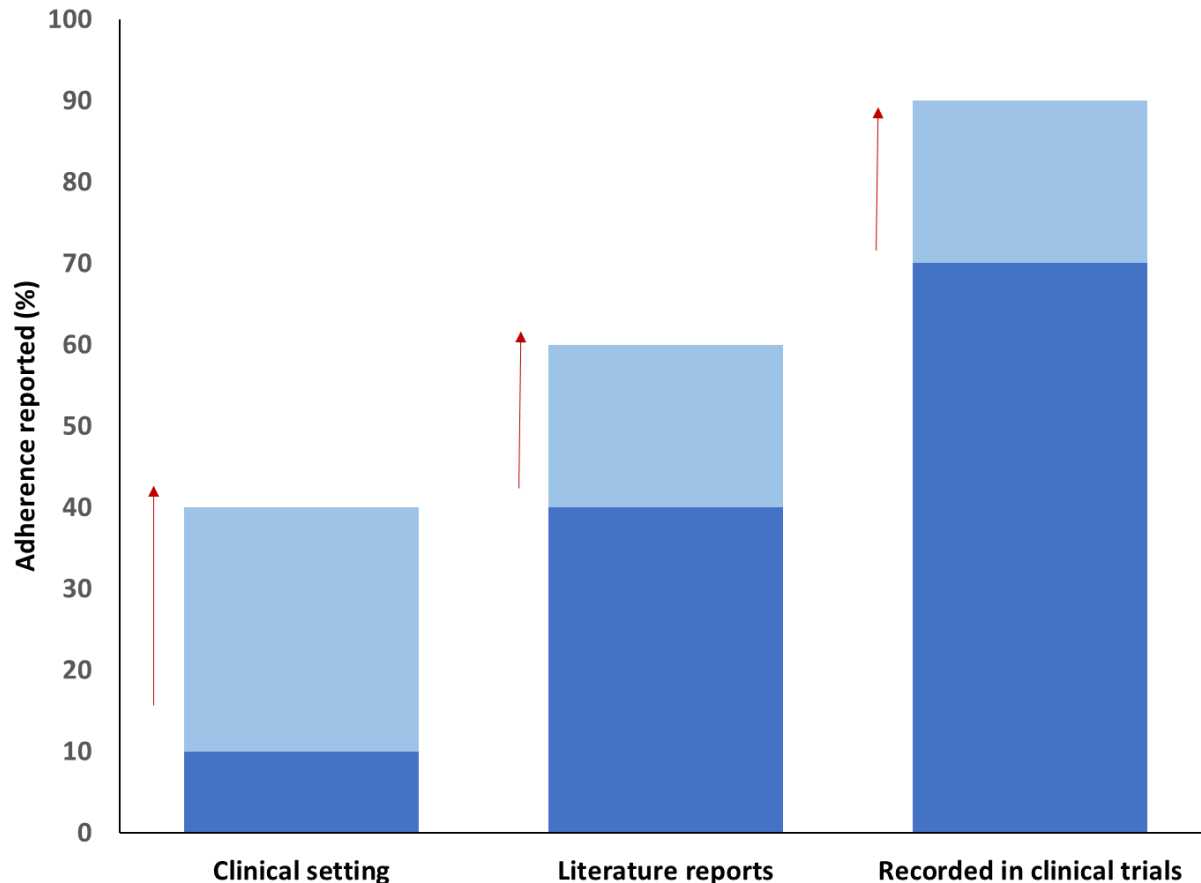


.... AFFECTS US ALL

- ❖ 92% of new year resolutions fail
- ❖ 25% eat 5 fruit & veg daily
- ❖ 37% maintain a BMI <25
- ❖ 76% drink 14 units alcohol/ wk or less



Respiratory Disease



Sanduzzi et al., 2014

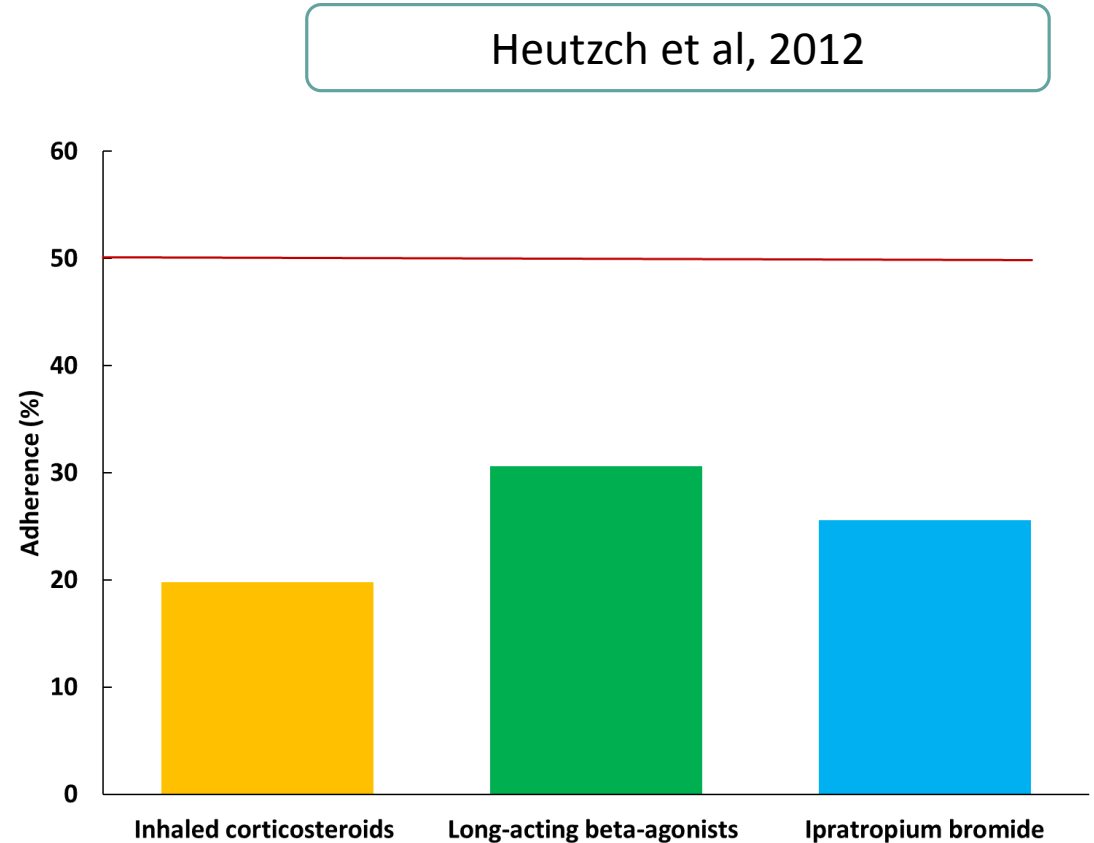
RCTs have repeatedly demonstrated the value of licensed COPD and asthma therapies

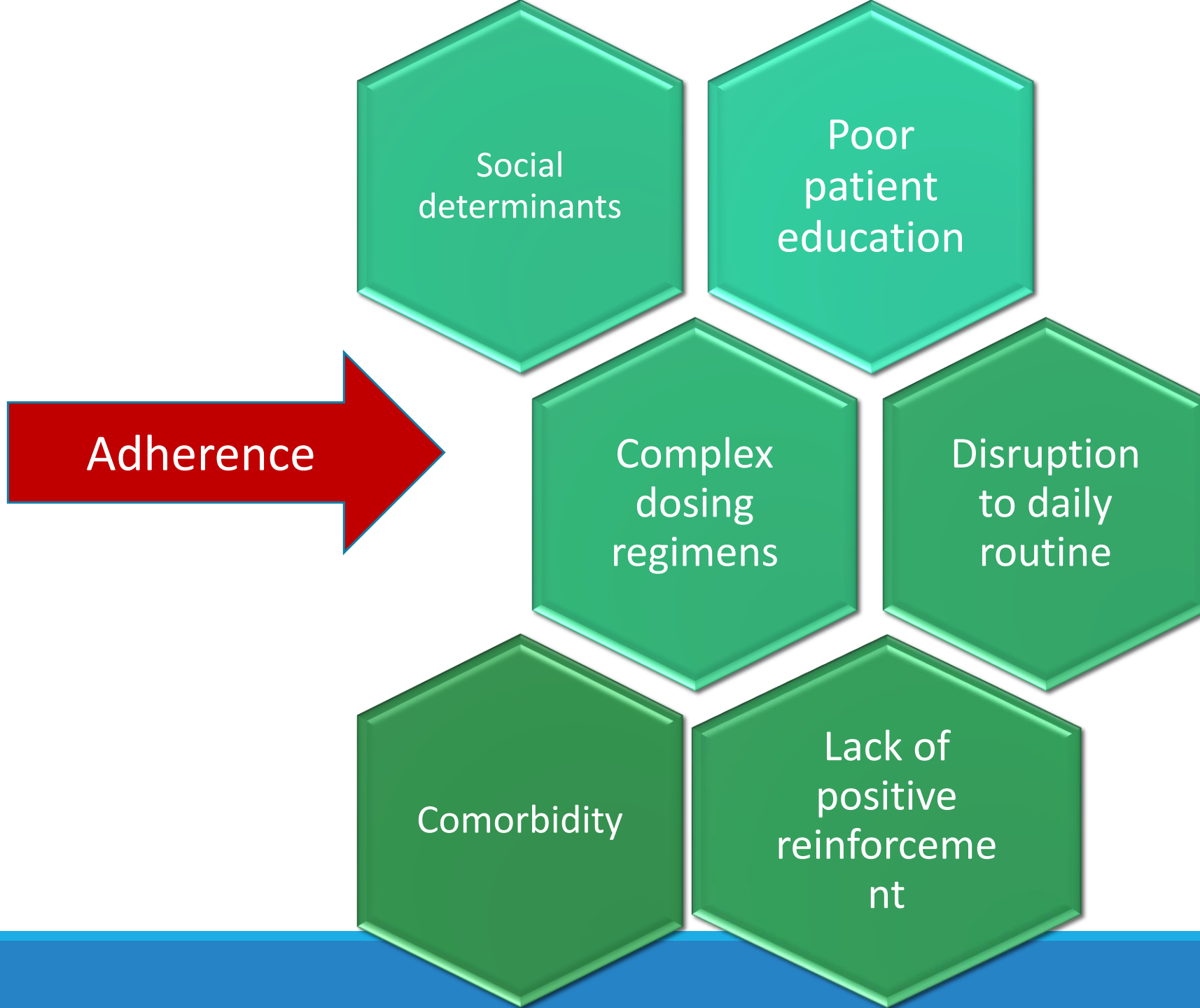
- ❖ ↓ Symptom burden
- ❖ ↑ Quality of Life
- ❖ ↔ Maintenance or slowing of disease progression

But In well controlled, highly selected populations, and in the shorter term

Adherence to treatment and treatment components

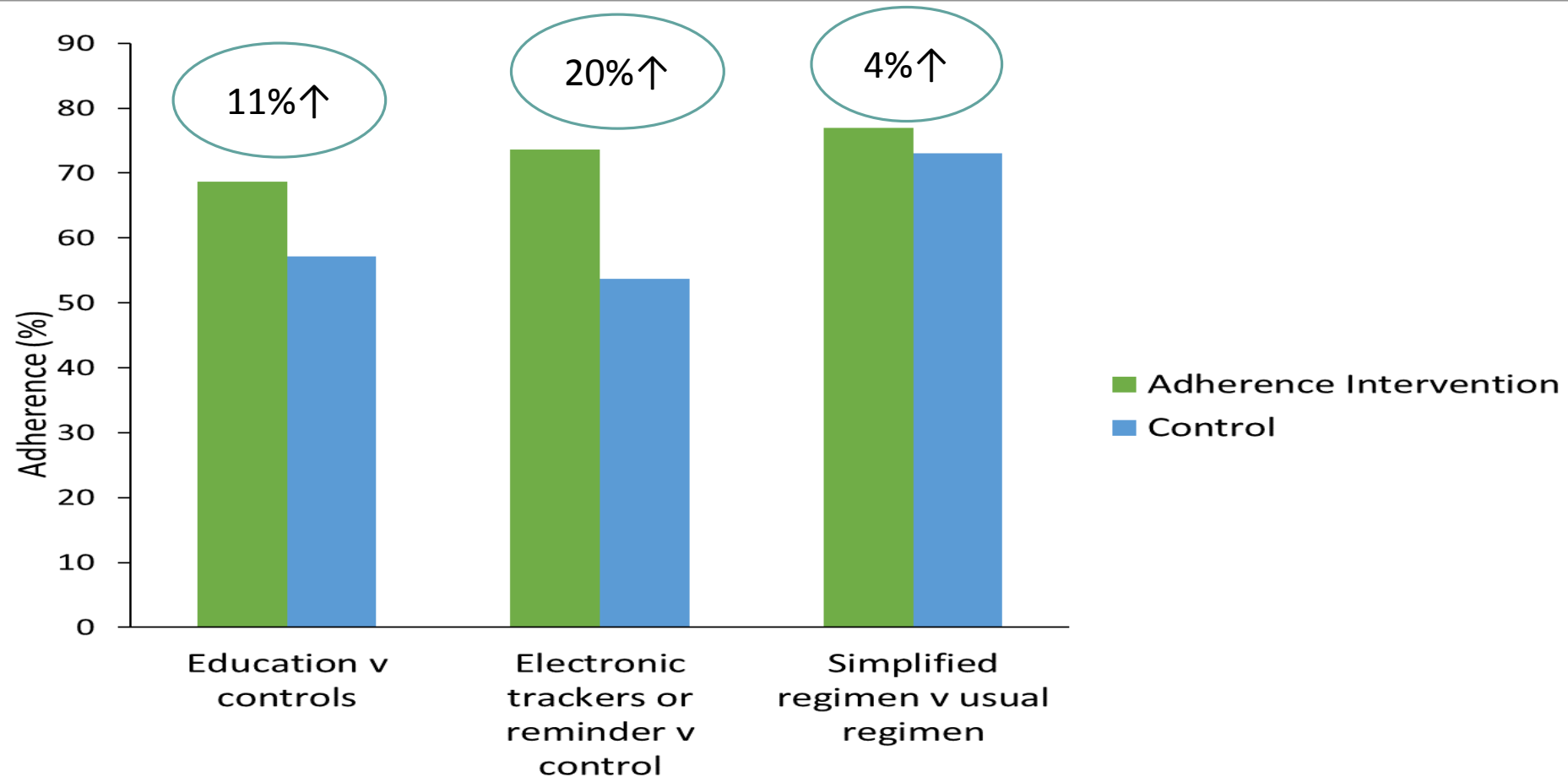
- ❖ WHO (2003) chronic conditions [50%]
- ❖ Bronchiectasis/COPD/asthma/CF [30-65%]
- ❖ Home nebuliser therapy [44% -50%]
- ❖ Long term Oxygen therapy [40-70%]
Gauthier et al (2018)
 - ❖ Increasing age and ambulatory O2 predicted adherence
 - ❖ 60% adherence overall





Cochrane Database of Systematic Reviews Interventions to improve adherence to inhaled steroids for asthma (Review)

Normansell R, Kew KM, Stovold E (2017)



Recommendations for future studies

- ❖ Use validated tools for outcome measurement, such as the Asthma Control Test (ACT), the Asthma Control Questionnaire (ACQ) and the Asthma Quality of Life Questionnaire (AQLQ)
- ❖ Provide adequate details regarding baseline severity among participants.
- ❖ Include some form of blinding or active control.
- ❖ Trialists to prespecify a threshold for 'acceptable' adherence and to perform a dichotomous analysis of those achieving this level and those not achieving it

This study examines the psychometric properties and predictive validity of a validated and reported medication adherence measure in patients with hypertension. To address this question, we conducted a validation study of adherence, using an electronic medical diagnosis for hypertension management, only 17% of hypertensive patients in a 2003-2004 survey were reported to have their...

Validated measures for adherence

Morisky scale

Do you sometimes forget to take your high blood pressure pills?

Over the past 2 weeks, how often have you...

Have you ever had a worse blood pressure reading when you were not taking your medicine?

When you take your medicine, do you ever forget to take it?

Did you take your medicine every day for the last 2 weeks?

When you take your medicine, do you ever stop taking it for a few days?

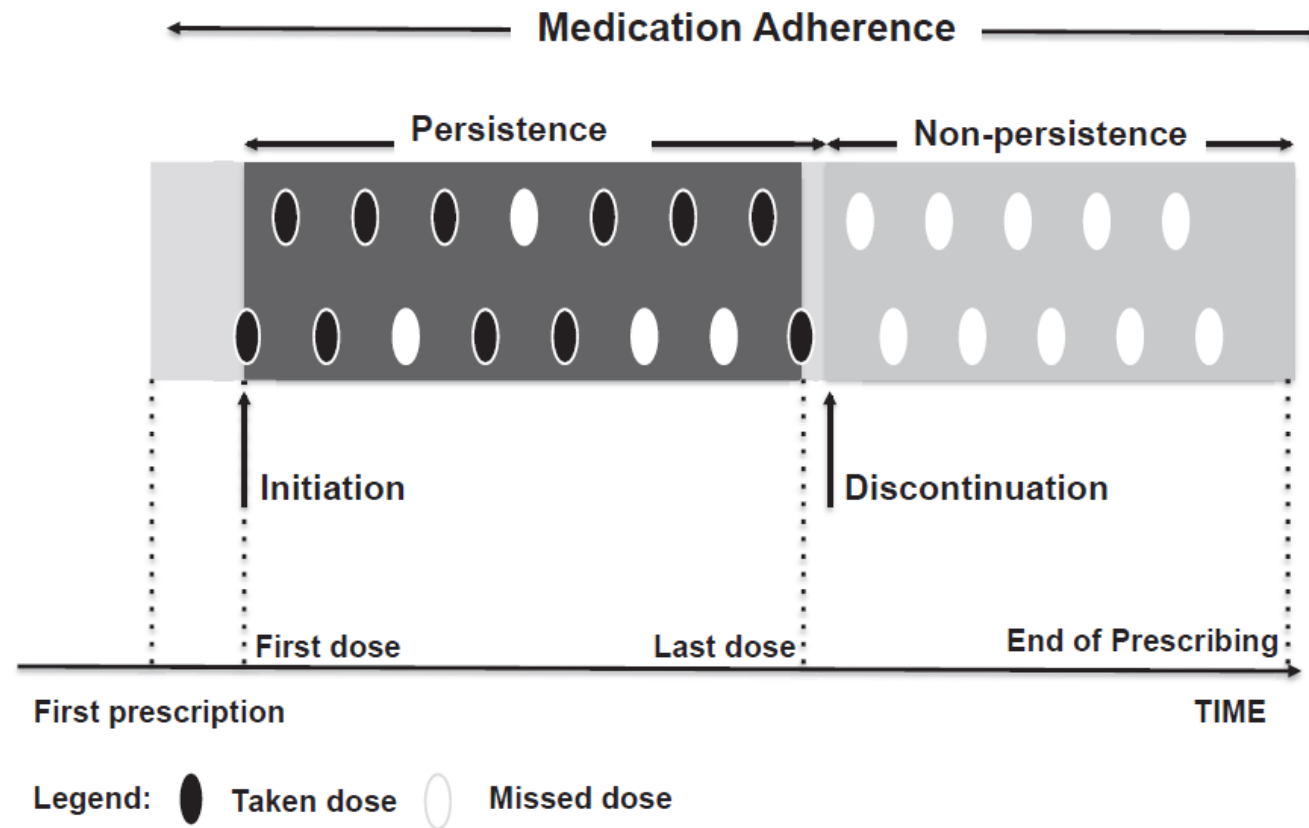
Taking medicine is a hassle, so I don't stick to it.

How often do you have difficulty remembering to take all your blood pressure medication?

Highly adherent 8 on the scale,
Medium adherers with a score of 6 to <8,
Low adherers with a score of <6 on scale

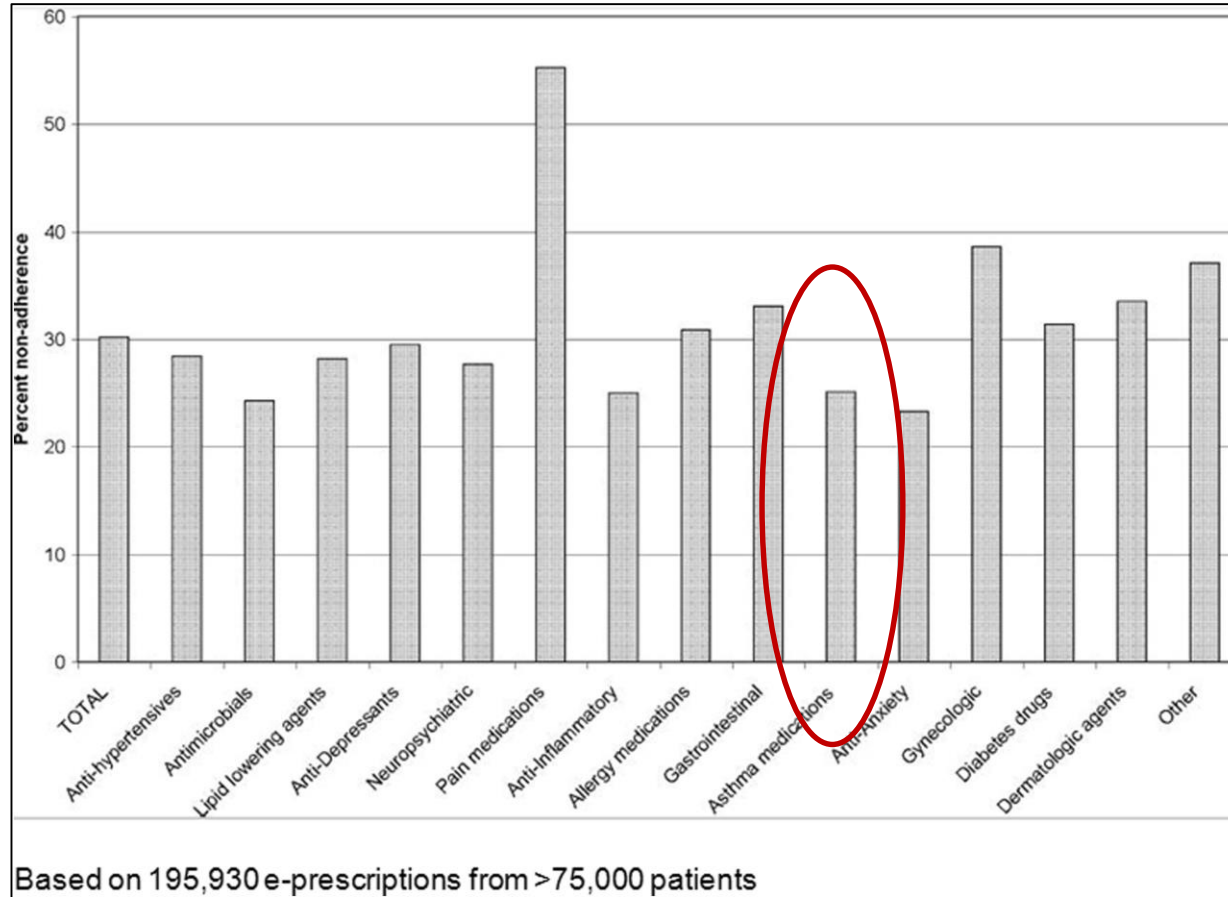
Sensitivity 93%
Specificity 53%

The phases of adherence outlined in the ABC taxonomy



Adapted from Vrijens et al. (2012)

Primary non-adherence to newly prescribed medications. Patients aged 19 and over



Although asthma medications were among the higher dispensed-prescriptions within the study, approximately one-quarter of patients prescribed new asthma therapy **failed to collect their first prescription**

Adherence measures

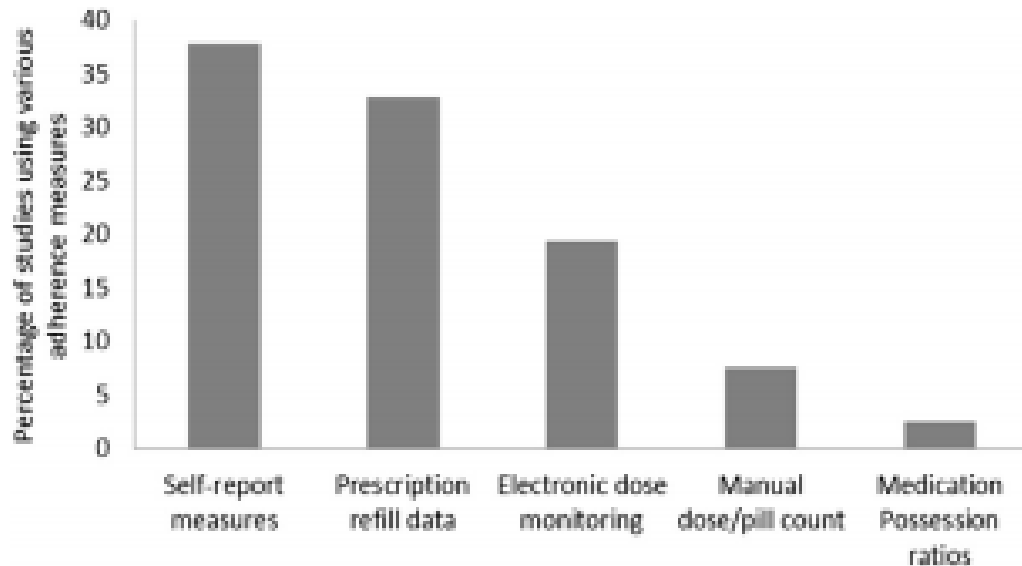


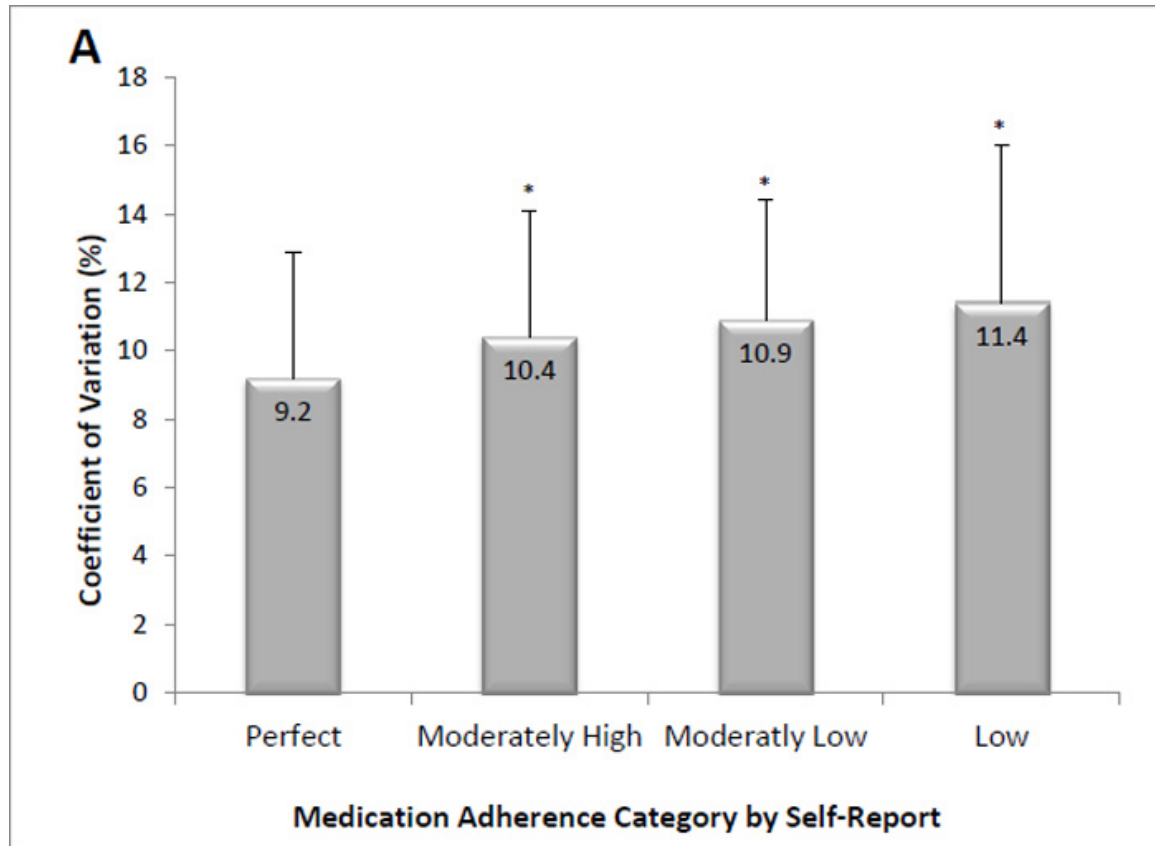
Fig. 1 Most commonly used measures of adherence in studies investigating inhaled asthma/chronic obstructive pulmonary disease therapies from 2000 to 2012. Total percentage may not add up to 100% as studies may have used more than one adherence measure.

- ❖ Self report
- ❖ Pharmacy refill
- ❖ Manual dose/pill count
- ❖ MPR – does the patient collect the prescription
- ❖ Electronic data – gives detail about variation in adherence

Conclusion

- ❖ Adherence is low
- ❖ Clinicians lack accurate methods to assess the issue
- ❖ Novel approaches to data analysis may aid understanding
- ❖ Digital technologies hold promise to overcome these barriers to care

Variation as a marker of adherence – early analogies with studies on blood pressure



Medication adherence and visit-to – visit variability of systolic blood pressure in African Americans with chronic kidney disease in the AASK Trial

Hong et al [J Hum Hypertens. 2016 Jan; 30\(1\): 73–78.](#)

Use of electronic data in adherence measurement?





Evaluating adherence and variation measures in Cystic Fibrosis

Variation in lung function as a marker of adherence to oral and inhaled medication in cystic fibrosis

Helen White^{1,2}, Nicola Shaw², Sarah Denman², Kim Pollard², Sarah Wynne² and Daniel Gavin Peckham^{2,3}

Affiliations: ¹Nutrition and Dietetic Group, School of Clinical and Applied Science, Leeds Beckett University, Leeds, UK, ²Adult Cystic Fibrosis Unit, Leeds Teaching Hospitals NHS Trust, Leeds, UK, ³Leeds Institute of Biomedical and Clinical Sciences, Faculty of Medicine and Health, University of Leeds, Leeds, UK.

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@ERSpublications

The coefficient of variation of FEV₁ is a significant objective predictor of adherence in cystic fibrosis
<http://ow.ly/kcrb30752T3>

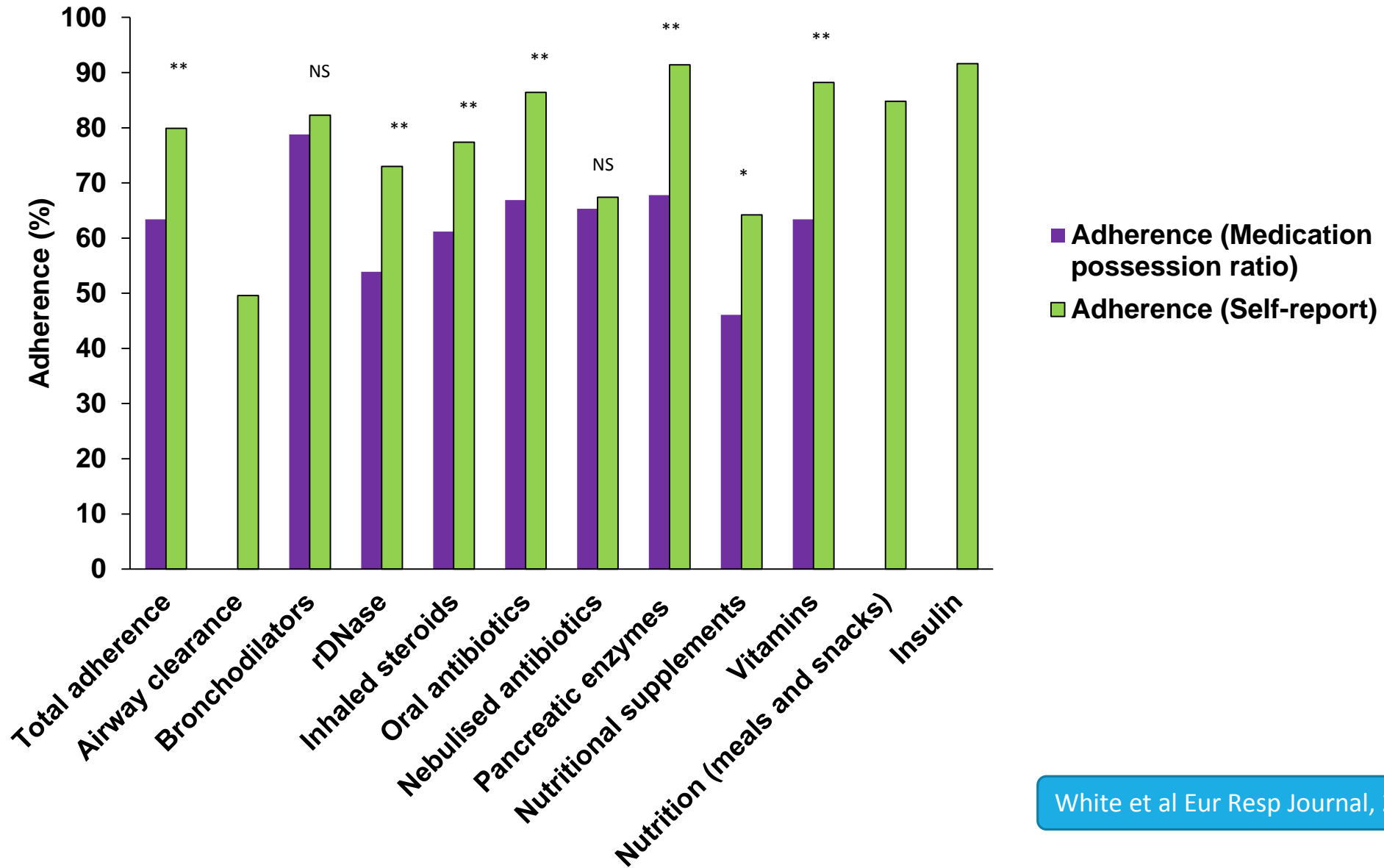
Cite this article as: White H, Shaw N, Denman S, et al. Variation in lung function as a marker of adherence to oral and inhaled medication in cystic fibrosis. *Eur Respir J* 2017; 49: 1600987 (<https://doi.org/10.1183/13993003.00087-2016>).

ABSTRACT The aim of this study was to characterise adherence in an adult population with cystic fibrosis (CF) and to investigate if variation in lung function was a predictor of adherence to treatment.

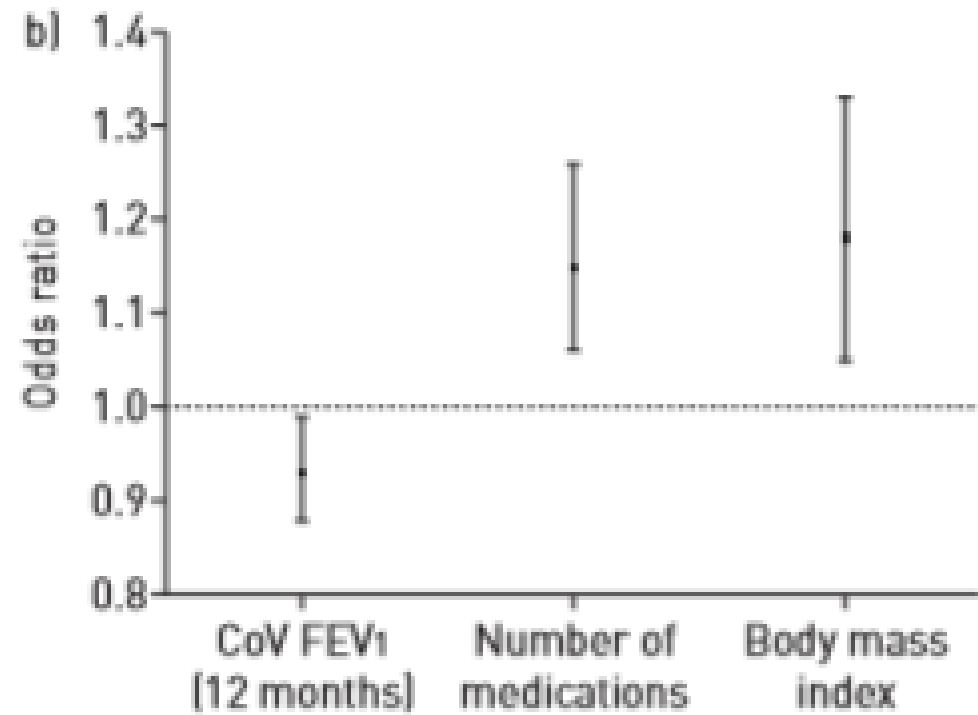
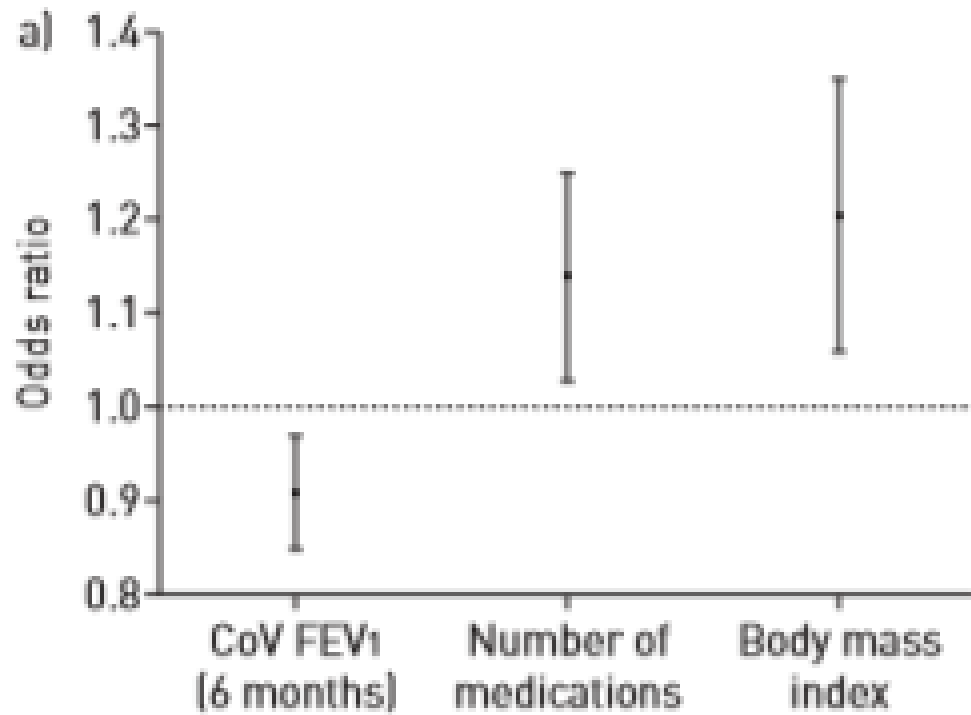
The adherence of patients aged ≥ 16 years from an adult CF centre was measured by medication possession ratio (MPR) and self-report. Patients were assigned to one of three adherence categories ($<50\%$, 50 to $<80\%$, $\geq 80\%$) by their composite score (MPR). Ordinal regression was used to identify predictors of adherence, including coefficient variation measures for forced expiratory volume in 1 s (FEV₁), weight and C-reactive protein concentration, measured from 6 months and 12 months before baseline.

MPR data for 106 of 249 patients (mean age 29.8 \pm 9.2 years) was retrieved, indicating a mean adherence of 63%. The coefficient of variation for FEV₁ was inversely related to adherence and was a univariate predictor of adherence (6 months: OR 0.92, 95% CI 0.87–0.98, $p=0.005$; 12 months: OR 0.94, 95% CI 0.93–0.99, $p=0.03$) and remained significant in the final models. The coefficient of variation of weight and C-reactive protein were not predictive of adherence.

The coefficient of variation of FEV₁ was identified as an objective predictor of adherence. Further evaluation of this potential marker of adherence is now required.



CoVFEV₁, Number of medications, BMI

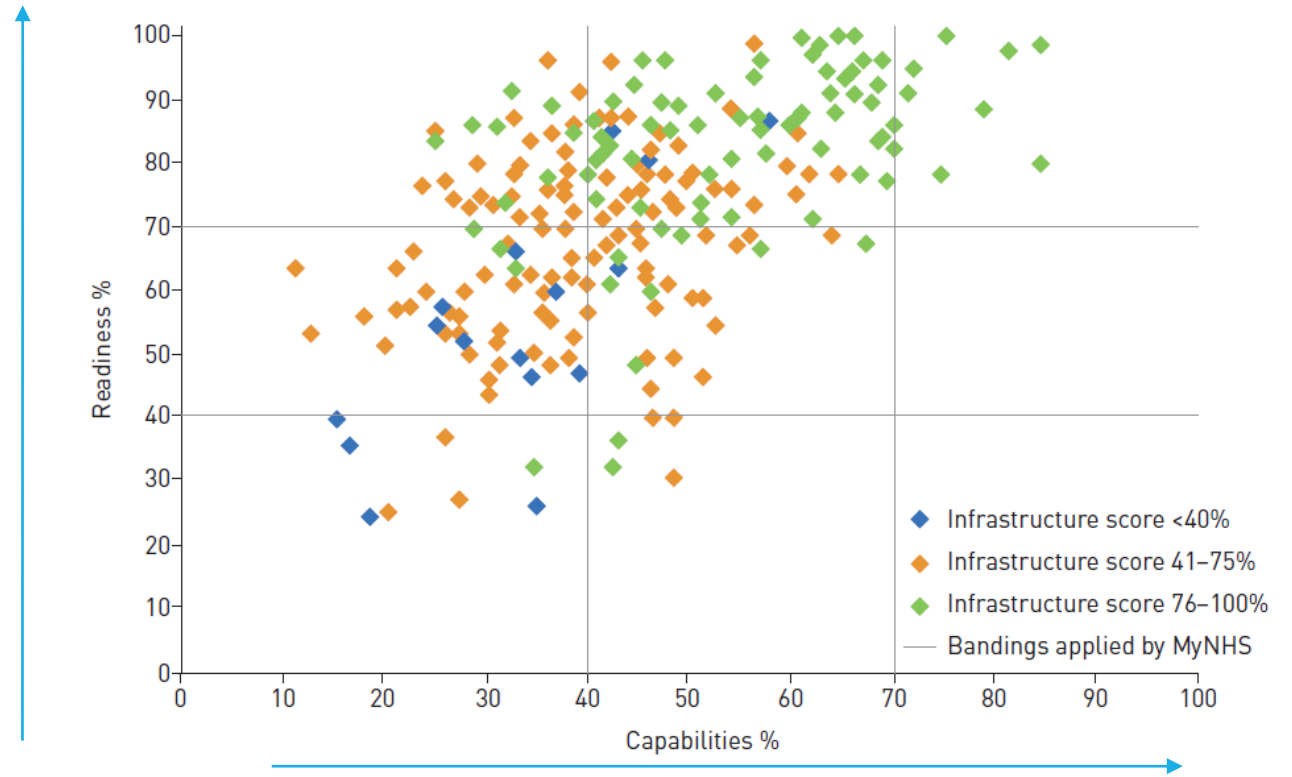


Digital Maturity Self-Assessment Survey (NHS England, 2016)

Challenges in maintaining anonymity and data security for data in transit and stored data are also a concern

Only 25% of the Sustainability and Transformation Partnership (STPs) with at least one trust with a high level of digital maturity (ie overall score above 80)

How well providers are able to plan and deploy digital services



Whether providers have staff with the digital skills needed

What might work?

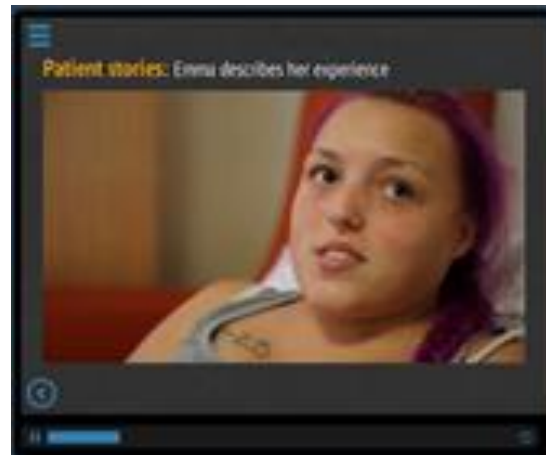
- ❖ Reported adherence rates in CF are as low as 40-50%
- ❖ In our own adult patient (n = 410) adherence is 63% (medication possession ratio) *White et al (2017)*
- ❖ On-line adherence programmes for adults with CF have not yet been fully evaluated
- ❖ We aimed to determine the impact on adherence of a web-based intervention for adults with CF

Evaluation of an RCT web-based intervention for adherence in cystic fibrosis

White H^{1,2}, Shaw N,³ Gillgrass L, Wood A,³ Chadwick H,² Peckham DG.^{2,3}
Leeds Beckett University,¹ University Leeds,²
Adult Cystic Fibrosis Unit (Leeds Teaching Hospitals Trust) Leeds, UK³

Phase 2 (Module development)

- ❖ On-line modules developed
- ❖ 40 video stories filmed and embedded giving reasons to change and motivations to take treatment eg
 - Parenthood
 - Further study
 - Availability for new treatments

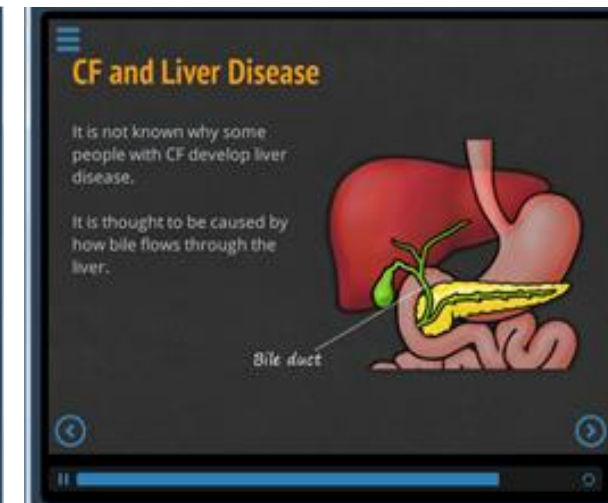
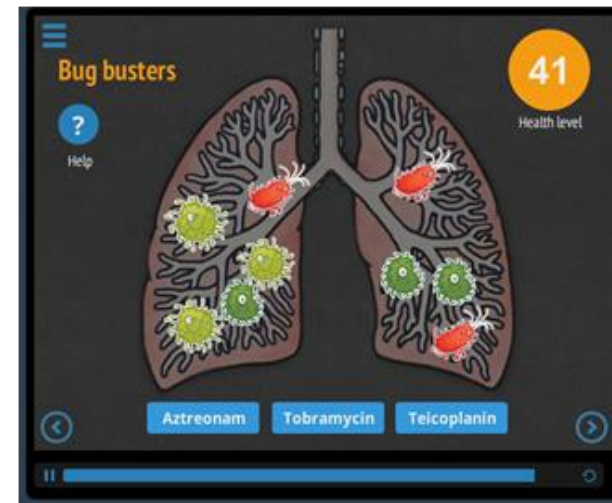
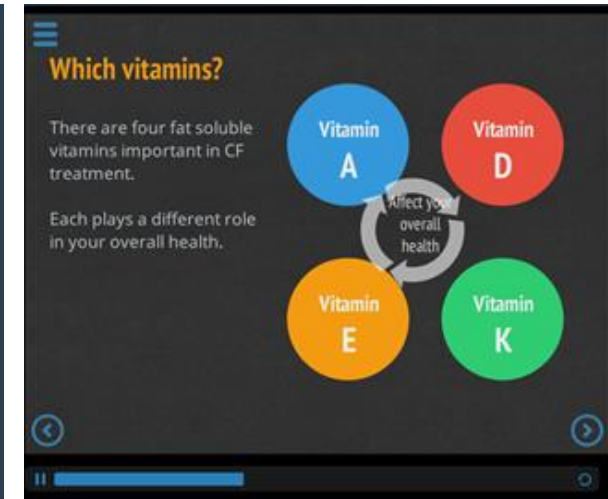
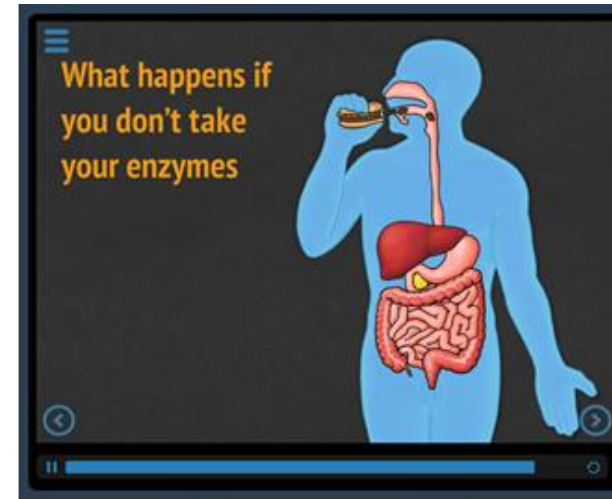
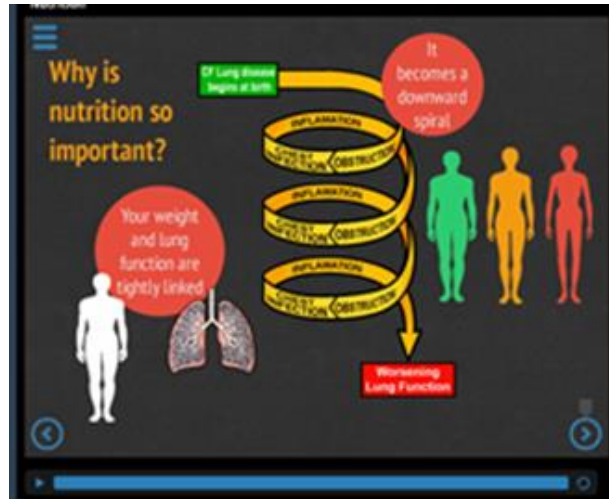


Development

Interactive material

Integrated 'drag & drop', games, quiz

- ❖ Nutrition
- ❖ Pancreatic enzyme replacement therapy
- ❖ Vitamins
- ❖ Airways & treatments
- ❖ Antibiotics
- ❖ Liver disease



3rd phase - RCT design

- ❖ Usual care or web-based intervention (n=100)
- ❖ Participants issued with tablet technology
- ❖ Granted structured access over 12 months
- ❖ Modules released at intervals
- ❖ Access tracked on-line
- ❖ Facility to gather participant feedback on the system



Results

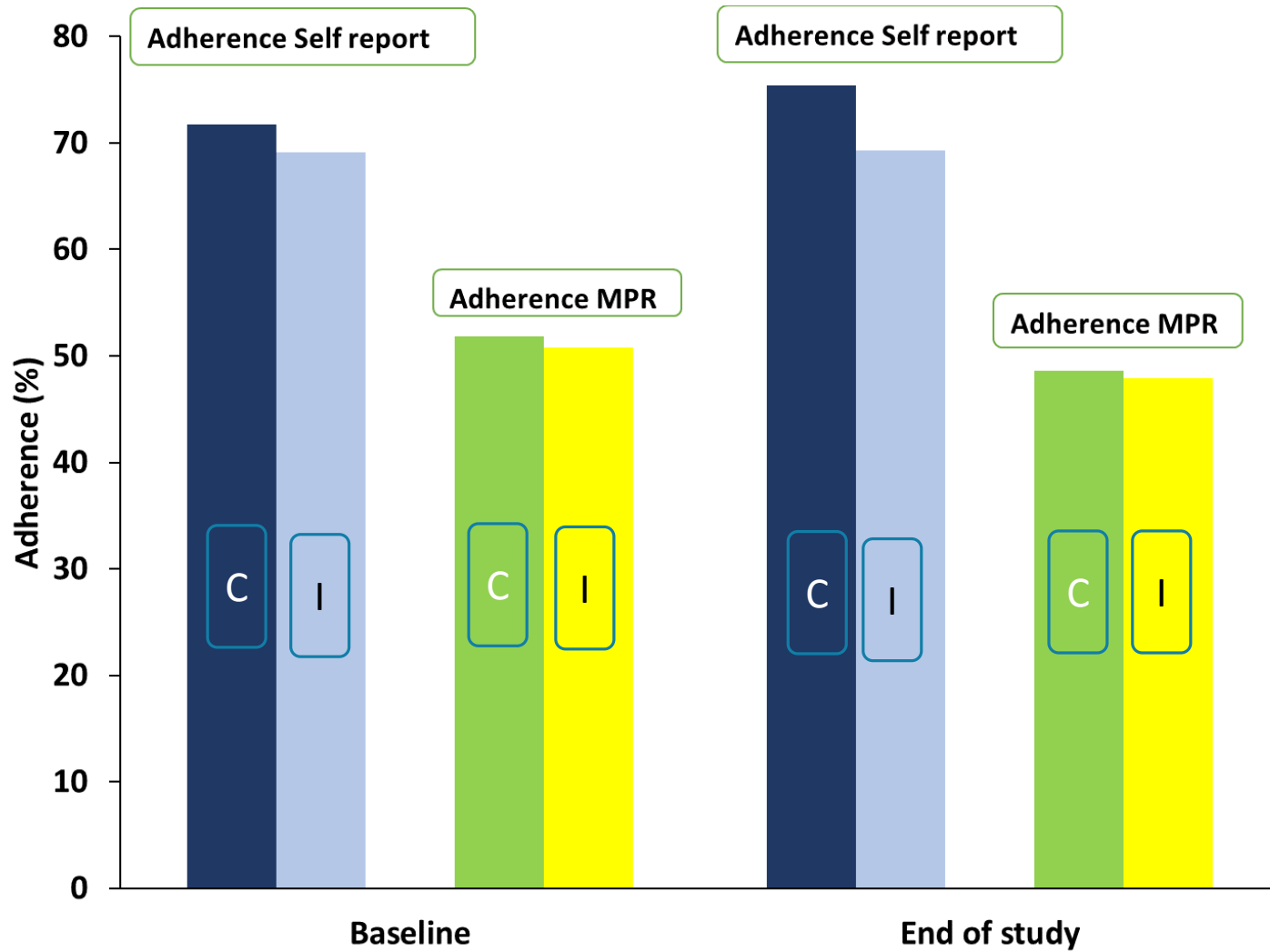
Data collected at baseline, 6 months and 1 year

- ❖ **Adherence (Medication possession ratio)***
- ❖ Knowledge questionnaire*
- ❖ QoL (CFQ-R)*
- ❖ Anthropometric data
- ❖ Respiratory function [FEV₁(%), FVC(%), FEV₁ rate of decline (%)and coefficient variation FEV₁ (%)
- ❖ Fat soluble vitamin status

* Collected at baseline and 1 year only

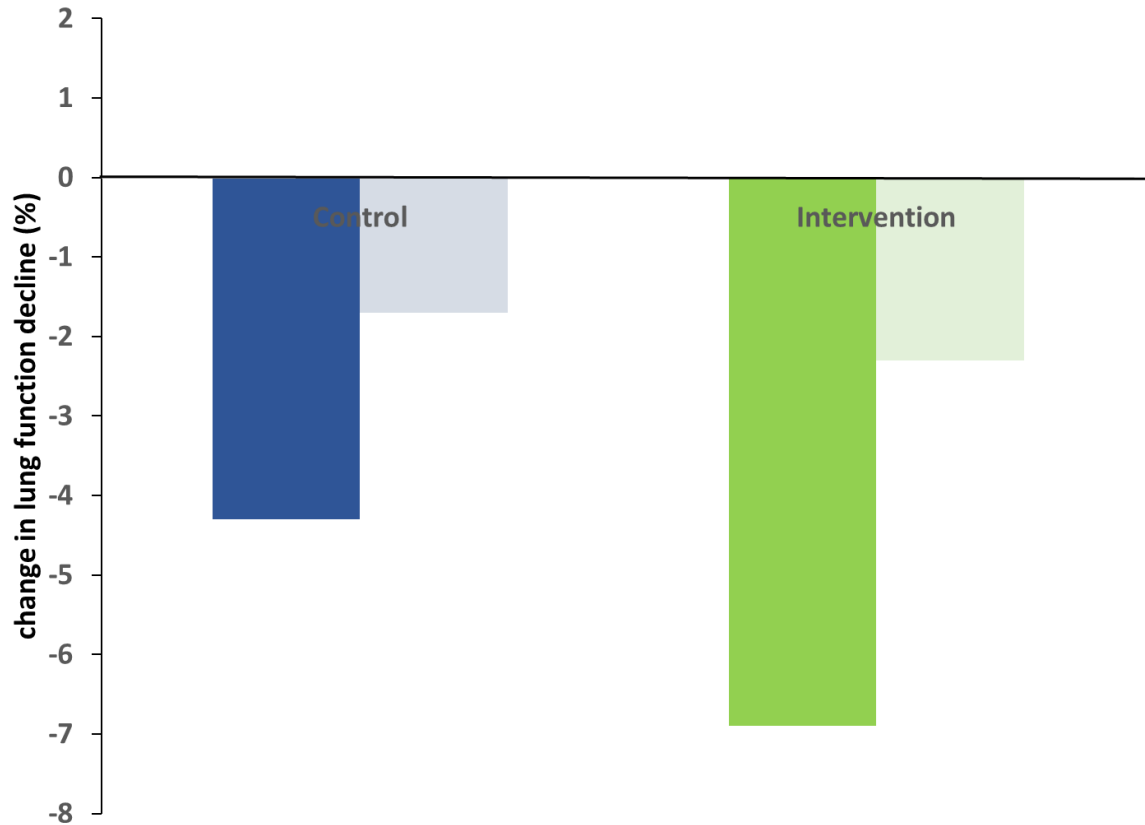
Subject Characteristics at baseline

N=100	Intervention	Control	P-value
Gender (male)	28 (51.6%)	15 (51.7%)	0.82
Age (years)	27.5 (\pm 6.8)	31.8 (\pm 9.1)	0.01
Pseudomonas	37 (75.5%)	33 (64.7%)	0.831
CFRD (check)	19 (39.5%)	17 (33.3%)	0.54
Genotype	30/15/4	33/13/5	0.84
DF508/DF508	61%/31%/8%	65%/25%/10%	
DF508/Other			
Other/Other			
FEV1(%)	47.8 (\pm 22.2)%	56.5(\pm 23.0)%	0.06
BMI (kg/m ²)	21.1 (\pm 2.9)	24.5 (\pm 5.1)	<0.001

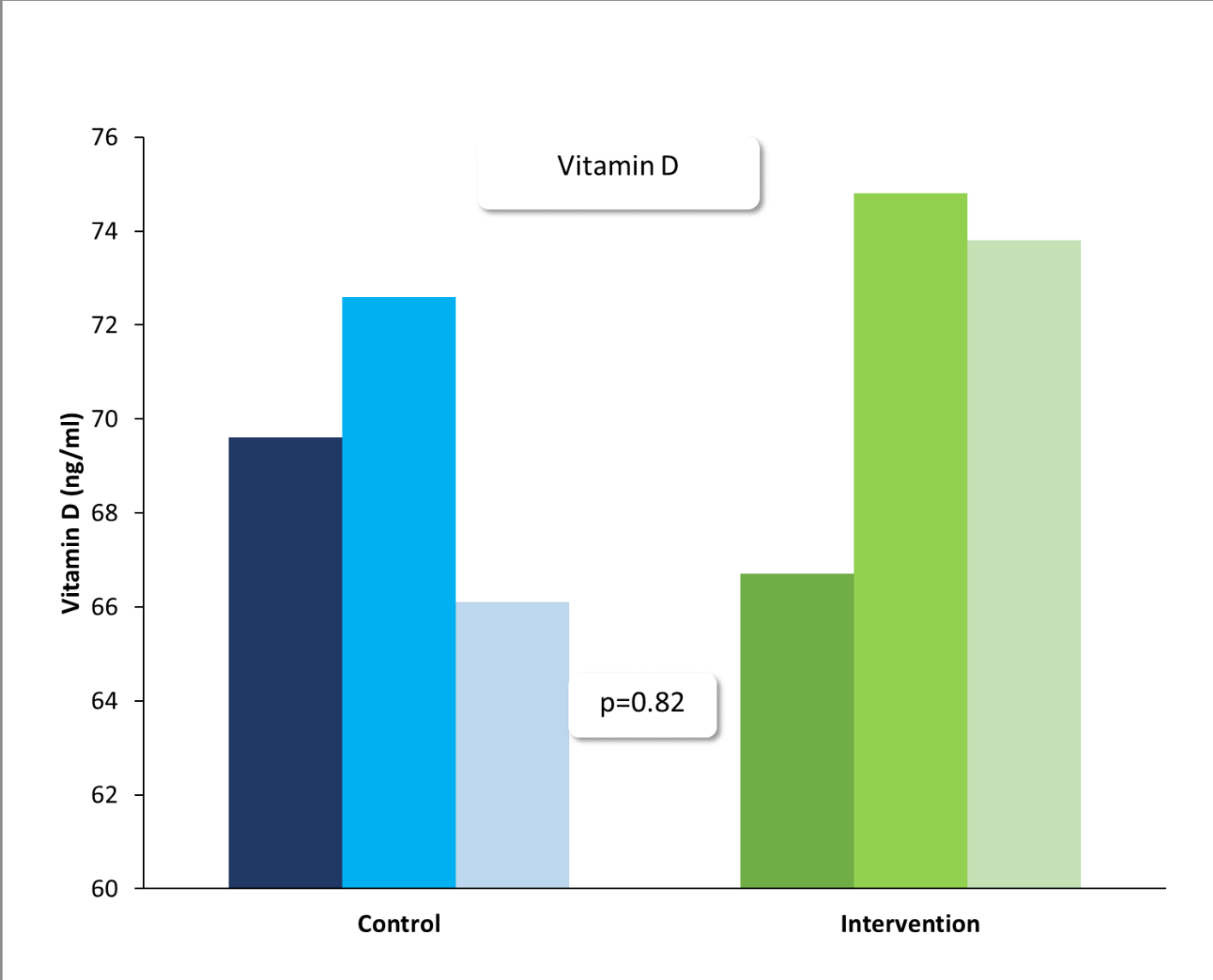
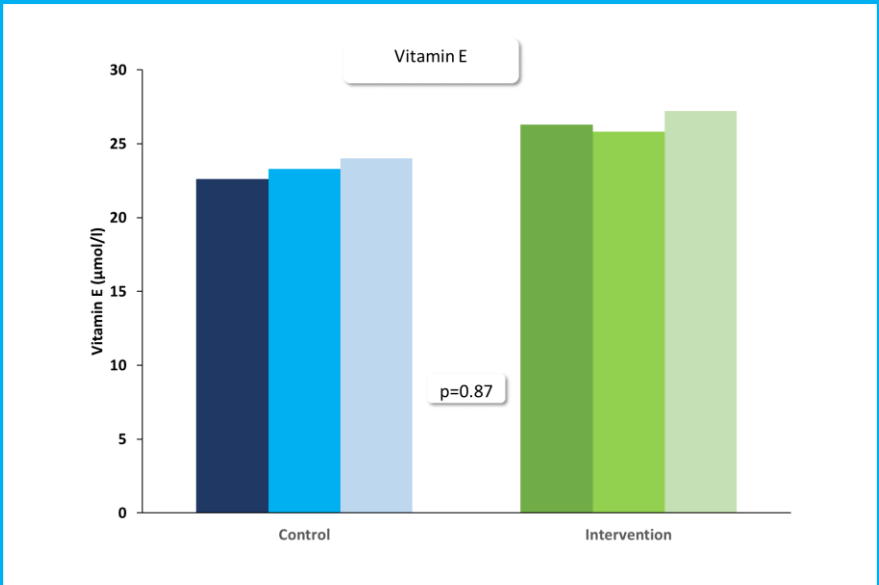
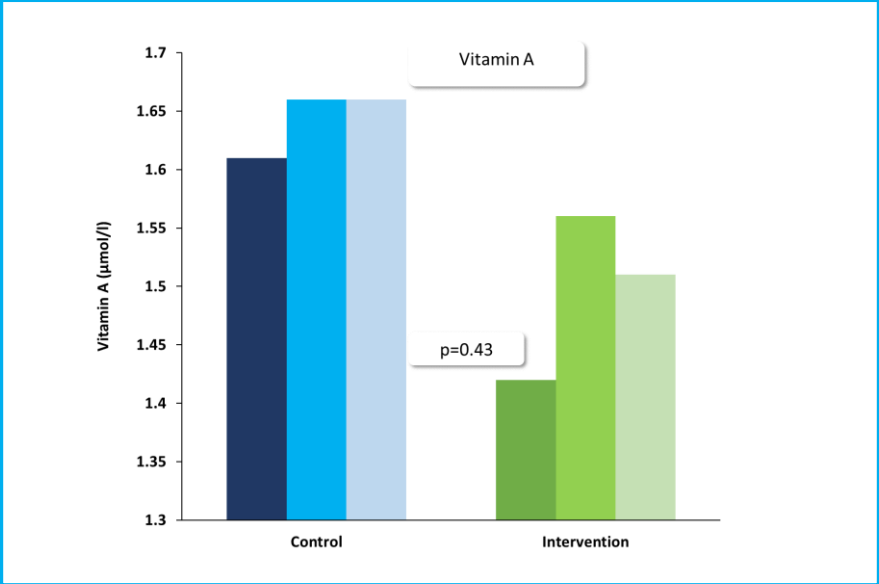


Adherence at
baseline and end
of study

Lung function



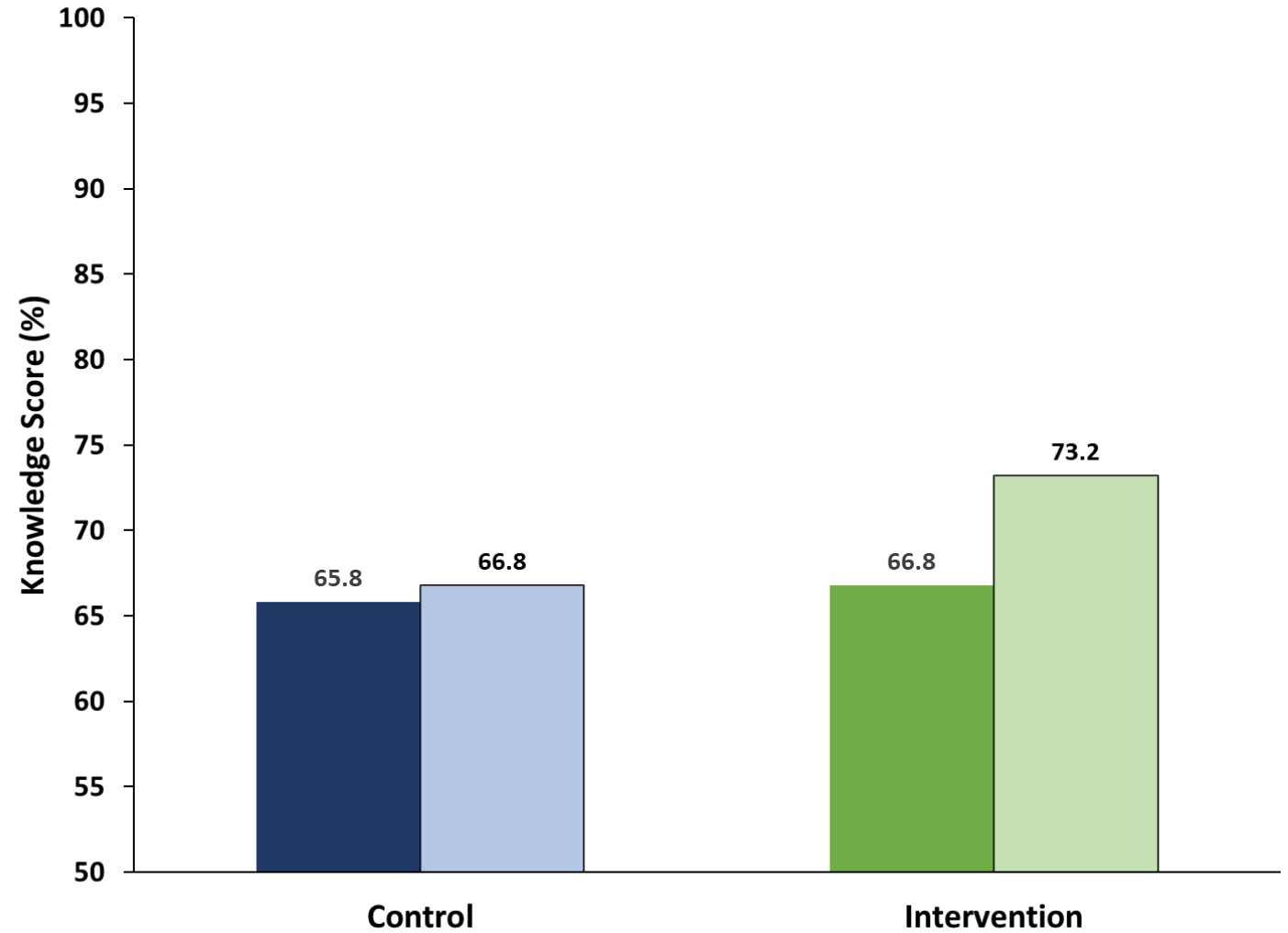
- No changes in
 - ❖ lung function,
 - ❖ variation in lung function or
 - ❖ rate of lung decline
 - ❖ 14 days
 - ❖ BMI
- above that of controls



Adjusted for BMI, Lung function and IV days at baseline

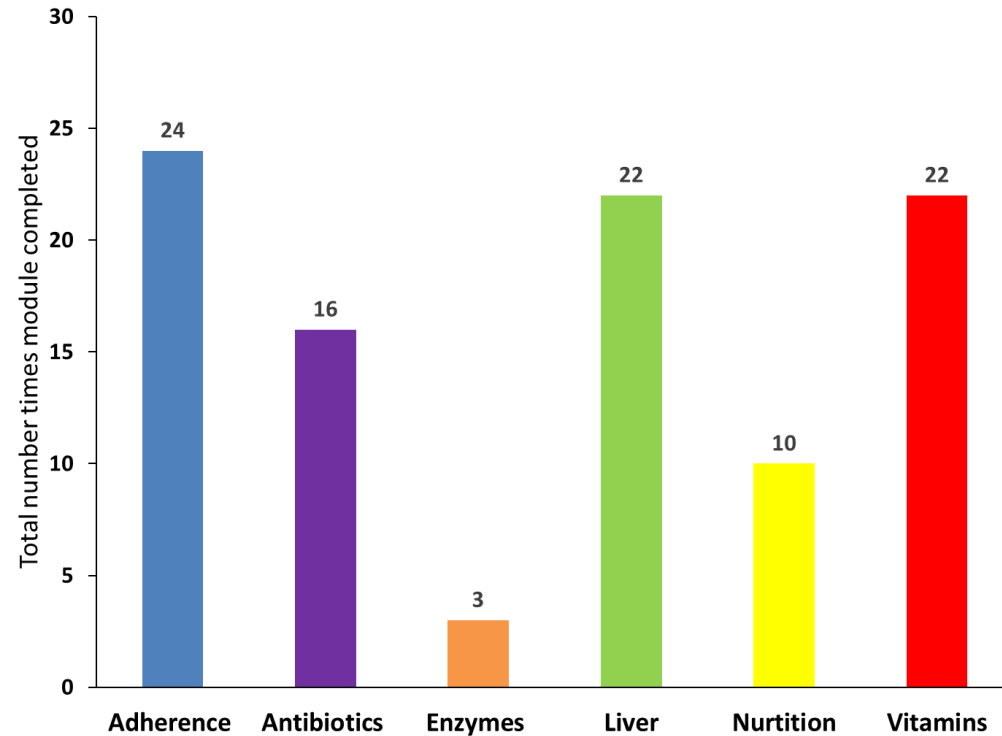
Knowledge

Significant increase in knowledge in intervention group compared to controls (p=0.046)

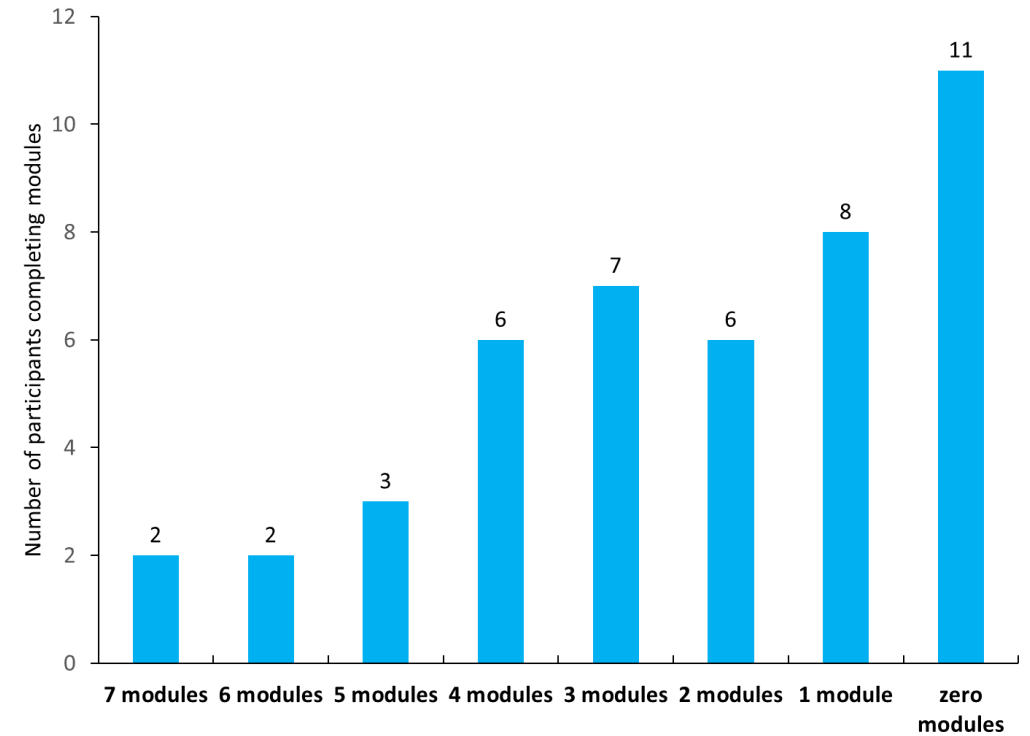


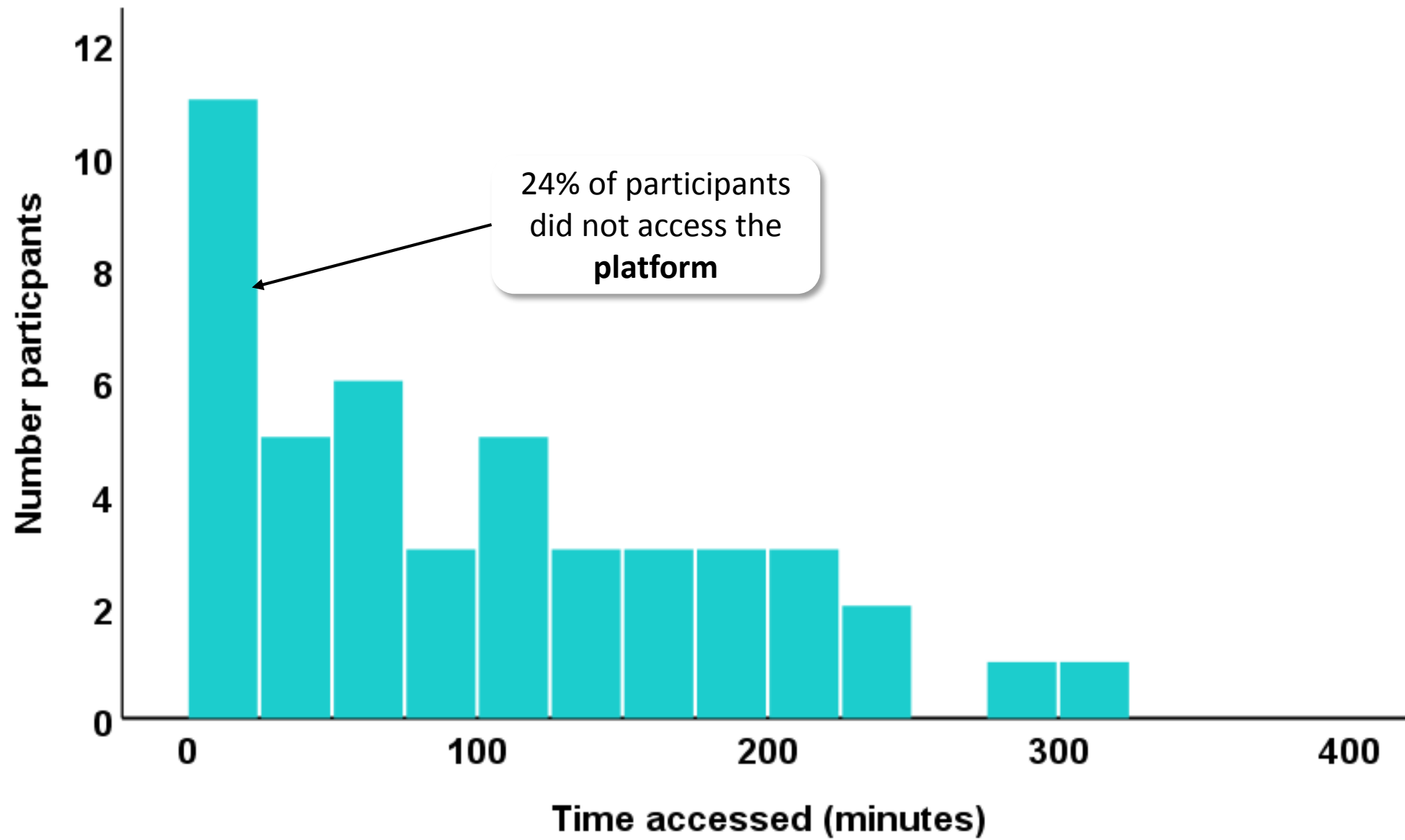
Engagement with the platform

TOTAL NUMBER OF TIMES MODULE COMPLETED

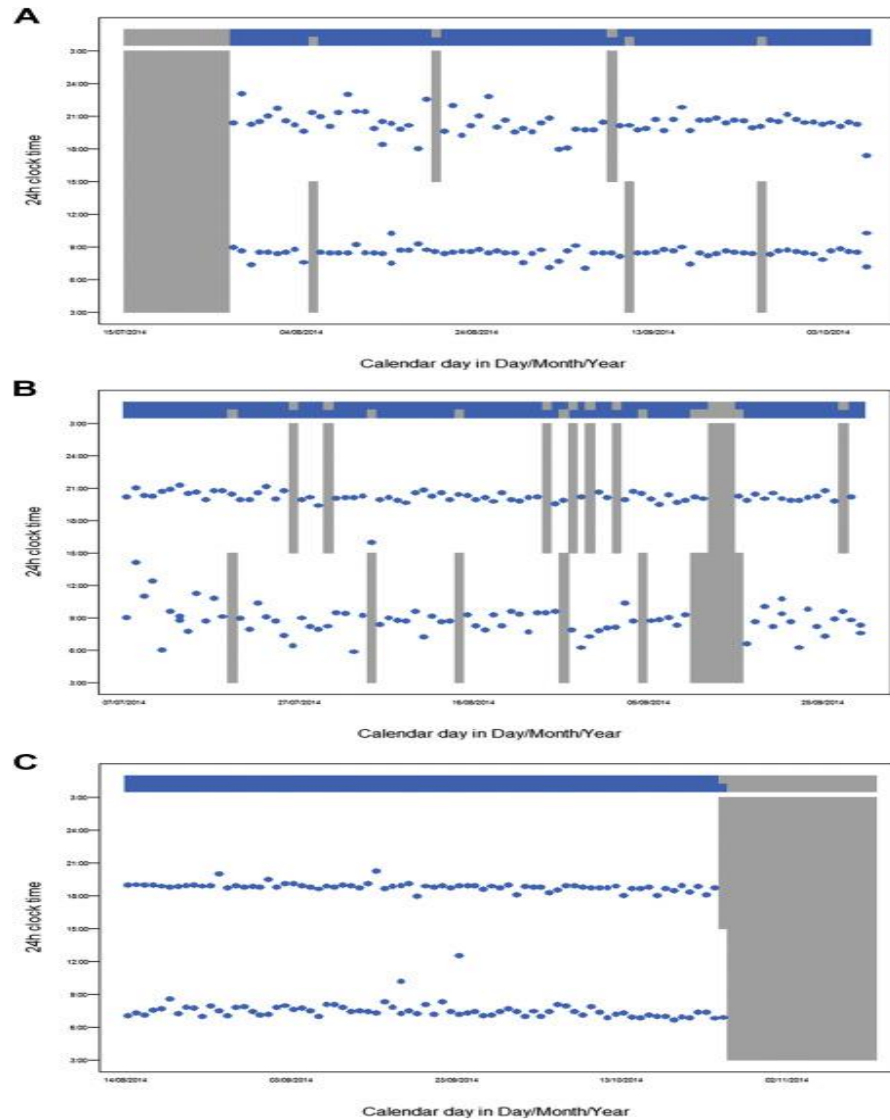


MODULE COMPLETIONS PER PARTICIPANT





Where next? Electronic monitoring



A, Patient with late initiation but good implementation.

B, Patient with suboptimal implementation (missed single and consecutive doses, large variability in timing of drug intakes).

C, Patient with excellent implementation but short persistence (early discontinuation).

CFHealthHub: Development and evaluation of an intervention to support adherence to treatment in adults with Cystic Fibrosis

- ❖ The aim of the programme is to develop and evaluate a complex behaviour change intervention (BCI) to support medication adherence for adults with Cystic Fibrosis (CF).
- ❖ The BCI includes the development of a web portal, CFHealthHub, to capture adherence data from patients' nebulisers and display this to clinicians and patients with CF (PWCF).
- ❖ CFHealthHub will facilitate a range of evidence-based interventions including **problem solving** and **setting implementation plans** to increase treatment adherence.

Patient engagement strategies

Synchronised dose
for multiple multiple
drug therapy

Self-management
self-monitoring &
problem solving

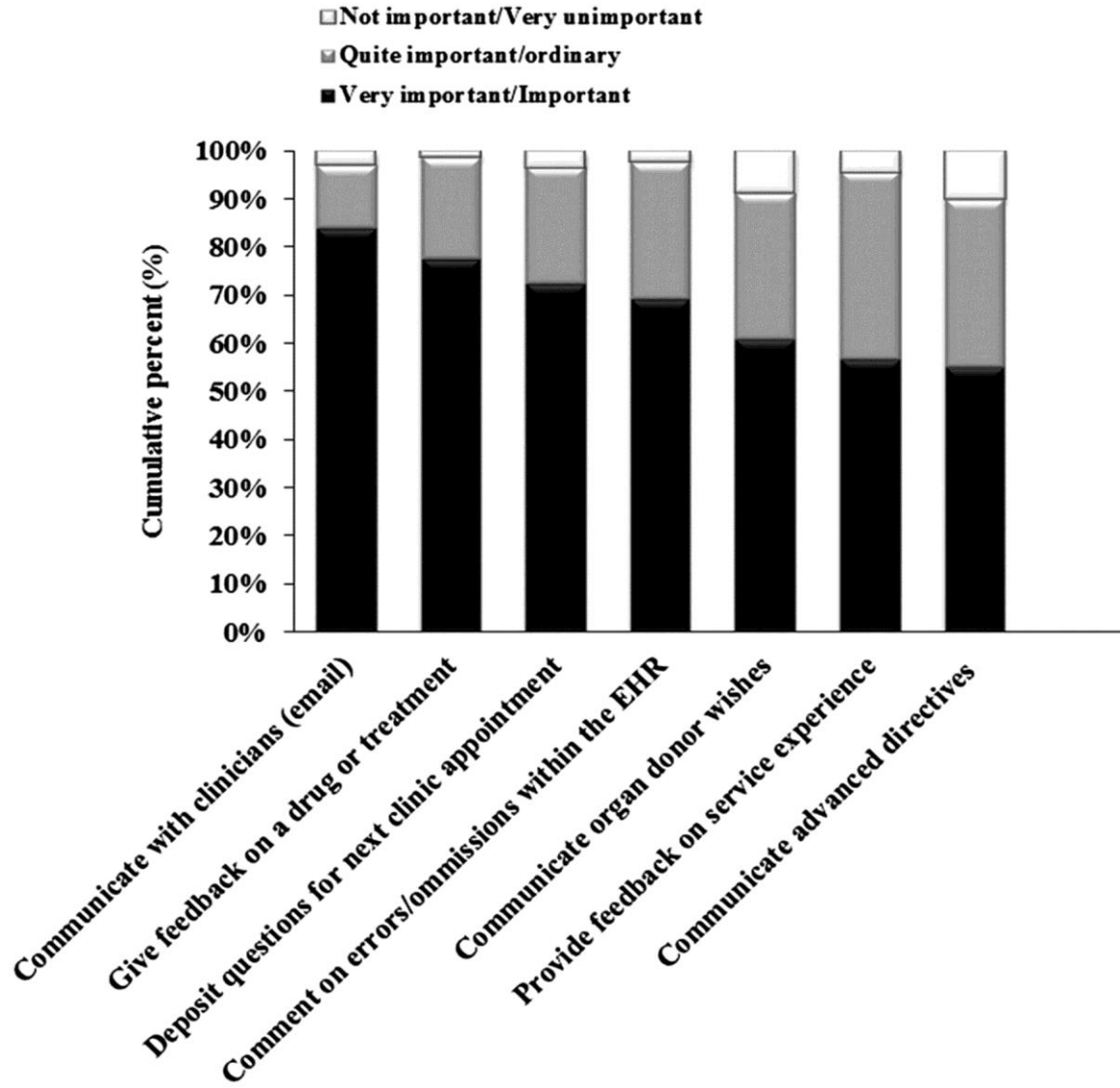
Use of action plans
(better knowledge
of the importance of
early intervention)



Improved
communication –
providing a rationale



Knowledge alone
rarely successful



Access to a secondary care clinical record?

Open Access

Research

BMJ Open Requirements and access needs of patients with chronic disease to their hospital electronic health record: results of a cross-sectional questionnaire survey

H White,¹ L Gillgrass,² A Wood,² D G Peckham³

To cite: White H, Gillgrass L, Wood A, et al. Requirements and access needs of patients with chronic disease to their hospital electronic health record: results of a cross-sectional questionnaire survey. *BMJ Open* 2016;6:e012257. doi:10.1136/bmjopen-2016-012257

► Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2016-012257>).

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ABSTRACT

Objectives: To identify patient's views on the functionality required for personalised access to the secondary care electronic health record (EHR) and their priorities for development.

Design: Quantitative analysis of a cross-sectional self-complete survey of patient views on required EHR functionality from a secondary care EHR, including a patient ranking of functionality.

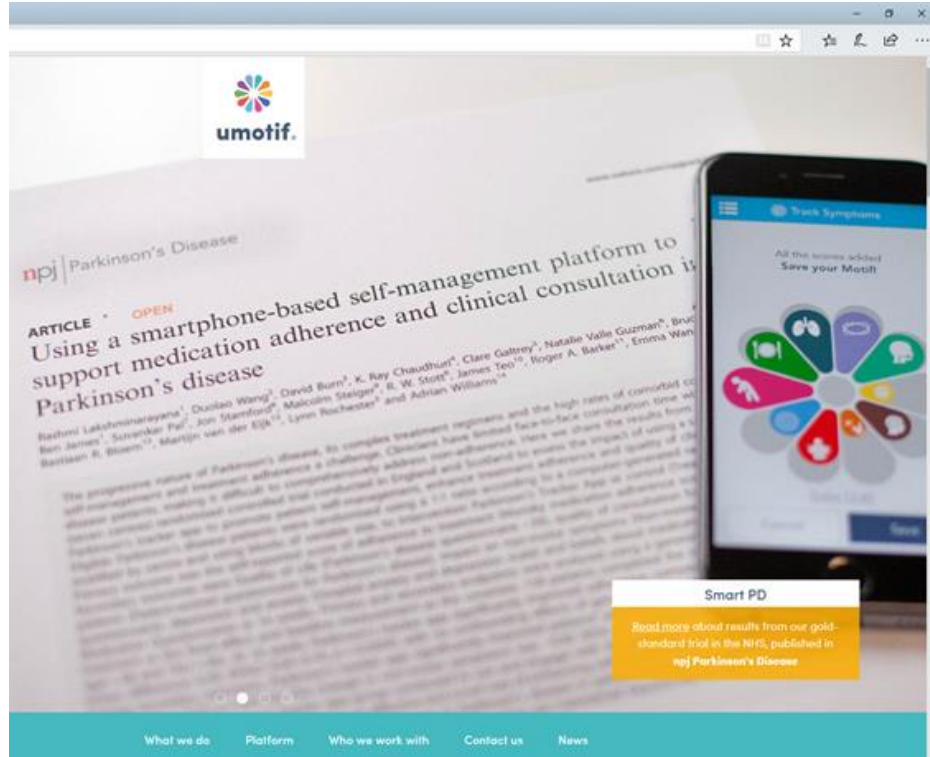
Setting: Secondary care patients attending a regional cystic fibrosis unit in the north of England.

Participants: 201 adults (106 (52.7%) males), median age 29 years (range 17–58 years), entered and completed the study. Inclusion criteria are as follows: a confirmed diagnosis of cystic fibrosis, aged 16 years and over, at the time of clinical stability.

Outcome measures: Quantitative responses within 4

Strengths and limitations of this study

- This is the first UK study to examine patient views and preferences to underpin the future developments of personalised access to a hospital electronic healthcare record.
- The strength of the study lies in its use of an informed, diverse patient population, familiar with the long-standing use of electronic health record (EHR) in their routine hospital care and able to provide views on a comprehensive range of access needs, sent information, communication and feedback requirements and ranking of priority areas for future development.
- The population studied were selected from a single chronic disease group with generic and also condition-specific access needs to their



Mobile apps - Umotif

Conclusion

- ❖ New technologies – used selectively when patients need and require them
- ❖ Collaborations – Apple Health – sending of data to the clinical record - addressing travel, out-patient waiting times and prompting early interventions
- ❖ Using electronic data to identify those patients who will benefit most