Self-management in Bronchiectasis: barriers and opportunities

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Thesis Abstract

A 2018 Cochrane systematic review of self-management for bronchiectasis found scarce, poor quality evidence. National Bronchiectasis Guidelines recommend self-management including '*basic principles of disease management*', recognition of exacerbation through health changes requiring action - either by self-initiation of treatment (airway clearance or antibiotic therapy) or seeking healthcare assistance.

Existing information sources and a new mixed-method randomised control trial were considered. The intervention aimed to improve self-efficacy in self-managing bronchiectasis. Outcomes were; quantitative patient reported outcomes; qualitative findings thematically analysed from participant focus groups, professional interviews and insights from participants during education. 220 people from 6 East of England hospitals with one or more exacerbations of bronchiectasis within 12 months participated. Randomisation was to treatment as usual alone or in addition to the Bronchiectasis Empowerment Tool (BET). Four brief telephone calls introduced BET which comprised an action plan, four educational sections: sputum, health changes, medications and health interactions (with notepads). Primary outcome at 12 months was the 6-item Self-Efficacy to Manage Chronic Disease Scale (SEMCD). Quantitative/economic data were collected quarterly via mailed self-reported questionnaires for one year. Participant focus groups investigated intervention acceptability and education comments exposed participants' self-management experiences.

Under-powered, with 12% greater than expected withdrawal the BET intervention did not measurably improve self-efficacy or secondary outcomes. BET did not affect SEMCD (mean difference (0.14 (95% confidence interval (95%CI) -0.37 to 0.64), p=0.59) and showed no significant difference in overall cost to NHS or in QALYs though participants valued the telephone education.

Recruitment success illustrates participant requirement for self-management support, withdrawals raise methodological questions such as literacy burdens (intervention and trial outcome measures). My contribution questions current evaluation methods for quality of life and self-efficacy in bronchiectasis, examining participant motivational needs, their healthcare and social insights, to elucidate the barriers and opportunities for self-efficacy and empowerment in future collaborative self-management.

Intellectual Property

This thesis was prepared by Claire Brockwell supervised by Dr Andrea Stöckl and Dr Mark Pasteur.

The Bronchiectasis Empowerment Tool study was conducted by Claire Brockwell with the support and advice of a steering group.
Details below:
Concept: the need for self-management support was identified by Dr Mark Pasteur.
Study Design and grant application: Was co-developed by Professor Andrew M Wilson and Claire Brockwell with the assistance of both the NIHR Research Design Service panel and one-to-one methodological advice from Dr Jean Craig and from patient and public advisors Patricia Mason and male advisor wishing to remain anonymous and PPIRes (also anonymous)

Conduct of the trial: Claire Brockwell conducted all aspects of the trial of which the grant holder and chief investigator was Dr Andrew M Wilson.

Data entry: Initial data entry was completed by Samantha Fulcher and subsequent double entry by Claire Brockwell.

Quantitative data analysis: statistical data was analysed by Dr Allan Clark and health economics by Professor Garry Barton.

Quantitative Interpretation: These have been summarised and interpreted by Claire Brockwell based on findings from Dr Allan Clark and Dr Garry Barton and guided by supervisory advice from Dr Mark Pasteur.

Qualitative data collection and analysis: These were collected and analysed by Claire Brockwell with review for rigour and supervisory advice from Dr Andrea Stöckl.

Qualitative interpretation: conducted by Claire Brockwell supervised by Dr Andrea Stöckl.

Author's note

As a nurse, researcher and PhD student I rely on information, communication and clinical evidence. In contrast, bronchiectasis identified in 1819 was a poorly researched condition until the last ten years. Guidelines for care published in the UK in 2010 (1) clearly identified gaps in knowledge that have renewed research interest and resulted in increased published findings. Though sharing the guideline information with those affected is advised within the document, the format and complexity may be more accessible to health professionals.

The professional standards of practice and behaviour for nurses and midwives set out the following behaviours relevant to self-management

code sections 2.1 to 2.3 pages 4 and 5(2)

> *'work in partnership with people to make sure you deliver care effectively]…[recognise and respect the contribution that people can make to their own health and wellbeing]…[encourage and empower people to share decisions about their treatment and care'*

Thesis structure

The introductory chapter provides the concepts and principles of self-management together with an overview of bronchiectasis. A literature review follows in chapter two exposing the paucity of guidance for the self-management of bronchiectasis. Chapter three using a quantitative methodology describes development of a novel intervention for self-management named the Bronchiectasis Empowerment Tool (BET) then evaluated via a randomised controlled trial. In the fourth chapter, a qualitative perspective is introduced. Qualitative aspects of this mixed-methods trial are explored from an interpretive perspective, seeking to understand the barriers and opportunities to self-management from the patients' perspectives and then from a professional outlook to identify process change opportunities. The concluding chapter reaches a revised position relating to self-management in bronchiectasis, arrived at using the original contribution to knowledge represented by the mixed method trial and synthesis of information within this thesis. Suggestions for future research are proposed to capitalise on these findings, promoting the development of effective, acceptable information to assist people with bronchiectasis in their self-management. Endorsement of self-management behaviours is required from healthcare providers whose principles, processes, policies and practice are likely to encourage high quality collaborative care.

TABLES OF CONTENTS

Chapter 1

Introduction to self-management in bronchiectasis

Chapter 2

Literature Review : self-management in bronchiectasis

Chapter 3

Randomised controlled trial evaluation of the BRONCHIECTASIS EMPOWERMENT TOOL (BET)

Chapter 4

Qualitative aspects of BET: Part 1

Participants' self-management insights

Chapter 4 continued

Qualitative aspects of BET: Part 2

FOCUS GROUP EVALUATION OF THE ACCEPTABILITY OF BET

Qualitative aspects of BET: Part 3

Health professional interviews

Chapter 5 Discussion, Conclusions & Future Directions

Opportunities for and barriers to self-management in bronchiectasis

Table of Tables

Table of figures

Supporting Documentation

Chapter 1

Introduction to self-management in bronchiectasis

Chapter 1

Introduction to self-management in bronchiectasis

Background

Chronic disease

The World Health Organisation (WHO) reports that globally 16 million people die prematurely largely of chronic diseases (3). Chronic respiratory diseases result in 4.2 million deaths annually (4). Wilkinson and Whitehead describe the effect of increased chronic disease prevalence on healthcare costs, workforce pressures and patient quality of life as driving the shift in healthcare policy toward greater involvement from the chronically ill in caring for themselves, namely self-care or self-management. Their paper highlights the conceptual shift in healthcare from *'responsibility for patients, to feeling responsible to patients'* (5). Pinnock et al. in their systematic meta-review of the evidence on supporting asthma self-management (6) suggest that for long term conditions (LTCs)

> *'Supporting self-management is inseparable from the high-quality care for LTCs. Commissioners and health-care providers should promote a culture of actively supporting self-management as a normal, expected, monitored and rewarded aspect of care. (6) page 6'*

Bronchiectasis

Thought in the past to be a rare (orphan) disease affecting a small percentage of the population bronchiectasis attracted little resource for innovation. People with this condition rely on information provided to them by individuals within healthcare though relatively few health professionals have specialist knowledge of bronchiectasis. De Soyza *et al.* in their 2013 paper identifying research priorities in bronchiectasis suggest that *'a network of specialised centres for patients with complex bronchiectasis would both stimulate research and improve patient care'* (7). De Soyza *et al.* declare epidemiology, pathogenesis and management of bronchiectasis as research priorities and point out that an impediment to research has been 'the heterogeneity of bronchiectasis due to significant variability in aetiology and clinical courses' (7). The diversity of healthcare delivery in the UK make it difficult to assess the quality of information received (8) though in asthma and chronic obstructive pulmonary disease (COPD) deficiencies in health professional knowledge have been acknowledged (9, 10).

The 2010 guideline for non-Cystic Fibrosis (CF) Bronchiectasis published by the British Thoracic Society defines bronchiectasis as *'patients with symptoms of persistent or recurrent bronchial sepsis related to irreversibly damaged and dilated bronchi'* (1). This chronic disease significantly affects quality of life and can lead to severe impairment of lung function and repeated hospitalisations (11). Admissions for treatment and visits to healthcare impact quality of life and are also significant healthcare costs (12-16) .People with symptoms of bronchiectasis cough, often with increased sputum production and repeated acute infections (1, 17, 18). The irreversible dilation of the bronchi, leads to chronic airway infection. This transition between acute illness with greater need for support followed by periods of more steady disease, permitting greater independence and autonomy, demands flexible, individualised, tailored support.

Annual bronchiectasis audits have taken place since the publication of the 2010 British Thoracic Society Guideline for non-CF bronchiectasis (1). The most recent audit of adult bronchiectasis published in 2018 for the period 0ct 2016 to Nov 2017 evaluated *'4845 clinical records from 105 hospitals (90 trusts) and 98 organisational records from 98 hospitals (86 trusts)'* (19). One of the key findings was *'infrequent use of written self-management plans in both paediatric and adult audits (around 40%)'* (19). The regular performance and evaluation of bronchiectasis audits and the creation and update of the British Thoracic Society bronchiectasis guideline (20) help push forward an agenda of innovation and quality improvement for people with bronchiectasis and their health services the period since 2010 has seen an exciting proliferation of bronchiectasis research enterprise.

First referred to in 1819 by Laennec (21), people with this condition still report suffering from repeated exacerbations that take a toll on all aspects of their lives (including life roles, employment and psychosocial wellbeing) (22, 23). Exacerbations are described by those affected as varying in intensity and duration, and can include change in sputum colour, density and volume, increased breathlessness, chest discomfort/pain, feeling unwell, exhaustion and cough.

A definition of bronchiectasis exacerbation for use in clinical trials was arrived at by an expert working group consisting of representatives from the European Multicentre Bronchiectasis Research Collaboration, the US Bronchiectasis Research Registry/COPD Foundation, Australasia and South Africa and published in 2017 (24) below.

> *'A person with bronchiectasis with a deterioration in three or more of the following key symptoms for at least 48 h: cough; sputum volume and/or consistency; sputum purulence; breathlessness and/or exercise tolerance; fatigue and/or malaise; haemoptysis AND a clinician determines that a change in bronchiectasis treatment is required.'*

Though this definition is helpful in ascribing a time period for the evaluation of symptoms, it has dealt a blow to self-management in its final requirement:

> *AND a clinician determines that a change in bronchiectasis treatment is required.'*

This appears to undermine the aims of bronchiectasis self-management, the ability to recognise an exacerbation and treat it swiftly as guidelines suggest (1) (Cochrane review of action plans for COPD suggest that this is possible (25). Emphasising the need for clinician determination is likely to maintain the demand on overstretched resources (26) needed to sanction the change in treatment rather than moderating healthcare use through collaboration education and self-management (27). Under-reporting of exacerbations data may also be an unfortunate consequence where reserve antibiotics are used but not after 'determination by a clinician' and hence not recorded on clinical systems (28-30).

The definition is framed in complex language though lay language is more likely to render this information accessible to those affected, families and friends assessing the situation in the first 48hrs. The Gunning Fog (Frequency of Gobbledygook) a readability test (31) used to evaluate whether text can be understood by the intended audience, suggests that for near universal understanding the index must be less than 8.

The definition as published has a Gunning Fog index of 13.6 whilst below a simplified version with an index of 6.0 is proposed.

> *a person with bronchiectasis with a worsening for at least 48 hrs of three or more of the following symptoms : cough; sputum volume, colour and/or texture; breathlessness and/or increasing shortness of breath when performing active tasks; feeling exhausted and/or unwell; coughing blood AND a clinician decides that a change in bronchiectasis treatment is needed.*

The advent of antibiotics in the early 20th century combined with improvements in science, socio-economic standard of living, and medicine in developed countries have facilitated a change of goal from mainly treating acute illness to the fostering of health, hence 'healthcare'. The improvement in population health has increased longevity and prevalence of chronic diseases such as bronchiectasis that have consequently altered the requirement for communication and collaborative skills in healthcare providers.

The roles of clinicians and patients have changed, people with chronic diseases are expected to manage their current and future help with guidance (32). This requires an alliance and trusting collaboration (33). The biomedical model of care focussing on disease, pathology and treatment inadequately matches the complex social, psychological and behavioural issues inherent in the complex care of chronic conditions (34). A more holistic model represented by the internationally acknowledged Chronic Care Model (35) appears successful in asthma (36).

During the 20th century advances in scientific diagnostic tools have permitted greater accuracy in diagnosis (37). Computerised x-ray transmission tomography (CT) is regarded as one of the most significant steps towards medical imaging in the 20th century (38, 39) it has facilitated the identification of lung damage in bronchiectasis (40) and more recently assist in one of the measures of bronchiectasis severity (41) Until recently the incidence and prevalence of bronchiectasis was largely unknown and the subject of controversy.

Chang *et al.* 2008 suggested a decline in bronchiectasis in affluent countries (42) as did O'Donnell in 2008 (43). Martínez-García and Soriano in 2009 (44) suggest that an increased lifespan puts people at risk of developing illnesses that might cause the lung damage categorised as bronchiectasis and described by Pasteur *et al.* (45). Stafler and Carr (46) in 2010 propose that increased diagnosis is due to heightened awareness and increasing availability of high resolution computed tomography. Seitz *et al.* note an increase in hospitalisation due to bronchiectasis (47). Quint *et al*. (48) in their UK based study published in 2015 report increased incidence and prevalence between 2004 and 2013 such that they report bronchiectasis as surprisingly common affecting over 1% of men and women over 70 but also more than 40 in 100,000 under the age of 30. There is even controversy as to which gender has the greater prevalence. Kwak *et al.* (49) explain that prevalence is thought to be higher in women and increases with age. In contrast Monteagudo *et al.* (50) in their study published in 2016 agreed that both prevalence and incidence increase with age but that they are highest in men over 65 years old.

Kwak *et al.* (49) report that the association of TB with bronchiectasis could explain the high prevalence of bronchiectasis in their adult Korean cohort. Suarez-Cuartin *et al.* (51) describe increasing incidence and prevalence throughout the world. Finally this year (2018) Chotirmall and Chalmers discuss a bronchiectasis epidemic (52).

The causes of bronchiectasis are many (51). Interventions to help people manage this heterogeneous disease (53) are needed (54). Flume *et al.* suggest that this heterogeneity creates difficulty in obtaining endpoints in clinical research (55). When conducting clinical trials, the greater the variation in a population the larger the sample-size needed to reflect that diversity, and therefore the greater need to recruit and retain participants within a study. A greater number of participants required in a study increases the need to engage multiple sites in the research, these sites may also vary in their availability and variety of health provision. Sample heterogeneity also presents a challenge when devising an intervention and evaluation. Without a clear characterisation of the population involved many questions present themselves. Do different presentations of disease within the sample of participants respond differently to the intervention? Does greater burden from co-morbidity or severity of disease inhibit completion of outcomes? Does the simplicity or complexity of the intervention and evaluation suit the participants? Are there age, gender or generational differences in response?

Interventions aimed at a broad spectrum of severity may only attract those who are affected enough by symptoms to wish to address them and who feel well enough to consider adding more responsibilities to their lives. Finally, evaluation methods are likely to influence trial participation.

Severity

When the intervention and evaluative study in this thesis were designed in 2010 there were no published measures of severity. There are now several Bronchiectasis Aetiology Comorbidity Index - BACI (56), Bronchiectasis Severity Index - BSI (57) not fully explored here due to their unavailability when the study took place, offer an opportunity to specifically target self-management interventions for bronchiectasis in the future. The FACED score (extract below) presented by Martinez-Garcia *et al.* in 2014 is a multidimensional score designed to represent a multidimensional disease. It involves collation of five separate variables that may present a procedural challenge in collection.

> *'The final seven-point score incorporates five dichotomised variables: forced expiratory volume in 1 s % predicted (F, cut-off 50%, maximum value 2 points); age (A, cut-off 70 years, maximum value 2 points); presence of chronic colonisation by Pseudomonas aeruginosa (C, dichotomic, maximum value 1 point); radiological extension (E, number of lobes affected, cut-off two lobes, maximum value 1 point); and dyspnoea (D, cut-off grade II on the Medical Research Council scale, maximum value 1 point).'*page 1357 (58)

The negative impact of exacerbations have been widely acknowledged (23, 59) but characterisation of the frequent exacerbator was not made in 2010. Martinez-Garcia *et al.* proposed *'the combination of two exacerbations or one hospitalisation per year'* (60) based on a large retrospective sample and published in 2018. Retrospective studies are lower on the evidence pyramid because bias can't be minimised by randomisation, diagnostic tools may be older and perhaps less accurate and treatment and healthcare provision may have changed.

The data available may be of variable quality and will have been collected for a different purpose that might affect accuracy. Martinez-Garcia et al. elaborated on the FACED score by considering exacerbations, arriving at E-FACED (61).

To permit individuals with this condition to promote their own wellbeing and care for their present and future health, support and education are required, the need to *'direct patients in becoming involved in their own care'* is advocated by the non-Cystic Fibrosis bronchiectasis guideline (1).

This year (2018) Hester *et al.* presented the unmet information needs of people with bronchiectasis in order to care for themselves (62, 63). She and her peers suggest that to develop effective resources

> *'the underlying needs and issues surrounding information and its uptake for patients with bronchiectasis must first be fully identified.'(63) page 7*

They also advise annual screening for depression and anxiety to identify those requiring additional psychological support. Coherent, accessible, reliable information, clearly communicated and drawn from evidenced interventions are needed to provide a solid foundation for people to self-manage bronchiectasis. This should enable clearer expectations, more fruitful interactions with healthcare and promote greater empowerment in collaboration to achieve personalised care and self-management.

Self-management in the UK

In the United Kingdom (UK) self-management as a concept and a policy has been successfully embedded in the treatment of diseases such as asthma, diabetes and heart disease for over twenty years (64) and more recently chronic obstructive pulmonary disease. This period of development has led to a proliferation of methods with which to meet the self-management, education and support needs of people who have chronic disease. Systematic reviews and meta-analyses summarise and critically analyse trials to evaluate compare and report their efficacy. A sample of systematic reviews and meta-analyses illustrate modalities in asthma self-management below:

For asthma: mobile phone interventions to support asthma self-management (65); peer-led self-management (66); interactive digital interventions (67); educating professionals to support self-management (68); support service from community pharmacists (69); self-monitoring of oxygen saturation levels using pulse oximeters (70); a healthcare perspective of self-management for asthma (6); internet-based support system (71); interventions to enhance the adoption of self-management behaviours (72); education and regular practitioner reviews (73).

The QUality Of Reporting Of Meta-analysis Quorum statement provides guidance on how meta-analyses should be conducted and presented (74) and the Prisma and Prisma–P statements relate to guidance and best practice relating to systematic reviews and meta-analyses (75, 76).

A more comprehensive list of Equator guidelines for the reporting of health research (77) is presented in the next chapter (literature review).

Patient activation and engagement

Barlow *et al.* note that self-management requires a movement away from paternalistic models of healthcare where patients were passive recipients (64). De Silva described the use of tools and techniques to support patient decision-making allied to a transformation in the patient-caregiver relationship to a collaborative partnership (78). This active involvement or ‘activation’ (79-82) of the patient requires the building of trust and rapport (p.195). Von Korff *et al.* 1997 describe the requirement for patients to be activated in order to be effective members of their own healthcare team, with the skills, knowledge and motivation to engage in the decision making required (83). By 2014 a systematic review performed by Simmons *et al.* (84) advocate that 'patient engagement should be quantified as part of a comprehensive health risk appraisal given its apparent value in helping individuals to self-manage effectively chronic disease' (p.1). There is little evidence in the literature search conducted here regarding the skills needed by the health professional or health team to engage, collaborate, support and motivate people with chronic disease as part of self-management.

Although joined-up services are frequently referred to in healthcare reform (85, 86), there have been few successful implementations although notable successes are the integration of falls assessments (87, 88) throughout care in England and pressure (ulcer) damage assessments (89-92). NHS England have a vested interest in patient activation. In '*The Patient Activation Narrative'* published in 2016 (93) NHS England discuss the establishment of the self-care support programme as part of a plan to assist the NHS in becoming *'better at helping people manage their own health'* enabling delivery of the *'Five Year Forward View'* (94*)*. The Patient Activation Measure (PAM) (95)is described as a validated tool to *'capture the extent to which people feel engaged and confident in taking care of their health'* (93) with the expectation that *'measuring and supporting improvements in patient activation locally will lead to patients having better outcomes'*(93).

This chapter explores the constituent elements involved in self-management such as the health environment, models of care, psychological concepts including motivation and gaining the confidence (self-efficacy) to collaborate with health providers. These elements impact on ability to manage symptoms, treatment and the ability to plan ahead. Self-management is defined, global and national health strategies reviewed including associated social, psychological and behavioural concepts. Barriers to self-management such as health literacy are considered, as are the impact of increasingly challenging health professional workloads on introduction of new concepts in treatment.

Health professional confidence may vary, learning and skill development (to maintain professional validity) may be relegated and take a back seat compared to the more urgent, continual and growing day-to-day clinical requirements of patient care.

Self-management

Although Creer *et al.* (96) first described self-management as part of asthma management, Bandura expanded and promoted self-regulation and health promotion using the self-management concept (97). Lorig and Holman (98) reinforce the inevitability of responsibility for 'day-to-day care and management in chronic disease' (p1) , they suggest that whether the person affected chooses to take an active role in their disease management or not is merely a different self-management style. Clark *et al.* (99) note the external and intrapersonal influences on the everyday process of therapeutic regulation of chronic disease and the self-regulation, self-observation and judgement necessary to improve health outcomes.

However, if people with bronchiectasis are unable to access or receive the care that they choose (and are advised is best), it may be less a personal self-management style (when disengaged) than apathy based on poor past experience. Self-care and self-management are terms often used interchangeably in various literature sources. Department of Health information favours self-care (100), published scientific papers refer to either term (101, 102).

Riegel *et al.* provide a comprehensive definition of self-care, dividing it into three constituent parts related to:

1. maintenance *'behaviours performed to improve well-being, preserve health and maintain physical and emotional stability' (*(103) p.196)
2. monitoring 'observing oneself for changes in signs and symptoms' ((103) p.196)
3. management '*response to signs and symptoms as they occur'* ((103) p.196)

Individuals govern their lives within monetary, environmental and psychosocial constraints.

Their learned expectations of the impact of their daily living may vary according to their life experiences and level of opportunity or deprivation. By the time chronic disease manifests disabling symptoms, poor health habits may be ingrained and difficult to change. Bandura (97) emphasises the increasing demand on healthcare resources as a result of damaging health habits.

He suggests that biomedical solutions are not the only ones with merit in addressing these issues and advocates a combination of researcher and practitioner collaboration. Syddall *et al.* (104) emphasise the relation between poor health behaviours as predictors of hospital admission and advocate life-course interventions to encourage the formation of behaviours known to have a beneficial impact on health in later life. The multiple influences of 'individual's place of care and residency, previous experiences, skills, coping strategies, confidence, cognitive status and level of caregiver support' ((105) p.2) on capacity for self-care are emphasised by Clark *et al.* (99). Engaging adaptive capacity and building resilience (106) should help translate theory into practical achievable steps to support self-management.

Education in self-management and adoption of health promoting actions and behaviours have the potential to assist those with chronic disease to minimise symptoms and reduce the rate and severity of disease progression, thus promoting and preserving quality of life (107). In asthma, despite interventions targeting management, treatment still often remains problematic according to Perez *et al.* who highlighted that patients who poorly navigate healthcare were also likely to have issues of literacy and poor understanding and technique in using inhalers (108). Health is influenced by environment, behaviours and genetic make-up (109).

Behaviour is therefore often targeted as the element most open to change. Improvement of these health behaviours may help compress the time between morbidity and mortality as explained by Fries (110). Health psychology explores the links between social, behavioural, biological and psychological factors (111). The link between thoughts, experience and behaviour are of importance in achieving self-management.

Initially, trust (112, 113) and collaboration (114) are required in order to promote an environment in which curiosity and learning, a relatively effortful (115) and energy consuming process, are engaged by both the health provider learning and appreciating the individual's personal priorities and by the person affected by chronic disease. Those affected by bronchiectasis have to evaluate risk, manage symptoms and seek help. Bourbeau *et al.* suggest that patient education facilitates the learning of healthy behaviour (116, 117). Adaptation to chronic disease can be difficult. Akyil *et al.* suggest that Roy's adaptation model assists with role-function, self-concept and physiological adjustment (118).

Pulmonary rehabilitation

Success in behaviour change has been achieved utilising pulmonary rehabilitation. This programme, with the greatest focus on physiotherapy and physical activity improves health related quality of life and symptoms in chronic obstructive pulmonary disease (the frequency of intervention is recommended to be 20 sessions within eight weeks). The concept consists of a multi-disciplinary approach and includes education about the disease, treatment management and recognition and action with regard to exacerbation. Güell *et al.* (119) call for a standardisation of quality indicators for the delivery of pulmonary rehabilitation to permit effective and extensive comparable treatment. Challenges for pulmonary rehabilitation have been in providing sessions close enough to home so that participants are able to attend (or in the provision of transport) (120), the cost of providing high quality multi-disciplinary care from ever more restrictive budgets (121), retaining participants for the duration of the programme when exacerbations frequently result in missed sessions (122) and maintaining benefits and good habits (123) although the creation of 'lung clubs' to maintain social and physical activity may bridge this gap. Discussion with people attending respiratory outpatient services who have been referred at some point to pulmonary rehabilitation frequently refers to increased confidence gained through improved exercise capacity under helpful encouragement of specialist staff in a safe environment where embarrassment due to symptoms and limited capacity are minimised.

In chronic conditions such as diabetes and heart disease a variety of evidence-based approaches are available from which to select a suitable format for the individual faced with self-management. The British Thoracic Society Guidelines for Bronchiectasis of 2010 advocate self-management (1).

Disappointingly the recently published European Respiratory Society guidelines for the management of adult bronchiectasis (124) do not refer to self-management.

Careful consideration of the self-management approach, allied with the environment and resources available to the healthcare team and patient are required in order to achieve success. A common foundation of understanding and goals are necessary to enhance the shift toward collaborative health, guiding patient and health provider actions for the maintenance of health in bronchiectasis. Current models of continuing professional development in health require self-identification of learning needs. Whilst permitting flexibility, this training model may also present added time pressure, burden of choice, and require objectivity. Altogether these issues are unlikely to foster uniformly high standards of specialist knowledge especially as time from graduation allows knowledge to fade.

Health environment

The Global economic downturn exerts greater pressure on the effective use of funds as opportunities for improvements in health. Financial constraints are factors affecting the influence of research evidence on policy and decision making (125). A greater alignment of research with policy is necessitated in order to expedite implementation and provide the basis of evidence-based practice (126). This thesis explores opportunities and threats to self-management in bronchiectasis within the United Kingdom, hence the NHS Five Year Forward View published in 2014 (94) is considered here

The document footer lists the following organisations: Care Quality Commission, NHS Health Education England, Monitor, NHS England, Public Health England and finally the Trust Development Authority (no steering group or authors are credited). Appendix 1 shows the structure of health and care in 2013. Table 1 displays a number of extracts from the document of relevance to self-management in chronic disease. Themes identified in the table are: empowerment of patients (ch 2 p12) by supporting people in *'making informed choices of treatment, managing conditions and avoiding complications.'* Also stating that the NHS *'requires a partnership with patients over the long term'* to care for long term conditions (ch3, p16). In (ch2, p14) a social movement to *'help shift power to patients'* is suggested.

Table 1: Extracts from the NHS Five year forward plan

Extracts from the document relevant to chronic disease and/or self-management				
No	**Section**		**Page**	**Relevant Passage**
1	Foreword		2	*'commitment to universal healthcare'*
2	Executive Summary		3 (5)	*'patients will gain far greater control of their own care'*
3	Executive Summary		4 (7)	*'England is too diverse for a 'one size fits all' care model'*
4	Executive Summary		4 (8)	Multispeciality Community Provider *'GPs to combine with nurses, other community health services, hospital specialists and perhaps mental health and social care to create integrated out-of-hospital care'*
5	Executive Summary		4 (9)	Primary and Acute Care Systems combining general practice and hospital services
6	Chapter 1		6	*'Changes in patients' health needs and personal preferences. Long term health conditions...now take 70% of the health service budget.'*
7	Chapter 1		6	*'many (but not all) people wish to be more informed and involved with their own care, challenging the traditional divide between patients and professionals, and offering opportunities for better health through increased prevention and supported self-care.'*
8	Chapter 1		6	*'breaking out of the artificial boundaries between hospitals and primary care, between generalists and specialists - all of which get in the way of care that is genuinely coordinated around what people need and want.'*
9	Chapter 1		7	Readily accessible GP services
10	Chapter 1		7	*'harness technology, and drive down variations in quality and safety of care,'*
11	Chapter 1		7	*'a future that empowers patients to take much more control over their own care and treatment'*
12	Chapter 1		8	*'organised to support people with multiple health conditions'*
13	Chapter 1	Box1. Ambitions on quality	8	*'Narrow the gap between best and worst'* (quality)
14	Chapter 1	Box1. Ambitions on quality	8	*'To reduce variations in when patients receive care'* (7 day services)
15	Chapter 2	Empowering patients	12	NHS patients' organisation National voices:*'personalised care will only happen when statutory services recognise that patients' own life goals are what count; that services need to support families, carers and communities; that promoting wellbeing and independence need to be the key outcomes of care; and that patients and their families and carers are often 'experts by experience'.'*
16	Chapter 2	Empowering patients	12	*'we will do more to support people to manage their own health-staying healthy, making informed choices of treatment, managing conditions and avoiding complications.'*
17	Chapter 2	Empowering patients	12	*'With the help of voluntary sector partners, we will invest significantly in evidence-based approaches such as group-based education for specific conditions and self-management educational courses, as well as encouraging independent peer-to-peer communities to emerge.'*
18	Chapter 2	Empowering patients	12	*'increase the direct control patients have over the care that is provided to them.'*
19	Chapter 2	The NHS as a social movement	14	*'help shift power to patients and citizens, strengthen communities, improve health and wellbeing, and - as a by-product-help moderate rising demands on the NHS.'*
20	Chapter 2	The NHS as a social movement	15	*'slow burn, high impact' actions are now essential'*
21	Chapter 3	New Models of care	16	*'divide between primary care, community services, and hospitals... are increasingly a barrier to the personalised and coordinated health services that patients need.'*
22	Chapter 3		16	*'Long term conditions are now a central task of the NHS; caring for these needs requires a partnership with patients over the long term'*
23	Chapter 3		16	*'Increasingly we need to manage systems – networks of care – not just organisations.'*
24	Chapter 3		16	*'And as we introduce them, we need to evaluate new care models to establish which produce the best experience for patients and the best value for money.'*
25	Chapter 3	One size fits all?	17	*'to meet the changing needs of patients, to capitalise on the opportunities presented by new technologies and treatments, and to unleash system efficiencies more widely, we intend to support and stimulate the creation of a number of major new care models that can be deployed in different combinations locally across England.'*
26	Chapter 3	New care model	21	*'Over the next five years, the NHS will do far better at organising and simplifying the system.'*
27	Chapter 4	Information revolution	31	*'the NHS has oscillated between two opposite approaches to information technology adoption'* 1. *'highly centralised'* 2. *'systems that don't talk to each other, and a failure to harness the shared benefits that come from interoperable systems'*
28	Chapter 4	Information revolution	31	*'we will focus on the key systems that provide the 'electronic glue''* *'To lead this sector-wide approach a National Information Board has been established'*
29	Chapter 4	Information revolution	31	*' An expanding set of NHS accredited health apps that patients will be able to use to organise and manage their own health and care; and the development of partnerships with the voluntary sector and industry to support digital inclusion.'*
30	Chapter 4	Information revolution	31	*'Fully interoperable electronic health records so that patients' records are largely paperless. Patients will have full access to these records, and be able to write into them.'*
31	Chapter 4	accelerated health innovation	33	*'Medicine is becoming more tailored to the individual'*
32	Chapter 4	accelerated health innovation	33	*'we are committed to accelerating the quicker adoption of cost-effective innovation -both medicines and medtech.'*

The table's extracts display a recognition from UK healthcare organisations of the issues faced by people with chronic disease and the necessity for innovative solutions to address them. This bodes well for the introduction of self-management support in bronchiectasis.
Released in April 2017 the NHS England research plan pledged to '*advance equality of opportunity'* and also to '*support NHS transformation*' '*addressing the future needs of patients and local NHS* systems' linking the various multi-disciplinary requirements of bronchiectasis through patient-held self-management records and advice aligns well with this national plan.

The long-term sustainability of the NHS within the UK has been the focus of an enquiry by a House of Lords Select Committee that concluded in April 2014 (127). To protect this tax-funded system, which is free at point of need an evaluation into its long-term sustainability was initiated. The select committee's enquiry, lasting twelve months included the review of oral evidence from 100 witnesses and 192 written submissions. Overall the committee advised moving from short term fixes to long term planning provided by an independent 'Office for Health and Care Sustainability' guiding a fifteen to twenty year evaluation and implementation cycle. The committee suggests that this Office would elevate strategic decisions away from the impediment of day-to-day struggles, thus enabling cohesive long-term workforce planning, realistic and consistent funding for services including public health and prevention, translation of research and innovation to practice and reduction in variation of patient outcomes to achieve improved cohesion and efficiency.

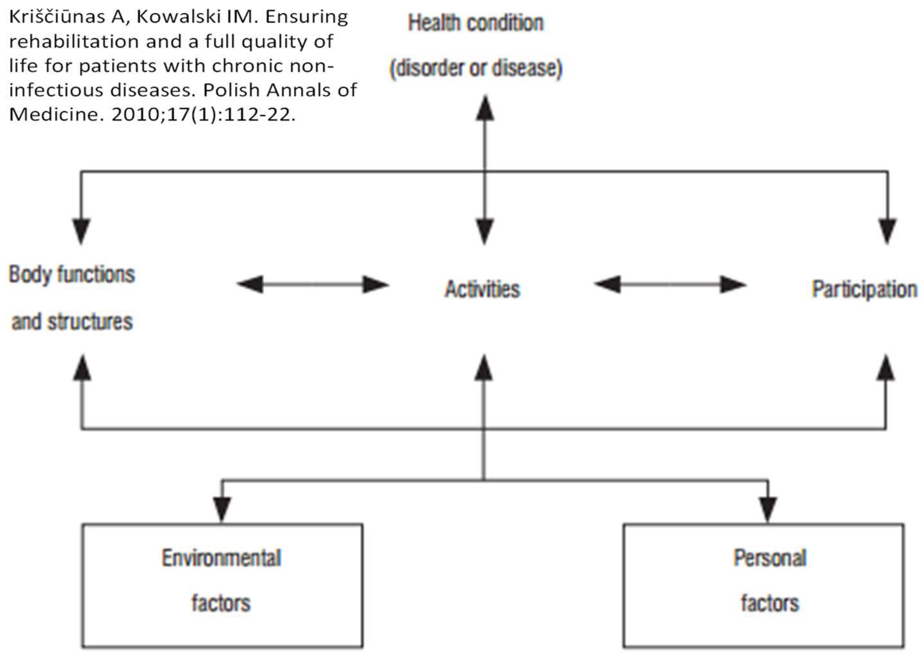
A model of care is the structure from which healthcare is delivered, it's guiding principles influenced by the perspectives of the creators. Many different models relating to self-management and to chronic disease exist, a few are considered here (128-133). Chronic diseases are without cure (99). The WHO have created a truly cross-cultural, multidisciplinary, global inclusive approach to the measurement of the long-term consequences of disease in 1980 (134). A refined version of this common language, systematic and scientific basis for studying health the *'International classification of functioning, disability and health (ICF)'* was published in 2001 (135). Since then, the challenge has been to coordinate wider aspects of health and economic resource and environmental and social factors to achieve improvements in health.

Wagner (136) helpfully illustrates the comprehensive requirements of chronic care using a collaboratively synthesised representation (figure 1 below) now referred to as the chronic care model and expanded by Barr *et al.* in 2003 (129).

Figure 1: Barr et al. 2003 Chronic Care Model

Barr VJ, Robinson S, Marin-Link B,
Underhill L, Dotts A, Ravensdale D, et al.
The expanded Chronic Care Model:
an integration of concepts and
strategies from population health
promotion and the Chronic Care Model.
Healthcare Quarterly. 2003;7(1).

Figure 2: Krisciunas & Kowalski components of functioning


Kriščiūnas A, Kowalski IM. Ensuring rehabilitation and a full quality of life for patients with chronic non-infectious diseases. Polish Annals of Medicine. 2010;17(1):112-22.

Kriščiūnas and Kowalski make a coherent case for a whole-system approach to rehabilitation in order to address elements identified by the integrated components of functioning figure (figure 2 above) (137). A shift in stronger social regulation is discussed by Soosar in 2007 who notes the growing focus on health as opposed to disease and attributes this change in medicine to the last few decades (138). Three years later Shilling describes a cultural change toward reduced acceptance of disability from short or long-term illness and increasing demands for enduring good health (139).

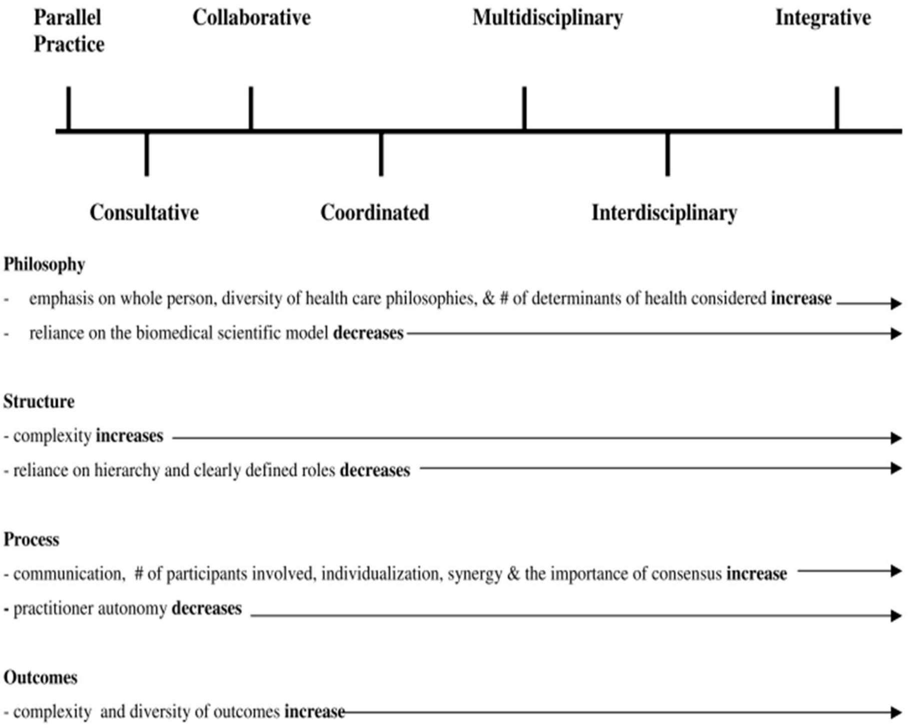
When The Public Health Act was first passed Gostin defines Public Health as '*Society's obligation to assure the conditions for people's health*'(140)(p.122). Public health has moved from Acheson's definition (1988) involving *'preventing disease, prolonging life and promoting health'* (141) to include medical care and rehabilitation requiring coordination and integration of diverse different organisations and services related to health (141, 142). Boon *et al.* (143) espouse the integration of services, these are clearly and convincingly illustrated in figure 3 on the following page which displays increasing levels of healthcare complexity beginning with the simplest parallel model and culminating in the complexity and benefits of an integrative model.

A 2015 Cochrane review suggested that

> *'personalised care planning leads to improvements in people's capability to self-manage their condition when compared to usual care.'(144)*

Stewart et al. provide six dimensions of patient-centred medicine (figure page 102) (145). In addition a subsequent five dimensions discussed by Mead and Bower (146) (figure page 105), although briefer, lacks the simplicity and therefore the transferability and utility for everyday interactions between heath providers and seekers. Engel discusses patients' expectations of their health providers regarding competence and motivation to relieve distress created by illness (147). Demand on healthcare services are forcing more innovative approaches to patient-centred care including peer support and education (148-150). *'No decision about me without me'* was a key element of the Liberating the NHS legislative framework (151). Shared decision making principles underpin medicine in the UK (152). It remains a complex task in clinical encounters requiring time and skill. Achieving this within the time allotted to patient visits may be a struggle.

Figure 3: Boon et al. From parallel to integrative care



Philosophy

- emphasis on whole person, diversity of health care philosophies, & # of determinants of health considered **increase** →
- reliance on the biomedical scientific model **decreases** →

Structure

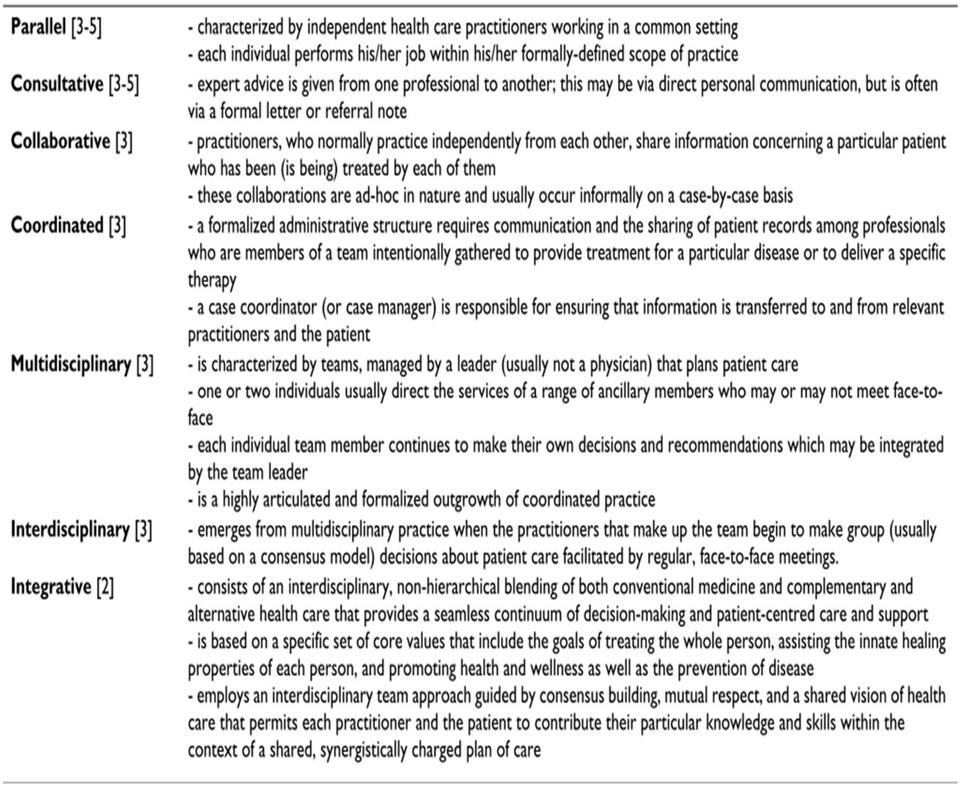
- complexity **increases** →
- reliance on hierarchy and clearly defined roles **decreases** →

Process

- communication, # of participants involved, individualization, synergy & the importance of consensus **increase** →
- practitioner autonomy **decreases** →

Outcomes

- complexity and diversity of outcomes **increase** →



Parallel [3-5]	- characterized by independent health care practitioners working in a common setting - each individual performs his/her job within his/her formally-defined scope of practice
Consultative [3-5]	- expert advice is given from one professional to another; this may be via direct personal communication, but is often via a formal letter or referral note
Collaborative [3]	- practitioners, who normally practice independently from each other, share information concerning a particular patient who has been (is being) treated by each of them - these collaborations are ad-hoc in nature and usually occur informally on a case-by-case basis
Coordinated [3]	- a formalized administrative structure requires communication and the sharing of patient records among professionals who are members of a team intentionally gathered to provide treatment for a particular disease or to deliver a specific therapy - a case coordinator (or case manager) is responsible for ensuring that information is transferred to and from relevant practitioners and the patient
Multidisciplinary [3]	- is characterized by teams, managed by a leader (usually not a physician) that plans patient care - one or two individuals usually direct the services of a range of ancillary members who may or may not meet face-to-face - each individual team member continues to make their own decisions and recommendations which may be integrated by the team leader - is a highly articulated and formalized outgrowth of coordinated practice
Interdisciplinary [3]	- emerges from multidisciplinary practice when the practitioners that make up the team begin to make group (usually based on a consensus model) decisions about patient care facilitated by regular, face-to-face meetings.
Integrative [2]	- consists of an interdisciplinary, non-hierarchical blending of both conventional medicine and complementary and alternative health care that provides a seamless continuum of decision-making and patient-centred care and support - is based on a specific set of core values that include the goals of treating the whole person, assisting the innate healing properties of each person, and promoting health and wellness as well as the prevention of disease - employs an interdisciplinary team approach guided by consensus building, mutual respect, and a shared vision of health care that permits each practitioner and the patient to contribute their particular knowledge and skills within the context of a shared, synergistically charged plan of care

Boon H, Verhoef M, O'Hara D, Findlay B.
From parallel practice to integrative health care: a conceptual framework.
BMC health services research. 2004;4(1):1.

Shared decision making

Fostering collaborative skills may also require regular support and evaluation in both patients and their healthcare workers. Elwyn suggests that steps involved include justification of the discussion, debate of options and alternatives, evaluation of patient preferences, collaboratively shared plan or decision (153). Useful models and frameworks to support shared decision making such as *'Open Communication'* and *'AskShareKnow'* are beginning to be tested and showing promising results (154). The health belief model was developed in the United States by public health psychologists to predict adoption of preventive health behaviours in the 1950s (155). It was revised to include health motivation and distinguish between health behaviour and illness and sick roles. Influenced by Kurt Lewin's theories (156) the model was based in social psychology. Thirty years later Janz was still advocating the value of the model in understanding individuals' health decision making relating to health (157), use of the model endures in current publications (158, 159).

Integration of chronic disease care

In 2013 NHS England one of the partners in the National Collaboration for Integrated Care and Support made a number of commitments to supporting local areas in delivering a system-wide approach named 'Integrated Care and Support: Our Shared Commitment'. To finance this the Better Care Fund of £3.8bn was announced by the government in June 2013. This project aims to move care from parallel practices toward integration (as described by *Boon et al.* in figure 3 earlier in this chapter). This more holist philosophy and practice is designed to provide a smoother and less fragmented experience for the person with disease engaging in self-management. The 'Realising the Value: Ten Key Actions to Put People and Communities at the Health of Health and Wellbeing'(160) programme was funded by NHS England to provide a guide to delivering the 'Five Year Forward View' (94, 161) the final report was published by NHS England and a number of partner organisations (see appendix 1) in November 2016 identified ten actions designed to create person and community centred health and well-being are proposed.

The programme is intended to 'identify evidence-based approaches that engage people in their own health and care'(162) appendix illustrates these and a list of publications created by the partner organisations by using extracts from a slide presentation by Suzanne Wood (163), Improvement Fellow at the health foundation.

Behaviour change

Sociological perspectives relating to self-management evolved from theories of behavioural change, social context and perspective are pivotal to the application of self-management (164). Lewin (165) suggested that behaviour is a function of person and environment. Cognitive approaches focus on belief and attitude (166), understanding cognitive styles impacts on the design of self-management documents to assist and support learning (167) and mental mode (168). The behaviour change wheel created by Michie *et al.* drew upon and consolidated many of these approaches (169). The dominant role of self-management in health policy is underlined by Ong *et al.* in 2014 in a helpful synthesis of sociological approaches. They underline the value of contextualising findings relating to self-management research using the socio-economic background of research participants (170) . The psychology of behaviour change is a fundamental aspect of self-management intervention design. Researchers and participants frequently focus on the expected outcomes of behaviour change, their behavioural beliefs (171). These outcomes are affected by what participants feel are the researcher's expectations, their own motivation to comply, and the wider context of societal norms discussed by Trafimow *et al.* as part of normative and behavioural beliefs (172).

Beliefs about factors that may act as barriers to, or opportunities for, the desired change are control beliefs (173) which Lachman *et al.* explore in terms of health and aging. The sum of these different beliefs in aggregate are described by Olson and Zanna as attitudes (174) toward behaviour change . Intention to make changes is affected by attitude to change, perceived control and subjective norm. When all three elements are very positive the intention to change is high. Intention per Cooke and Sheeran (175) is important but if there is a lack of actual control over the task intended frustration can ensue. Hence actual control is the mediator between intention, action and achieving the intended goal. Highly motivated individuals may be very disillusioned by lack of actual control and hence inability to carry out tasks to achieve their goals.

The theory of reasoned action is extended to planned behaviour (176) Armitage and Conner explore the efficacy of planned behaviour theory. For individuals with lifelong illness which is often the case in bronchiectasis, past experience and behaviour affects self-management engagement (177), Ajzen dissects this influence of past and present behaviours. Past behaviours can provide insight into predicting future action. Habituation to behaviours that are supportive of health minimises the need for conscious control (178) and effortful decision making explored by Schneider and Shiffrin as part of information processing.

Measuring health

Health status is not measured by any single observable factor. Mortality measures are crude and do not give any insight into how day-to-day life is experienced. Since health affects multiple aspects of living, evaluation of the effects of treatment or dysfunction must be similarly multi-faceted. Kaplan *et al.* in 1982 (179) suggested an index with 1.0 as full health and 0.0 as death, made up of three components: mobility, physical activity and social activity. These formed a formula from which to calculate a functional level. In addition, weights or levels of wellbeing were applied depending on societal views of symptom importance. Guyatt *et al.* (180) reviewed how quality of life measures assess physical and emotional function. Ware's passionate commentary on the effect of these measures on hypothesis testing reveal a variety of concepts to evaluate impact on activities of daily living (181). More recently the adoption of the QoL concept is illustrated by the Encyclopaedia of Quality of Life and Wellbeing published in 2014 by Rojas (182).

Quality Adjusted Life Years or QALYs are one of the methods used to economically evaluate the cost of intervention effects in clinical trials. QALYs are a measure of quality of life (183). Weights derived from participant questionnaire completion such as the EuroQol five dimensions assessing mobility, self-care, usual activities, pain or discomfort, anxiety and depression to provide a measure of the impact of disease on the participant. Economic evaluations are essential in providing the basis from which to decide how to distribute the limited funds available within the NHS (184).

Health communication

As Thompson *et al.* (185) express with clarity, communication in healthcare is elevated beyond common enquiry because outcomes dependent on the interaction affect daily life and have consequences relating to quality of life or even absence of life. Channels for health communication include face-to-face, telephone interactions with healthcare staff, clinic letters and discharge from hospital letters, media health messages on television, the world-wide-web or in books, from peers, carers or family members. This year (2018) guidance on direct communication with patients in clinic letters was acknowledged in the 'Please write to Me' initiative released by The Academy of Medical Royal Colleges (The Academy 2018). This marks a substantial step toward a proper acknowledgement of the person affected as a partner and collaborator in their care. This movement highlighting the importance of shared understanding in health communications was illustrated in mainstream television broadcasting by a BBC breakfast news item in September 2018 calling for Doctors to *'ditch Latin and use plain English'* (186) During communication a complex interchange involving co-participation, assertiveness, empathy and self-advocacy take place, and in healthcare there is often the added pressure of time and appointment availability. A key component of health communication is uncertainty.

Generational attitudes to health interactions

Generational differences in respect for authority and confidence in interaction with health professionals may be limiting factors in the adoption of self-management. Tolbize (187) usefully acknowledges generational differences in social stances that are likely to affect their interactions with health.

Her research relates to the workplace though it has relevance to healthcare, attitudes toward self-management and response to information. She identifies traits in four generations relevant to healthcare communications particularly as these generations age.

The Traditionals born before 1945 habituated to formality and hierarchical structures (187) brought up to respect authority and in a paternalistic healthcare structure when patients were expected to passively follow advice.

Baby Boomers were born between 1945 and 1965 during social turmoil and sexual revolution, learning to mistrust the older generation (187) they may also have less trust in healthcare than the previous generation. Generation X born between 1966 and 1979 are reported by Tolbize to be independent and self-reliant, questioning authority and requiring feedback (187). It seems likely that this X generation seek health information and may be more likely to engage collaboratively with self-management due to their social upbringing. Generation Y born 1980 to 2002 are deemed by Tolbize to be demanding and confident (187) they have grown up with the world wide web and may therefore be able to collaborate in self-management using a variety of information support tools with a greater degree of self-reliance than previous generations. Targeting of healthcare communication to account for these generational differences has the potential to assist health professionals and service users share common expectations and goals. Immediate almost visceral reactions to communication may be diverse; satisfaction/disappointment, reduction/increase in anxiety, and improved understanding or confusion based on information shared. Intermediate effects where action advised may be practiced, impact of information absorbed, confidence or trust in collaboration increased or decreased based on reflection and longer term evaluation. Finally long-term effects when goals are either reached with the potential of cementing trust in further collaboration. If expectations are not met then the fragile hope and faith needed to attain personal goals may be threatened and replaced by apathy or loss of trust.

Patient and public involvement in health

Multi-faceted effects result from the impact of bronchiectasis on daily activities. Involving people with the condition in the development of interventions harnesses the opportunity offered by involving key stakeholders.

A project management approach involves: identifying stakeholders, developing processes with respect to their needs and interests, establishing and building trust, delivering a user-friendly solution in accordance with organisational objectives within time and target (188).

Although a patient-led NHS is described as a cornerstone of the service (189), public and patient involvement in the design of research interventions has been patchy (190).

The requirement set out by the National Institute for Health Research (NIHR) for clearly identifiable patient and public involvement at all stages of research funding applications, development, conduct, analysis, reporting and translation to practice has driven integration of patients and the public as valuable collaborators.

> ‘*Applications that are technically excellent but have little patient or public involvement may be asked to address this before an offer of funding is made.’ (P.3.) (191)*

The NIHR provide advice in a variety of forms to help researchers integrate patient and public involvement into their designs which include eight different resources one of which is face to face advice from their Research Design Service personnel.

The teaching of self-management skills to patients initially appealed to both patients and policy makers with the potential to provide truly patient-centred care and reduce the burden on health utilisation (192). However, several randomised controlled trials have been unsuccessful in meeting their aims (193-195). A recent systematic review and meta-analysis conducted by Wang *et al.* of self-management education in chronic obstructive disease concluded that self-management can be a useful strategy in reducing hospitalisation, improving disease specific knowledge and QoL (196). These conflicting findings may be due to the variety of duration, intensity and method of intervention suggest Jonkman *et al.* (197).

Self-efficacy

Based in cognitive theory, self-efficacy is a person’s self-perceived belief in achieving desired outcomes and is frequently referred to in terms of managing the symptoms of a disease with confidence (198). Arnold *et al.* suggest that it is control over behaviours required to manage an illness (199). Bandura suggests that people’s convictions regarding their effectiveness affects their coping (200).

He and Schunk also made the connection between the fostering of intrinsic motivations in order to cultivate competence and self-efficacy (201). O'Leary also emphasises the significance of behavioural medicine and self-efficacy in health (202). Lorig *et al.* discuss the need to measure self-efficacy in arthritis care and the development of a self-efficacy scale.

The self-efficacy for managing chronic disease six-item scale (Stanford) represents a validated method for the brief evaluation of the confidence with which people can manage common symptoms of chronic disease (203).

> *'Empowering and engaging people is about providing the opportunity, skills and resources that people need to be articulate and empowered users of health services.'* (204, 205)

The WHO global strategy on people-centred and integrated health services (p 21) makes the empowering and engaging of people (in the statement above) their first strategic direction within their 2015 Interim report. The WHO established in 1948 clearly states its objective for all people worldwide to attain *'the highest possible level of health'* (206). This objective appearing at the forefront (chapter1 article1 p2 of the forty-eighth edition) of the WHO basic documents. Gibson (207) describes empowerment as a

> *'social process of recognizing, promoting, and enhancing people's abilities to meet their own needs, solve their own problems, and mobilize necessary resources to take control of their own lives.' p.359*

In order to support empowerment equitably it is important to consider how to reach the whole population. Lau (208) advocates combining the knowledge of patients as experts of their illness and healthcare professionals as experts on healthcare resources. This mutual recognition of skill provides a platform for teamwork and partnership to maintain functional ability described by Holman and Lorig (209). The beginnings of academic interest in people caring for themselves and hence promoting their health developed in the seventies (210) and were espoused by the women's movement in particular in relation to self-care skills relating to reproduction evidenced by the publication *'Our Bodies Ourselves'* (211). In the United States a major journal relating to health promotion was published as *'medical self-care'* for a number of years. This decade of increasingly popular self-help heralded groups encouraging learning and support to boost independence and coping with chronic illness.

The influence of people on their health was highlighted with the success of self-help in addiction (212).

Nancy Milio discussed the impact of socio-economic circumstances and their influence on behavioural choices or lifestyles (213).

Pivotal works related to health promotion convincingly make the case for this approach below.

> *'Health promotion represents a comprehensive social and political process; it not only embraces actions directed at strengthening the skills and capabilities of individuals, but also action directed towards changing social, environmental and economic conditions so as to alleviate their impact on public and individual health. Health promotion is the process of enabling people to increase control over the determinants of health and thereby improve their health. Participation is essential to sustain health promotion action.'*

Organization WH. Ottawa charter. Geneva: World Health Organization. 1986.

Wanless D.
The Wanless Report. Securing our Future Health: Taking a Long-Term View London:
HM Treasury. 2002.
Advised engaging people in their own health

Darzi A.
High quality care for all: NHS next stage review final report:
The Stationery Office; 2008.
Emphasises prevention (health promotion)

Marmot MG, Allen J, Goldblatt P, Boyce T, McNeish D, Grady M, et al.
Fair society, healthy lives: Strategic review of health inequalities in England post-2010.
2010.
Again advocates prevention as one of six strategies

Goodwin N, Smith J, Davies A, Perry C, Rosen R, Dixon A, et al., editors.
Integrated care for patients and populations: Improving outcomes by working together.
A report to the Department of Health and the NHS Future Forum London: The King's Fund and Nuffield Trust; 2012.
Presentation of making every contact count (below)

Lawrence W, Black C, Tinati T, Cradock S, Begum R, Jarman M, et al.
'Making every contact count': Evaluation of the impact of an intervention to train health and social care practitioners in skills to support health behaviour change.
Journal of health psychology. 2016; 21(2):138-51.

The WHO drove forward health promotion with *'Indicators of behaviours conducive to health promotion'* (214) and *'Targets for health for all'* (215).

Health promotion has developed beyond public health messages of sanitation and immunisation to individual behaviours impacting health such as smoking. Kickbusch (210) refers to a definition of lifestyle proposed by WHO as *'individual and collective experiences relating to conditions in life'* and Coreil *et al.* (216) suggest that in this socio-cultural context it is essential and that behaviour modification is not a personal responsibility alone. In order to promote health, individual avoidance of risks, self-monitoring and adoption of rituals enabling well-being are required within a broader supportive context. Self-care actions may be easier when ritualised as a part of everyday life.

The WHO health promotion glossary (217) defines health literacy:

'Cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health.'(p357)

The importance of health literacy in meeting the knowledge and care requirements of health in society are emphasised by Sørensen *et al.* (218). We know that deprivation is correlated with a greater burden of chronic disease (219). Deprivation is also associated with poorer literacy.

The effects of hypoxia in chronic lung diseases can result in neurophysical and neuropsychological effects with impact on cognitive ability (220). This may hamper people with respiratory disease in the acquisition and internalisation of essential information relating to their health. Cohen suggests that growth in social skills also positively relate to perceived support (221).

Reduced social contact due to ill-health may affect social skills and compound the isolation experienced acting as a compounded barrier to communication and collaboration with healthcare staff. Although Schulz and Nakamoto (222) set out to link empowerment and health literacy they fall short of actually doing so. However, they do draw attention to the interdependence of the two concepts.

Measures of health literacy and confidence in health communications exist, however, a natural reluctance to being assessed at the outset of a health encounter is a risk that could jeopardise a collaborative interaction.

Wolfe *et al.* (223) concluded that shame and embarrassment was caused by a literacy evaluation undertaken in order to identify and support people with lower literacy. Consequently, sensitivity in health literacy and confidence assessment and innovative ways to address education for self-management are required.

The best chronic disease management requires a level of collaboration and responsibility on the part of all those involved. Worryingly, pressure on resources may create anxiety in patients related to taking personal responsibility for their health and add to their burden of chronic disease. In an illustrative case study Bishop and Brodkey (224) highlight the pitfalls of this approach (within the United States). By disadvantaging hard to reach groups, the danger is that the very people who might benefit the most from a positive and collaborative support and education to achieve self-care and management are further marginalised.

Rather than one succinct definition of motivation there are a number of constructs that reflect human diversity and the complexity of the psychology involved. A few of these constructs relevant to self-management are discussed here. Wentzel (225) suggests that a goal is ‘a cognitive representation of what it is that an individual is trying to achieve in a given situation’.

Pintrich (226) views goals as the purposes or reasons that an individual pursues a task. Perceived control is central to self-management in chronic disease.

The ability to affect personal outcomes is central to behaviour change, to the wish to take responsibility for health and to the navigation and collaboration in treatment. Staunton *et al*. view perceived control and intrinsic motivation as key constructs interacting in self-determined, behaviour change (227).

Understanding differences between extrinsic and intrinsic motivation are important in creating education and support materials (228). Intrinsic motivation relating to a task that is in itself rewarding in some way. In contrast, extrinsic motivation is the means to an end, the task that permits movement towards a goal. In terms of self-management learning about chronic disease might be intrinsic by assuaging curiosity, may be interesting and explain or help understand symptoms, reduce isolation through a realisation that others feel the same and increase confidence and self-worth when collaborating with health professionals.

However, if literacy levels are low or fear is high, knowledge acquisition may be more extrinsic, more of a chore, a necessary evil in order to be able to minimise the disruption presented by ill health and affect future in terms of health.

Similarly help-seeking may seem natural to those with better communication skills where comfort is gained from interaction with a carer or health professional (an intrinsic motivation) or contrarily be viewed with trepidation, used only as a means to an end for access to prescriptions or referral to specialist care (thus extrinsic). Maslow in his theory of human motivation presents a hierarchy of needs (229). Essentially health and quality of life are based on meeting human needs. Thielke *et al.* advocate using Maslow's model to help researchers, health providers and patients in evaluating health interventions (230).

Locus of control is recognised in Rotter's social learning theory (231) reflecting the extent to which people attribute the consequences of their behaviours to external or internal factors. When related to health this is the subjective belief in control over health or illness (232). An internal locus of control reflects belief that our own behaviour affects our health. This belief is central to coping mechanisms and to self-efficacy. External locus of control and avoidance are associated with poor coping (233) and negative impact on health.

Choice as a concept has been made much of in the NHS. Unless roles and responsibilities in the clinician-patient relationship are made clear then barriers to choice ensue.

Gafni, Charles and Whelan (234) explain with clarity the opportunities and pitfalls of two models of interaction described here. The person seeking advice in the informed treatment model is informed of risks and benefits and makes their choice accordingly. In the agency model the patient delegates the health professional to make health decisions for them based on their preferences. Brief consultation times in both general practice and hospital outpatient consultation may create difficulty for physicians in utilising these models in the UK.

Ryan and Deci (228) suggest that people can be engaged and constructive or alienated and passive depending on their social conditions. They explain that self-determination hinges on the psychological need for competence, autonomy and relatedness which in turn influence motivation or apathy.

In selecting motivators for action Sibitz *et al.* suggest that it is important to remember that extrinsic motivators such as bribes, coercion, fear of evaluation or failure have less motivational longevity and may cause long term harm (235), whereas intrinsic motivators, tasks which are intrinsically valued by the individual are internalised and retained more easily. In education, Cheon *et al.* noted that students taught in a more controlling manner display less initiative, whilst those taught with supportive autonomy (236) show greater enthusiasm, curiosity and skills which put them at an advantage in facing future challenges. Security and attachment in infants predict greater exploratory behaviour and hence Ryan and Deci's third psychological requirement for relatedness.

Fear of being branded as incompetent, dependent or powerless affect help-seeking behaviour according to Lee (237). Seeking assistance is an interpersonal exchange requiring trust (238). By framing the request the individual has defined their vision of the issue requiring resolution. Availability of skilled assistance does not necessarily mean that this will be sought when required. Understanding the mechanisms of how help can be best provided and most frequently accessed should help design better services. Help-seeking also applies within inter-disciplinary teams and should be encouraged (239). Shared knowledge, greater efficiency, an atmosphere of collegiality and shared goals provide an environment of greater job satisfaction and teamwork, valued specialist contribution and increased individual development exposure to knowledgeable others (240).

As the burden of chronic disease increases it is inevitable that family and friends provide support between appointments (241). Awareness of family, friends and carers as part of the collaborative care team in chronic disease management is necessary to preserve those supportive structures maintaining the emotional and physical wellbeing of all concerned (242). Chronic disease often has an isolating effect, the support of a partner in life can be particularly important in sickness as well as in health (243, 244). The impact of ill health on relationships can be toxic (245) and sadly lead to separation (246).

Social changes that have affected the duration of marital union also affect health and wellbeing (247). The geographical distribution of families can make caregiving difficult, where it is possible the responsibility brings a combination of satisfaction and stress (248, 249).

The increase of the older adult population, longevity and commensurate chronic morbidity may outstrip support available from offspring. Involvement of caregivers in education interventions is a positive way of supporting both the carers themselves and the individual cared for (250).

Discussion

The diagnosis of bronchiectasis does little to address the accompanying burden of multiple and varied associated issues including emotional, social, cognitive and economic impacts discussed by Akyil and Ergüney with relevance to Roy's adaptation to chronic disease (118). These frequently affect roles within life, within families and perception of self and self-perceived ability to self-care and self-manage. This chapter has reviewed the foundations of a collaborative self-management approach through literature relating to a variety of chronic conditions. Models of care, sociological and psychological perspectives are summarised to form the foundation for understanding the concept of self-management and inherent barriers and opportunities affecting it. The multi-disciplinary, multi-process, multi-factorial, context-dependent basis of informed self-management are illustrated by the diagrams on pages 28, 29, 30 and 96. Of the concepts discussed, self-efficacy (a person's self-perceived confidence in managing the symptoms of their disease) seems most appropriate as a self-reported measure of the impact of self-management.

Conclusion and implications

Socially and financially driven changes have created the requirement for a more collaborative model of care in which the person affected by disease is expected to take a more active role in the management of their own health. Self-management requires adaptation for both the person self-managing and their personal, professional and health support networks. There is a need to foster self-management skills using materials and processes allied with health professional, social and psychological support systems enabling the shift in autonomy.

Health and social care professionals will require a framework of training, support and evaluation to develop and maintain the skills necessary to promote this change creating a coherent, healthcare wide integrated inter-professional self-management strategy facilitated by enhanced digital, management and communication solutions

Chapter 2

Literature Review : self-management in bronchiectasis

Chapter 2

Literature Review : self-management in bronchiectasis

Background

The developments in clinical research, described below give context for the evaluation of the literature extracted and reviewed in this chapter. The advent of easier travel, better communication tools including telephone, video-conferencing, world-wide web, databases for information storage together with global health conferences have provided a fertile environment, rich with information and more easily accessible information-technology that create new challenges for rigorous evaluation (251, 252).

In Bhatt's 2010 paper describing the evolution of research, Avicenna's rules for testing drugs 1025 AD in his 'Canon of Medicine' sound remarkably similar to inclusion and exclusion criteria used today (253). Bhatt credits the first "controlled clinical trial of the modern era to Dr Lind (1716-94)" (253). Lind described the need for systematic review of literature, in discussion relating to published materials on scurvy he noted that " before the subject could be set in a clear and proper light it was necessary to remove a great deal of rubbish" (254). Characterised by measurement and based on the need for empirical evidence (verified facts) quantitative methods are often described as positivist. In this approach the aim is to collect data objectively from which to derive theories and conclusions that are generalisable to much larger populations. Striving for this objectivity the first double-blind clinical trial was conducted in the UK and is attributed to the British Medical Research Council. The large multi-centre trial was conducted in 1943 to evaluate an extract of patulinum on the common cold (255). The first documented randomised-controlled-trial was conducted by Crofton and published in 1948 investigating Streptomycin resistance in pulmonary tuberculosis (256). Participants were assigned alternately to the intervention or control. These advances in research and evidence for healthcare achieved in the relatively recent past have gained momentum with the availability of evidence on which to base practice growing exponentially. The National Library of Medicine index grew from 1600 to 10 million references between 1865 and 2006 (257). In 2010 the aptly named 'Seventy-five trials and eleven systematic reviews a day: How will we keep up?' explores issues of increasing volume of information and the need for quality research (258).The obstacles to and opportunities for interpreting evidence in order to translate and integrate into practice are eloquently described by Kazdin (259).

He vividly depicts the gap between research and practice and the reliance of service funders on evidence to justify expenditure that emphasises the importance of high quality, articulately presented evidence. Health research studies are undertaken based on perceived need, this need exerts pressure to deliver results speedily at odds with the somewhat slow methodical precision required to collect, analyse, synthesise and then publish research findings. Government based guidance, policy and investment based on research and the ability to synthesise information from research benefit from standards and guidelines (260).

The **E**nhancing the **QUA**lity and **T**ransparency **O**f health **R**esearch network (**EQUATOR)** acts as a repository for standards of reporting research and was formally launched in 2008 (77). Appendix 2 synthesises the multiple standards relevant to clinical research in adult health.

This is a literature search rather than a systematic review the principles for evaluating research described in the 2009 PRISMA statement are utilised here as a framework from which to explore the literature in this review (261). The PRISMA statement for systematic reviews although very detailed is congruent with much simpler ones detailed in Garrard's matrix method in 2013 (262).

The evaluation of research evidence and literature searching are the foundation for evidence-based practice and researcher development (263, 264). The evidence pyramid Fig 1, based on the quantitative paradigm, reflects a positivist need for objective generalisable data (derived using established statistical methods (265-267)) from which to justify healthcare interventions. Evidence-based medicine is founded on policy and guidance resulting from inferences derived from clinical research (268). In order to evaluate the effect and safety of treatments these are tested through clinical research. However, this is founded on the assumption that multi-disciplinary clinicians are able to understand and interpret evidence from research and from clinical practice guidelines (269). Drolet and Lorenzi (270) describe the *'translation continuum'* of adoption of scientific discoveries through clinical applications to public health improvement as '*difficult*'. They propose a framework to clarify the translation for the reader called the *'Biomedical Research Translation Continuum'*.

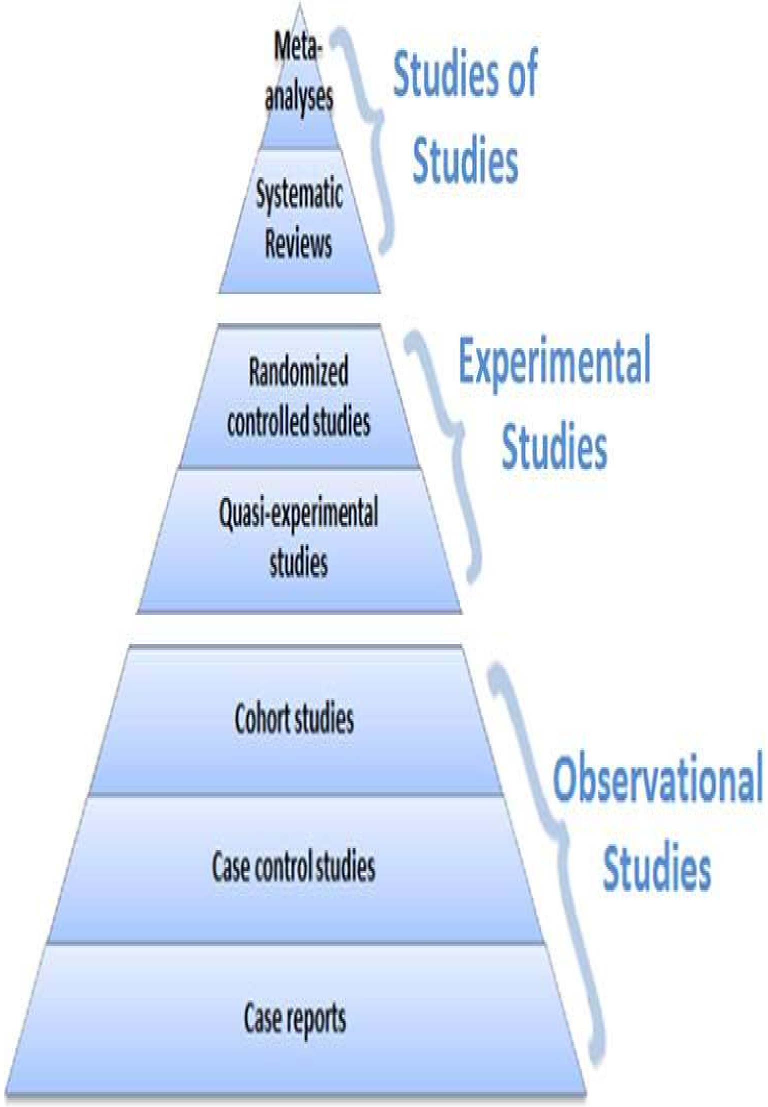
Methods

Electronic searches were made using the East of England Libraries network accessible at www.eel.nhs.uk . This is an online resource, permitting healthcare database advanced searches (HDAS), making accessible online documents to the National Health Service and students. The search strategy consisted of using the search terms self*management and self*care with the Boolean operator AND to combine search lines and limit the searches to bronchiectasis only. Databases searched were the following (their descriptors transcribed from HDAS); Allied and Complementary Medicine 1985 to present – Allied and Complementary Medicine 1985 to present – AMED; British Nursing Index 1992 to present – BNI; Cumulative Index to Nursing and Allied Health Literature 1981 to present - CINAHL; Excerpta Medica Database 1974 to present – EMBASE; Health Business Elite 1922 to present – HBE; Health Management Information Consortium 1979 to present – HMIC; Medline general medical database produced by U.S. National Library of Medicine 1946 to present- MEDLINE; Psychology and related disciplines international literature 1806 to present - PsycINFO; Medline from PubMed 1946 to present - PUBMED.

Only trials at the top two levels of the evidence pyramid are considered here i.e. meta-analyses, systematic reviews and randomised controlled trials.

These are considered high quality evidence on which generalisable treatments should be based. This literature search considers interventions specifically designed to guide and support self-management. Existing services relating to the care of bronchiectasis such as hospital outpatient services, community matrons, specialist nursing, early discharge services, pulmonary rehabilitation, nutritional, psychological and helpline support represent individual aspects of multidisciplinary care with varying availability throughout the UK. They are not patient-held and patient managed self-management programmes and therefore not part of this literature review.

Figure 4 Evidence Based Medicine Levels of Evidence



Library, D. M.
EBM Levels of evidence. E. L. o. evidence.

EBM Internal Medicine Portal, Darnall Medical Library.

Findings

The search resulted in sixteen papers, four on Medline and twelve on PubMed. Four were immediately excluded as duplicates. Only adult studies were considered therefore the child study was excluded. Four further studies were excluded because they weren't bronchiectasis specific. Three more papers representing protocols rather than randomised controlled trials were excluded. Only three papers remain, one high quality Cochrane systematic review of self-management for bronchiectasis by Kelly *et al.* (271) evaluating sources up to 13th December 2017 concluded that there was *'insufficient evidence to determine whether* *self-management interventions benefit people with bronchiectasis'*. Of the two papers evaluated in the Cochrane review by Kelly *et al. (271)* the Lavery *et al.* comparison of an expert patient self-management programme with usual care in bronchiectasis (272) is summarised in the evaluation matrix on the next page. The other paper in the Cochrane review by Kelly et al. related to pulmonary rehabilitation and was excluded (individual aspect of multidisciplinary care rather than self-management programme see previous page). This exclusion is further supported by the systematic review of pulmonary rehabilitation for bronchiectasis conducted by Lee *et al.* who concluded that

> *'Short-term improvements in exercise capacity and HRQOL were achieved with supervised PR and ET programs, but sustaining these benefits is challenging in people with bronchiectasis.' Abstract page 774 (273)*

An expert opinion paper by Hester *et al*. relating to 'Patient information, education and self-management in bronchiectasis: facilitating improvements to optimise health outcomes' (63) is highly relevant to self-management in bronchiectasis though low on the evidence pyramid. Published in 2018 this paper was not available when the Bronchiectasis Empowerment Tool and study were designed and conducted. Table 3 is an extract from the Hester *et al.* paper presenting an evaluation of online bronchiectasis patient information resources, that demonstrates the proliferation of information largely in written format and untested by research (63). It is difficult to evaluate the value of these resources without information relating to their skill development aims, how they are introduced or integrated with health services and without data relating to their acceptability from a user perspective.

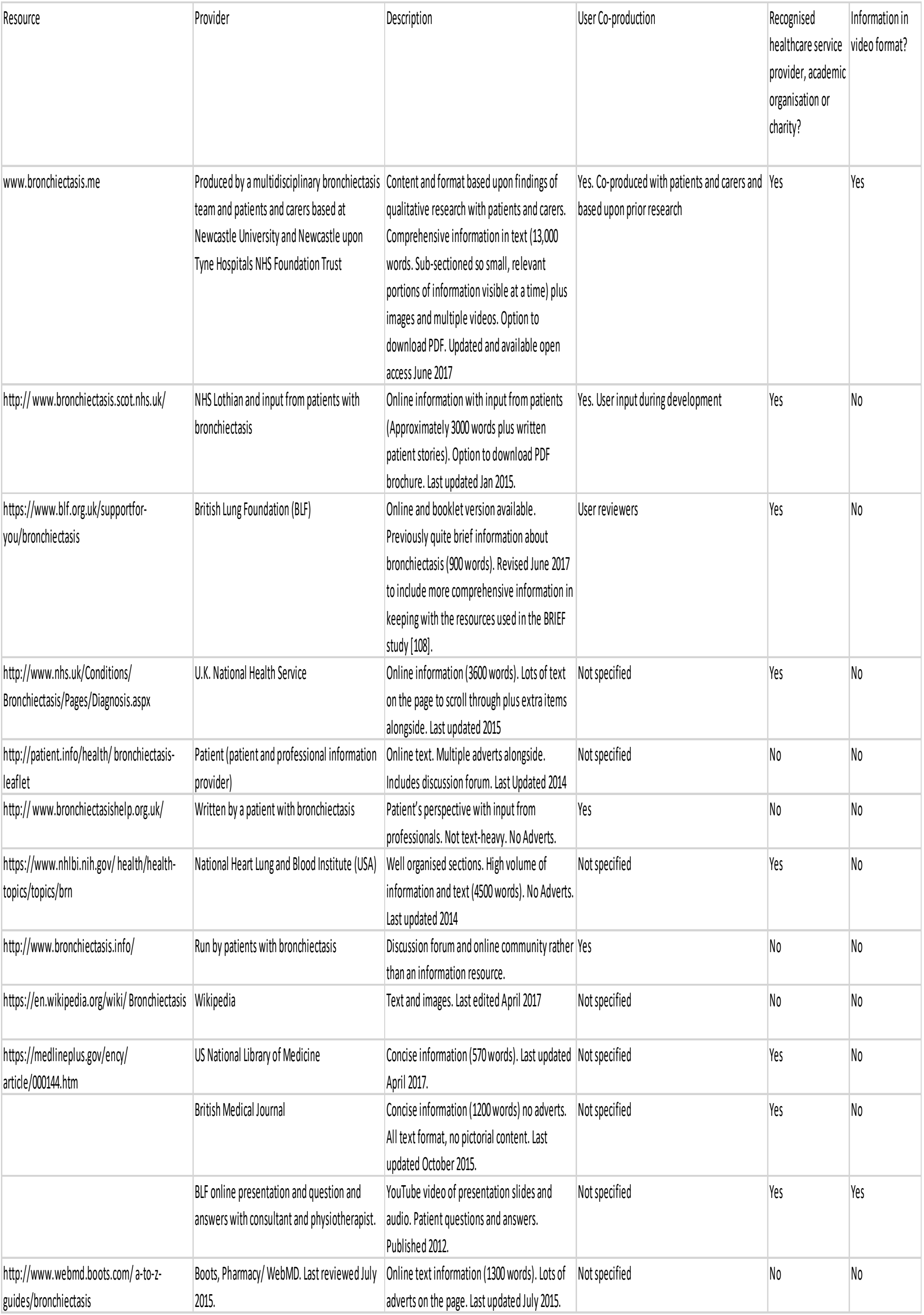
Jonkman *et al.* (197) in their meta-analysis of individual patient-data relating to complex self-management in chronic disease emphasise the importance of the *'causal mechanism underlying the intervention'* and the evaluation of these interventions. This causal mechanism is even more obscure in grey literature (see Hester *et al.* table 3 next page) than in the published materials Jonkman analysed.

Table 2 Evaluation matrix for papers considered.

Paper No	Database/s	Eval Headings	Reference & Critical evaluation
1	Medline and Pubmed	Paper Ref	**Kelly C, Grundy S, Lynes D, Evans DJW, Gudur S, Milan SJ, et al. Self-management for bronchiectasis. Cochrane Database of Systematic Reviews. 2018(2).**
		Design & Participants	High quality Cochrane Systematic review (places this evidence at the pinnacle of the evidence pyramid. Only two randomised controlled trials met the inclusion criteria one of which was a proof of concept. No data aggregation possible. Only 84 UK participants took part.
		Aims	Assessed the benefits and possible harms of self-management strategies
		Data Collection	Sources: Cochrane Airways Specialised Register of trials, clinical trials registers, reference lists of included studies and reviews. Two review authors independently screened searches to 13th Dec 2017, extracted study characteristics and outcome data and assessed risk of bias for each included study.Random effects model was used for analyses with standard Cochrane methods. articles, and relevant manufacturers' websites up to 13 December 2017.
		Key Findings	No adequately powered studies. Scarce, poor quality evidence. Recommend further research and adherence to current guidelines advocating self-management pending further research findings.
		Strengths	Clearly identifies a lack of evidence
		Limitations	Not enough information to assess benefit or harm.
2	Medline and Pubmed	Paper Ref	**Lavery KA, O'Neill B, Parker M, Elborn JS, Bradley JM. Expert patient self-management program versus usual care in bronchiectasis: A randomized controlled trial. Archives of Physical Medicine and Rehabilitation. 2011;92(8):1194-201.**
		Design & Participants	Quantitative randomised control trial n=64 at Belfast Hospital.
		Aims	To investigate the efficacy of disease specific expert patient programme compared to usual care for people with bronchiectasis.
		Data Collection	Questionnaires at baseline, 3 and 6 months.
		Key Findings	Short term improvement in self efficacy as measured by the chronic disease self-efficacy scale.
		Strengths	Used validated programme and validated questionnaires.
		Limitations	Not adequately powered, rise in self-efficacy may have been actually during the EPP programme. Format of the study did not overtly encourage participants to take control of the condition or future care decisions.

Table 3 Hester et al. BMC Pulmonary Medicine (2018)

A selection of online bronchiectasis patient information resources



Resource	Provider	Description	User Co-production	Recognised healthcare service provider, academic organisation or charity?	Information in video format?
www.bronchiectasis.me	Produced by a multidisciplinary bronchiectasis team and patients and carers based at Newcastle University and Newcastle upon Tyne Hospitals NHS Foundation Trust	Content and format based upon findings of qualitative research with patients and carers. Comprehensive information in text (13,000 words. Sub-sectioned so small, relevant portions of information visible at a time) plus images and multiple videos. Option to download PDF. Updated and available open access June 2017	Yes. Co-produced with patients and carers and based upon prior research	Yes	Yes
http:// www.bronchiectasis.scot.nhs.uk/	NHS Lothian and input from patients with bronchiectasis	Online information with input from patients (Approximately 3000 words plus written patient stories). Option to download PDF brochure. Last updated Jan 2015.	Yes. User input during development	Yes	No
https://www.blf.org.uk/supportfor-you/bronchiectasis	British Lung Foundation (BLF)	Online and booklet version available. Previously quite brief information about bronchiectasis (900 words). Revised June 2017 to include more comprehensive information in keeping with the resources used in the BRIEF study [108].	User reviewers	Yes	No
http://www.nhs.uk/Conditions/ Bronchiectasis/Pages/Diagnosis.aspx	U.K. National Health Service	Online information (3600 words). Lots of text on the page to scroll through plus extra items alongside. Last updated 2015	Not specified	Yes	No
http://patient.info/health/ bronchiectasis-leaflet	Patient (patient and professional information provider)	Online text. Multiple adverts alongside. Includes discussion forum. Last Updated 2014	Not specified	No	No
http:// www.bronchiectasishelp.org.uk/	Written by a patient with bronchiectasis	Patient's perspective with input from professionals. Not text-heavy. No Adverts.	Yes	No	No
https://www.nhlbi.nih.gov/ health/health-topics/topics/brn	National Heart Lung and Blood Institute (USA)	Well organised sections. High volume of information and text (4500 words). No Adverts. Last updated 2014	Not specified	Yes	No
http://www.bronchiectasis.info/	Run by patients with bronchiectasis	Discussion forum and online community rather than an information resource.	Yes	No	No
https://en.wikipedia.org/wiki/ Bronchiectasis	Wikipedia	Text and images. Last edited April 2017	Not specified	No	No
https://medlineplus.gov/ency/ article/000144.htm	US National Library of Medicine	Concise information (570 words). Last updated April 2017.	Not specified	Yes	No
	British Medical Journal	Concise information (1200 words) no adverts. All text format, no pictorial content. Last updated October 2015.	Not specified	Yes	No
	BLF online presentation and question and answers with consultant and physiotherapist.	YouTube video of presentation slides and audio. Patient questions and answers. Published 2012.	Not specified	Yes	Yes
http://www.webmd.boots.com/ a-to-z-guides/bronchiectasis	Boots, Pharmacy/ WebMD. Last reviewed July 2015.	Online text information (1300 words). Lots of adverts on the page. Last updated July 2015.	Not specified	No	No

Discussion

There are no validated interventions to support people with bronchiectasis in their self-management. The multiple needs and complexities that people face in managing bronchiectasis and often multiple chronic co-morbidities require structure and support. A shift from the paternalistic medical models require enhanced collaborative and motivational skills on the part of health professionals to meet the needs of patients with lifelong chronic diseases. Pressures exerted by increasing population, restrictive health funding and increasing health expectations combine to demand clearer shared communication and effective information and support interventions. There is a clear gap in the literature with regard to validated systems of self-management information, education and support to permit people with bronchiectasis to achieve the best care for themselves.

The goal of self-management being to cultivate the skills, knowledge and confidence to make decisions, take action and adopt behaviours designed to maintain or improve quality of life. For true collaboration patient and health professionals need to share knowledge and progress along clearly mapped pathways to promote health.

Although the paternalistic term ‘compliance’ has been replaced in published research by the term adherence (indicating mutual interaction and collaboration between health providers and service users) it is difficult to evaluate whether the mind-set change required has taken place. Do health providers actually have the resources and processes in place to collaborate successfully?

Similarly, have people with bronchiectasis moved beyond deferring to expert opinion at each step, do they await health professional confirmation rather than build their knowledge, experience and autonomy by taking control? This mind-set change is key to encouraging self-management.

Patient experiences and opinions provide perspectives relating to decision making dilemmas, diverse physical, personal and social impacts experienced due to bronchiectasis. These qualitative experiences inform beyond the physical symptoms presented in bronchiectasis shedding light on the burden of multiple and varied associated emotional, social, cognitive and economic impacts (118).

This insight into altered perception of self, self-perceived ability to self-manage and influence on self-management behaviours, roles within life and confidence are of import in devising support interventions.

The success of pulmonary rehabilitation in chronic respiratory disease and the exciting short-term improvements in self-efficacy reported by Lavery *et al.* (272) with respect to their expert patient programme (though it was not powered and therefore generalisable) provide a glimpse of aspects of multi-disciplinary care that encourage learning and provide coping skills. The integration of these aspects has the potential to provide a smoother route of support from which people with chronic conditions can self-manage within the framework of a self-management programme.

The WHO has provided the ICD-10 framework promoting standardised and meaningful health data interrogation and comparison. Analysis and interpretation of these ICD-10 codes provides a platform from which global initiatives are comparable and data that can be used to inform NHS strategy. Close ethical monitoring and governance must be carefully implemented to provide the protection necessary to safeguard patient interests while utilising enhanced information availability.

Conclusion

Guidelines for bronchiectasis advocate self-management. The published literature evaluated lacked a clinically tested guide to self-management for people with bronchiectasis. This paucity contrasts with the prominence of the self-management concept in the management of chronic disease globally and plethora of guidance for other chronic diseases.

This thesis explores the barriers and opportunities for self-management in bronchiectasis.

Chapter 3

Randomised controlled trial evaluation of the BRONCHIECTASIS EMPOWERMENT TOOL (BET)

Chapter 3

Randomised controlled trial evaluation of the BRONCHIECTASIS EMPOWERMENT TOOL (BET)

Abstract

Bronchiectasis guidelines promote self-management. Self-management for bronchiectasis aims to promote confidence in self-care between appointments, recognition of health changes requiring action, and either initiation of treatment (airway clearance or antibiotic therapy) or seeking healthcare assistance. A 2018 Cochrane systematic review evaluated existing bronchiectasis self-management interventions finding insufficient evidence to determine benefit.

A randomised mixed methods evaluation of the effect, cost and acceptability of the Bronchiectasis Empowerment Tool (BET) intervention was conducted using patient reported outcomes and focus groups. 220 people consented (ISRCTN18400127 Ethics13/SC/0140) from 6 hospitals within East Anglia (UK) with HRCT evidence of bronchiectasis and one or more exacerbations within 12 months. Randomisation was to treatment as usual alone or in addition to BET. BET was introduced via four brief telephone calls. It comprised an action plan in addition to four educational sections: sputum, health changes, medications and health interactions (each with patient self-record notepads). The primary outcome change between baseline and retest at 12 months was the 6-item Self-Efficacy to Manage Chronic Disease Scale (SEMCD). Quantitative and economic data were collected quarterly via mailed self-reported questionnaires for one year. Participant focus groups investigated intervention acceptability.

BET did not affect SEMCD (mean difference (0.14 (95% confidence interval (95%CI) -0.37 to 0.64), p=0.59) or SGRQ and there was no significant difference in overall cost to NHS or in QALYs. The study was under-powered with 12% greater than expected withdrawal. Participants responded well to telephone education.

BET did not improve self-efficacy or secondary outcomes. Recruitment success suggests a need for self-management support in bronchiectasis but withdrawals raise questions regarding the dual burden of literary intervention and evaluation. The patient information within the intervention aligns with BTS guideline and NHS bronchiectasis advice. Future research should consider greater multi-disciplinary integrated support and less literate delivery and evaluation.

Background

Bronchiectasis is *'characterised radiologically by permanent dilation of the bronchi, and clinically by a syndrome of cough, sputum production and recurrent respiratory infections'* (274). Recognising and treating these variously named infections/flare-ups/or exacerbations is key to self-management because '*exacerbations are both an indicator of severity and a driver of disease progression'* as described by Professor J.D. Chalmers in the aptly named paper '*Bronchiectasis Exacerbations Are Heart*-Breaking' (23).

Once considered a rare disease Quint *et al.* (48) report point prevalence rates in 2013 were 5.6 per 1,000 for women and 4.9 per 1,000 for men with an increase each year over their study period 2004-2013 based on analysis of 14 million primary care records from within the United Kingdom. Despite these growing numbers, health professionals in primary care may only see a small number of patients with bronchiectasis. Self-management guidance could increase coherence between specialist and general healthcare. Kozlowska *et al.* (275) in their paper published 2018 note that factors inhibiting integration of primary and specialist care include conflicting objectives, limited resources, poorly functioning information technology and inadequate care pathway and finances. They suggest that well-defined and evidence-based services with clearly articulated roles, responsibilities and committed collaboration enhance integration. This coincides with the approach advised by Boon *et al.* and the Barr *et al.* expanded chronic care model illustration both discussed in chapter one.

Self-management has been embedded to good effect in the treatment of common chronic diseases such as asthma (6), diabetes (276) and heart disease (277). Increasing longevity and therefore greater prevalence of chronic disease has caused rising pressure on individuals living with disease and on health services (278). These, combined with social changes in which patients expect to be kept informed (279) in a more collaborative care model (280) with varied and complex support from multiple providers creates a requirement for harmonisation, coherence and continuity of patient-centred care (281). Self-management is intended to provide the person with disease and their immediate and wider care team with a patient-centred care pathway (282).

A 2018 Cochrane systematic review (271) concluded that there was insufficient evidence to support or refute the existing interventions tested (272, 283) for self-management in bronchiectasis, recommending providing self-management guidance as advised by international guidelines. Updated British Thoracic Society (BTS) guidelines for bronchiectasis are expected at the end of 2018 or start of 2019 the 2010 guidelines already appear in BTS archived materials because they are more than five years old.

What should the self-management intervention include?

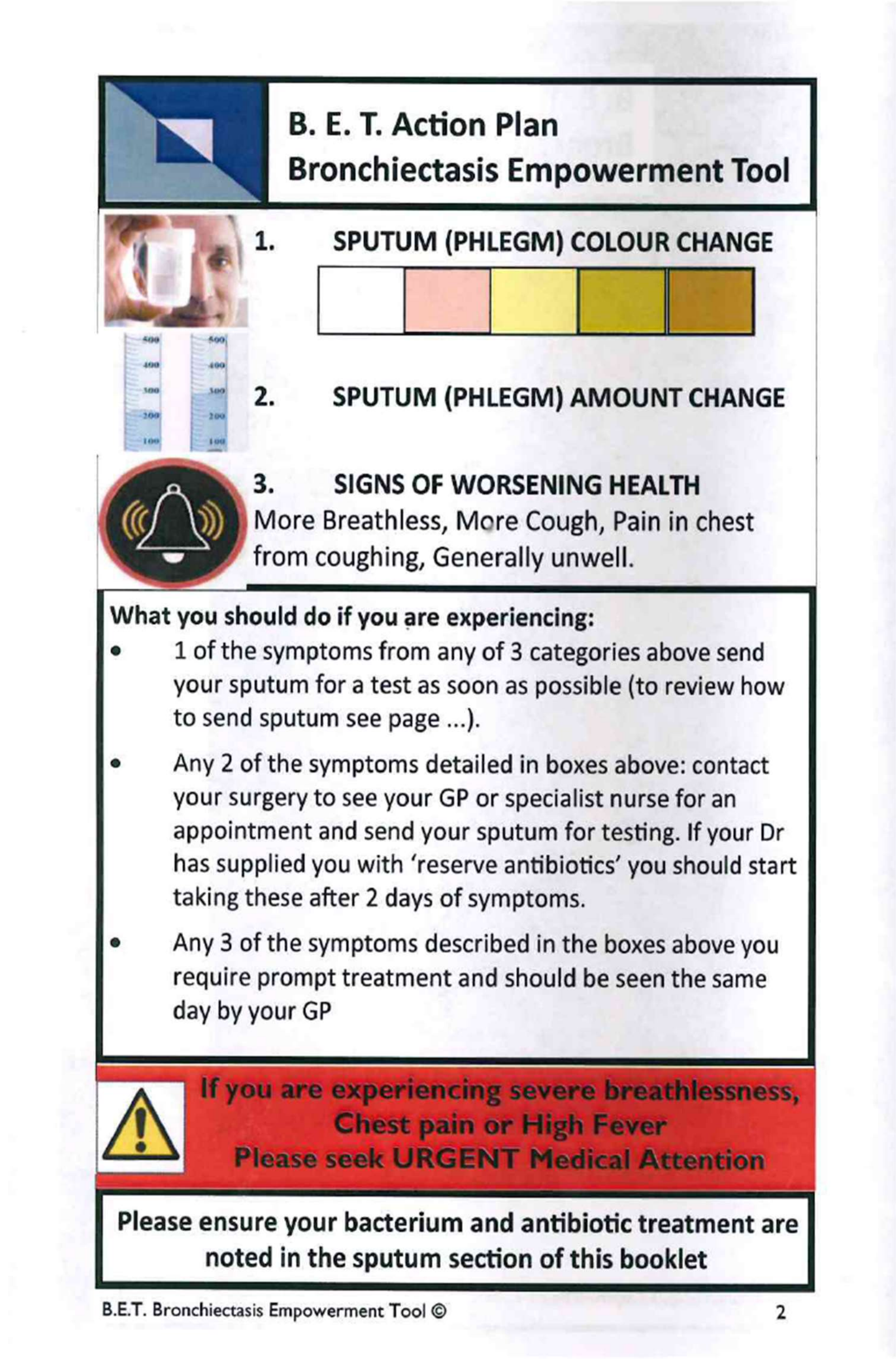
The Good practice suggestions within the BTS bronchiectasis guideline 2010 (1) comprise a written explanation of bronchiectasis and treatments including airway clearance techniques, exacerbation recognition (284) involving recording sputum volume and character, other symptoms, results of sputum culture and efficacy of treatments prescribed.

Our intervention design panel was made up of the following specialists: respiratory physiotherapist, respiratory pharmacist, bronchiectasis specialist consultant, respiratory researcher/honorary respiratory consultant, community matron, GP researcher, nurse researcher/PhD student, health economist, statistician and patient advisors collectively helping design and obtain funding for our self-management intervention for bronchiectasis.

In addition to our panel we received advice relating to designing the evaluation study and application for funding from the Research Design Service (285) funded by the National Institute for Health Research (NIHR) in the form of multi-disciplinary design workshops and valuable one to one methodological advice. We received assistance in completing our funding application from the Norfolk and Norwich University Hospitals NHS Foundation Trust Research and Development Department and from the University of East Anglia Research and Development.

Our intervention booklet named the Bronchiectasis Empowerment Tool (BET) included a three point action-plan consistent with the number of action points advised for asthma (286) and relevant to the aspects recommended in the BTS guideline (1). Instructions were brief and simple, combined with pictorial illustrations to reduce the need for literacy (287) (see next page).

The remainder of the BET booklet was divided into four educational sections: sputum, health changes, medications and health interactions (288) (with notepads). Primary coloured borders (289) defined the sections and each section was organised in a consistent way (see Appendix) with key information conveyed simply and then followed by examples and suggestions related to making notes and keeping track of each aspect of bronchiectasis management.



B. E. T. Action Plan
Bronchiectasis Empowerment Tool

1. SPUTUM (PHLEGM) COLOUR CHANGE

⬜ 🟧 🟨 🟨 🟫

2. SPUTUM (PHLEGM) AMOUNT CHANGE

3. SIGNS OF WORSENING HEALTH
More Breathless, More Cough, Pain in chest from coughing, Generally unwell.

What you should do if you are experiencing:

- 1 of the symptoms from any of 3 categories above send your sputum for a test as soon as possible (to review how to send sputum see page ...).
- Any 2 of the symptoms detailed in boxes above: contact your surgery to see your GP or specialist nurse for an appointment and send your sputum for testing. If your Dr has supplied you with 'reserve antibiotics' you should start taking these after 2 days of symptoms.
- Any 3 of the symptoms described in the boxes above you require prompt treatment and should be seen the same day by your GP

If you are experiencing severe breathlessness,
Chest pain or High Fever
Please seek URGENT Medical Attention

Please ensure your bacterium and antibiotic treatment are noted in the sputum section of this booklet

B.E.T. Bronchiectasis Empowerment Tool © 2

1. The sputum section includes a simplified diagram reminder of the active cycle of breathing and a section to record results of sputum microbiology and whether the antibiotic prescribed was effective. Advises that if unsure of how to clear the lungs to contact their GP, Respiratory Consultant or specialist nurse to obtain respiratory physiotherapy referral. Guidelines for the physiotherapy management of the adult, medical, spontaneously breathing patient Web Appendix 6 – Respiratory (chest) physiotherapy for people with Bronchiectasis (290) were provided to all BET study participants.
2. The health changes section encouraged recognition and documentation of health changes likely to denote infective exacerbation with examples, a notepad was provided for this.
3. The medication changes section explained the action and different presentation of antibiotics for identification. This section also re-enforced the difference between allergy and side-effect in relation to antibiotics.
4. Finally, the health interactions section listed multi-disciplinary health professionals and a notepad to record appointments, reasons for seeking help and outcomes to encourage better coordinated care, better communication and easier recall for the participant in a patient-centred hub and spoke model.

Methods

Potential participants were identified from secondary care clinics. Treating clinicians asked their clinic attendees whether they wished to receive information about the study, this was subsequently mailed by the research team and followed up by telephone to arrange a discussion and possible consent. 1351 clinic attendees were assessed for eligibility (see figure 4), of which 1002 did not meet the inclusion and exclusion criteria, 128 declined and 1 failed screening due to the minimum of at least one exacerbation in the previous twelve months. The target 220 people provided consent under good clinical practice (291). This was an ethically approved (13/SC/0140) controlled parallel study.

The participants were randomised to standard treatment that included the British Lung Foundation (BLF) patient information for bronchiectasis (292) (advocated by the National Institute for Health and Care Excellence) and the British Thoracic Society/Association of Chartered Physiotherapists Respiratory (chest) physiotherapy for people with Bronchiectasis (290) alone or with the addition of the Bronchiectasis Empowerment Tool. Adult participants (18 and over) irrespective of gender with high resolution computed tomography (HRCT) confirmed diagnosis and at least one exacerbation (requiring antibiotics) within 12 months. Exclusions were cystic fibrosis, traction bronchiectasis and severe and uncontrolled co-morbid disease.

Choosing the primary outcome.

Self-efficacy outlined in chapter one is a person's self-perceived belief in achieving desired outcomes and is frequently referred to in terms of control in managing the symptoms of a disease (198). It provides a simple framework from which to evaluate progress in acquiring confidence in self-management behaviours and has been used in the evaluation of bronchiectasis self-management (272). The 6-item Self-Efficacy Measure for Chronic Disease (SEMCD) (293) was chosen by our public and patient advisors as being succinct (0ne page) and easy to complete with only six questions each measured on a ten point scale evaluating confidence. 154 participants would give 80% power to detect a treatment difference (two sided 5% significance) of 1 unit of the SEMCD with a standard deviation of 2.2 units. Self-report questionnaires received by participants every 3 months for a year measured quantitative outcomes. Secondary outcomes measured included St George's Respiratory Questionnaire (SGRQ) (294), validated in bronchiectasis(295) (296), the EuroQol-5D 3 level version (EQ-5D-3L) (297), and cost questionnaires. The Lung Information Needs Questionnaire (LINQ) (298) assessed knowledge and behaviour and is validated for chronic obstructive pulmonary disease. Participants also received non-validated questionnaires evaluating knowledge and confidence in managing bronchiectasis, particularly exacerbations and the design/presentation of BET. The number of exacerbations of bronchiectasis (42), medical contacts and sputum analyses were obtained from cost questionnaires and hospital records.

Feasibility and acceptability of BET was investigated qualitatively through focus groups at the end of the study (299).

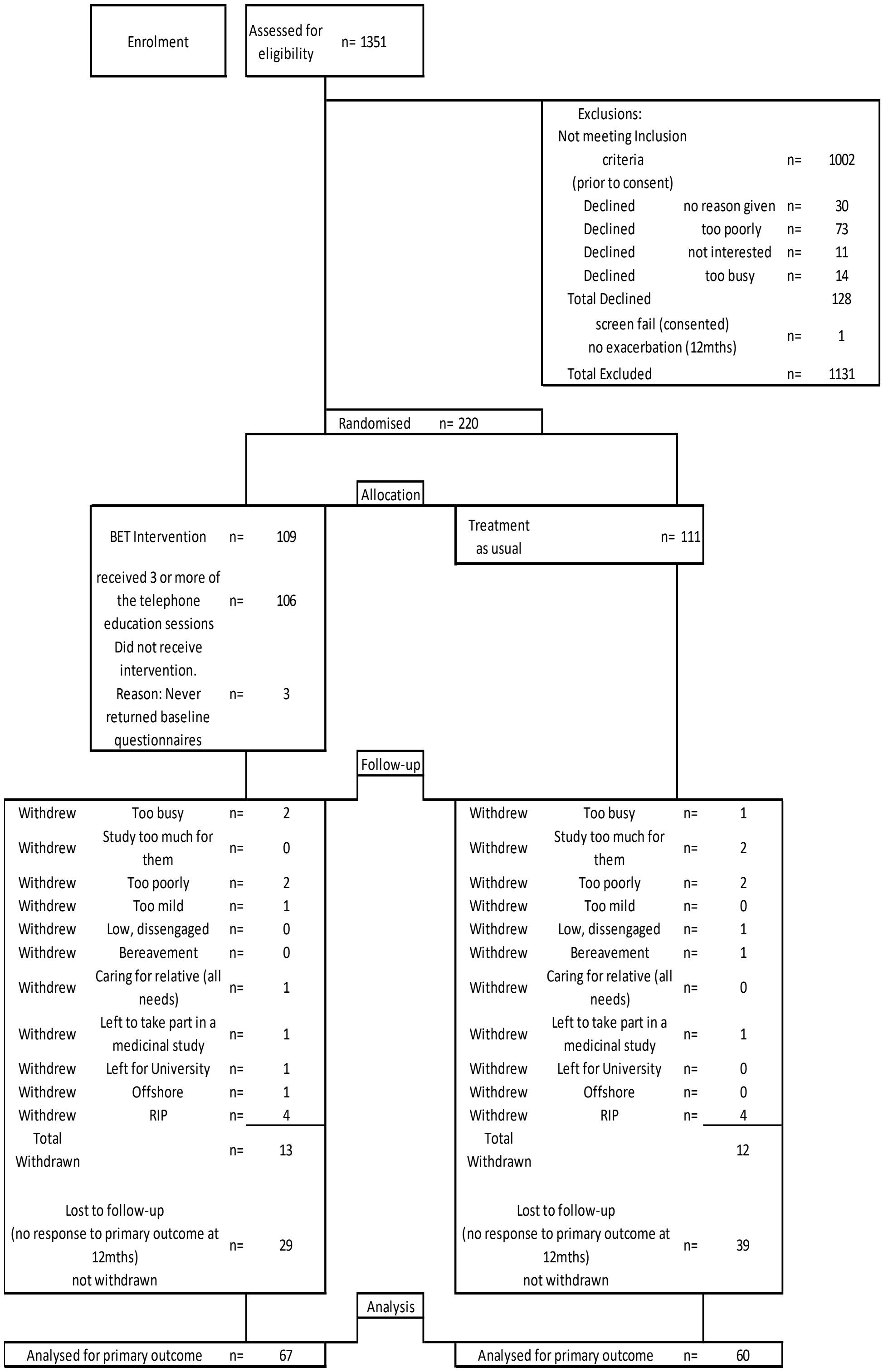
The hospitals involved included one bronchiectasis specialist centre with bronchiectasis specialist nursing support, 4 district general hospitals with specialist respiratory nursing support and 1 community hospital located within East Anglia, UK. Participation was for a twelve month period and outcomes were measured as changes from baseline. Study recruitment was conducted from May 2013 to April 2015 with follow-up the study completed in April 2016.

Eligible participants were randomised to the intervention or control groups on a 1:1 basis using a computer generated code created by the study statistician with stratification according to hospital centre and severity of disease (four or more exacerbations in the last 12 months versus less than four) code concealment in sequential opaque envelopes. Unblind researcher CB enrolled participants and assigned sequential envelopes.

Participants randomised to the intervention received the BET document (48 pages) plus education provided by researcher CB (to promote standardisation and reduce the chance of cross-contamination of the control group) via four brief semi-structured telephone interactions including how to use the action plan, information, monitoring and reference sections.

Participants were encouraged to practice using the tool and ask questions, a contact number was provided for information about the study and use of BET (not for clinical queries). Participants' healthcare providers were informed of their participation within the trial. No additional care was provided to the treatment as usual comparison group who continued to be guided by their usual health practitioners at routine appointments.

Figure 5 BET enrolment and retention



Data were double entered using Microsoft Excel software and discrepancies resolved by re-examining the source data. LINQ was analysed using the LINQ Scoring Tool (www.linq.org.uk). The Bronchiectasis Aetiology Co-morbidity Index was calculated from clinical data (56). Analysis was based on an intention-to-treat approach. Changes from baseline for primary and secondary endpoints was compared between groups using a general linear model adjusted for the stratification of severity used in the randomisation schedule. Total exacerbations and unscheduled care were both compared using negative binomial regression and reported as the incidence rate ratio which is the ratio of the event rates between the study arms. Adjusted analyses were undertaken with adjustment for baseline values of the outcomes. The analysis of LINQ subscales were based on a Mann-Whitney test as the values were not normally distributed.

Transcribed recordings of the semi-structured focus groups were reviewed in relation to personal self-management and the acceptability and utility of BET then analysed in parallel to increase rigour (300). Microsoft Office Excel and qualitative data analysis software (Nvivo11) were used to perform an inductive thematic analysis where patterns and clusters of linked data were organised into themes (301, 302)

Economic evaluation

The intervention consisted of four separate telephone education sessions provided by a specialist nurse, who would require 2 hour 1:1 training if delivered in clinical practice. Costs were calculated with time for preparation and arranging of phone calls and the BET booklet. These intervention costs were totalled and apportioned equally across all the intervention group participants. Costs were estimated from the perspective of the NHS. In the cost questionnaires, participants reported;
i) hospital visits (out-patient, day-case and in-patient admissions) and ii) community health visits (GP, practice nurse, physiotherapist and any other health professional contacts). Unit costs were assigned to all items of resource use (£GBP for the 2014-15 financial year) (303, 304). Responses to the EQ-5D-3L were converted into utility scores (305) using the UK York A1 tariff (306). Quality Adjusted Life Year (QALY) scores were subsequently calculated using the area under the curve approach (307).Multiple imputation was performed to account for missing cost and outcome data (308).

Regression analysis (309) was subsequently used to estimate the mean incremental cost between the two groups (mean difference in cost) and the mean incremental effect (QALY).

Patient and public involvement (see also appendices)

Patient and public advice during all stages (design, conduct, analysis and preparation for publication) of this trial improved patient-centric considerations and accessibility of reporting. The multiple ways in which we were assisted by our patient and public advisors are presented on the table 4 (next page).

Table 4 Patient and public involvement

Tabular consolidation of PPI using Staley Model: Context, Mechanism & Expected Outcome
Staley K. 'Is it worth doing?'Measuring the impact of patient and public involvement in research. Research Involvement and Engagement. 2015;1(1):6.

Task	Advisors	Context	Mechanism	Expected Outcome	Duration of advice
Evaluation of self-management needs and challenges of people with bronchiectasis	Fifty people identified by their secondary care clinician were telephoned and asked whether they wished to comment and felt the need for guidance relating to the self-management of bronchiectasis and whether they would welcome a self-management	Patients were telephoned at home and asked whether they were happy to give an opinion relating to the question (calls lasted less than five minutes).	1 to 1. Telephone calls in the evening from a respiratory nurse.	An understanding of whether this population felt the need for self-management guidance.	Less than 5 minutes - only once
Self-management document development brainstorming	Two advisors one of whom Patricia Mason was happy to be named and the other Male advisor with a scientific background preferred to remain anonymous. Specialist bronchiectasis clinician. Respiratory Research Clinician. Nurse researcher / facilitator. A flip chart and post-its were used to explore	In a large purpose built meeting room within the clinical research and trials unit at the University of East Anglia	Five people present in a pre-arranged meeting post-it recorded ideas	Futher exploration of what is and isn't possible and useful within a written document	1.5 hrs (Patricia Mason 2 year advice giving, anonymous adviser 1 year advice).
To design a document supporting self-management	Two advisors one of whom Patricia Mason was happy to be named and the other Male advisor with a scientific background preferred to remain anonymous. Advised on a one to one basis 45 mins at a time with the nurse researcher/study co-investigator to discuss the content and development of the bronchiectasis self-management document	Patricia Mason preferred to meet in her own home and the male advisor preferred to meet in a trials meeting room within the University of East Anglia (purpose built meeting room).	1 to 1 Pre-arranged meetings to evolve and comment on the self-management document	A refinement and evolution of the self-management document to make it user-friendly and informative	advised during grant submission period (2 years) 3 meetings each lasting 45 minutes 1 to 1 in addition to telephone calls and review of funding submissions
Evaluation of the Bronchiectasis Self-Management Study Design, protocol and outcome measures	PPIRes advisor was sent the documentation by mail and responded in writing	Documentation regarding the study design, protocol and outcome measures were sent by the respiratory research clinician to the PPIRes service and forwarded by mail to the advisor.	Written response no 1 to 1 meeting	Insight into feasibility and acceptability from a patient and public perspective.	Duration of evaluation unknown but likely more than 1 hour (once)
Immediate feedback to draft self-management document	6 patients awaiting clinic appointments within the hospital environment were invited and accepted the task of reviewing a draft self-management document and providing feedback.	1 to 1 evaluation with a research nurse following a semi-structured questionnaire format.	Completion during a 1 to 1 interview of a semi-structured questionnaire - see appendix 12	Brief pilot of patient reaction to draft self-management document	15 mins once
Steer the project from a bronchiectasis patient and public perspective	Cathy Spinks and Morag Butcher attended all project steering meetings	Conducted in a very large meeting room on the second floor of a purpose built research and academic building within view of the hospital. Agenda, attendee roles and synopses and name labels.	Interaction during meetings (lasting 1 hour each time)	Maintain a realistic patient-centred focus to the progress	Meetings lasting one hour each taking place six monthly for three years
Advise on content and conduct of the qualitative focus groups	Cathy Spinks and Morag Butcher agreed to take part in 'mock' focus group meeting with Nurse researcher and expert qualitative advisor/supervisor	Review of focus group data in a small meeting room within an academic environment, both advisors, nurse researcher, qualitative advisor/supervisor present.	By reviewing the topic guide, invitations and advising on the actual conduct, style etc	More polished and patient-centric focus group delivery.	In person 1.5hrs (also steering members for 3 year duration of the trial)
Review of patient outcome measures	Patient Research Ambassadors Noreen Neal and Rosalinde Bailey	2 meetings of 1 hour in duration with the nurse researcher and both the research ambassadors present. Conducted in a meeting room within an academic building within sight of the hospital.	Both advisors were provided with all the outcome measures and asked to comment on all aspects of format and completion.	Obtain a better understanding of factors that may have affected attrition within the study.	2 meetings of 1 hour in duration. The ambassadors provided advice spread over a two year period
Qualitative Focus group review and analysis	Patient Research Ambassadors Noreen Neal and Rosalinde Bailey	2 meetings of 1 hour in duration with the nurse researcher and both the research ambassadors present. Conducted in a meeting room within an academic building within sight of the hospital.	Both advisors were provided with the anonymised transcripts to absorb without any guidance or agenda then their impressiona were explored in a relaxed interchange. This was the advisors first experience with qualitative data	To get patient and public feedback on qualitative aspects without creating pre-conceptions and assumptions.	2 meetings of 1 hour in duration the ambassadors provided advice over a two year period
Review of thesis from a patient and public perspective	Geoffrey Spittle (initially patient research ambassador)	Meetings of two hours each to discuss each chapter, generally in an academic meeting room but sometimes at Geoff's home.	Mailing the written document and discussing feedback.	To encourage clarity, transparency and accessibility of the thesis.	Regular advice over a 2 year period.

Results

The intention to treat analysis included 220 randomised patients (Figure 5). They had an average (standard deviation) age of 66.9 (12.0) years, forced expiratory volume in 1 sec (FEV1) 1.84 (0.69) L, SEMCD 7.02 (2.0), SGRQ 42.4 (19.1), average time from diagnosis was 11.02 (15.2) years and 69 (31.4 %) were male. The two groups were well balanced at baseline and hence no adjustment to the analysis was required to account for baseline factors (Table 5). The withdrawal rate was higher than expected with only 127 individuals returning the primary outcome questionnaire at 12 months.

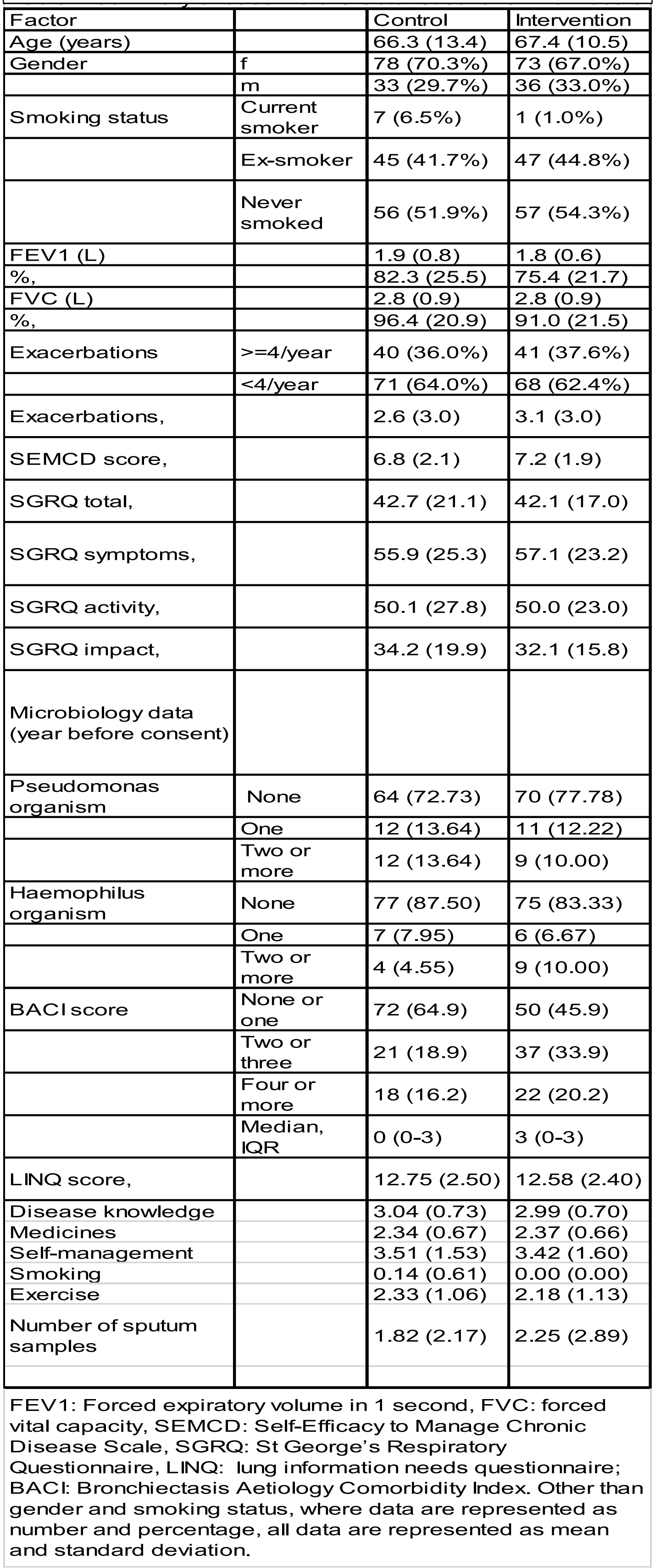
Participant comment:

> "*I think I do understand what is required but forms, oh no, I'll do what I can!*"

There was no difference in the change in SEMCD between the two groups studied. The data were very slightly negatively skewed, but re-analysis using the bootstrap with 1,000 iterations gave similar results particularly for the adjusted analysis (unadjusted p=0.96, adjusted p=0.60). There were no significant differences between intervention and control for change in SGRQ, exacerbation rate, LINQ score or sputum microbiology requests (Table 6). In addition there were no differences between the intervention and control at any of the three month time points for any of the variables (online repository). Both groups were confident in managing their condition at the end of the study (Table 7).

Table 5 Baseline Characteristics

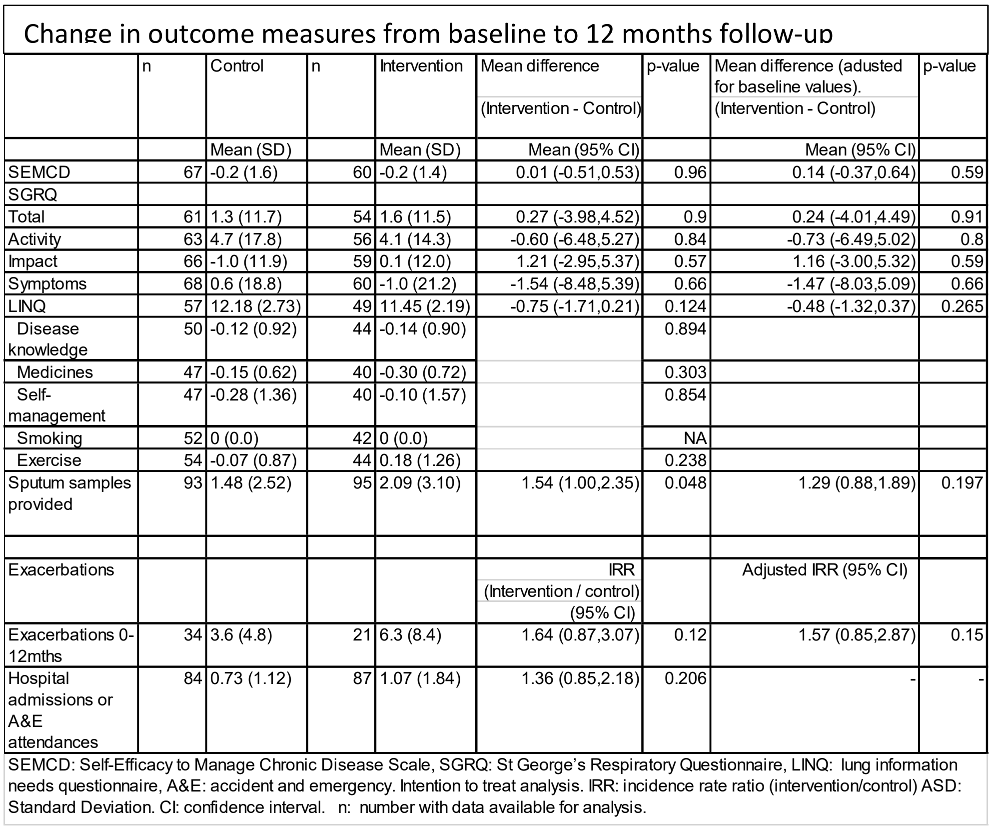
Baseline characteristics of BET participants



Factor		Control	Intervention
Age (years)		66.3 (13.4)	67.4 (10.5)
Gender	f	78 (70.3%)	73 (67.0%)
	m	33 (29.7%)	36 (33.0%)
Smoking status	Current smoker	7 (6.5%)	1 (1.0%)
	Ex-smoker	45 (41.7%)	47 (44.8%)
	Never smoked	56 (51.9%)	57 (54.3%)
FEV1 (L)		1.9 (0.8)	1.8 (0.6)
%,		82.3 (25.5)	75.4 (21.7)
FVC (L)		2.8 (0.9)	2.8 (0.9)
%,		96.4 (20.9)	91.0 (21.5)
Exacerbations	>=4/year	40 (36.0%)	41 (37.6%)
	<4/year	71 (64.0%)	68 (62.4%)
Exacerbations,		2.6 (3.0)	3.1 (3.0)
SEMCD score,		6.8 (2.1)	7.2 (1.9)
SGRQ total,		42.7 (21.1)	42.1 (17.0)
SGRQ symptoms,		55.9 (25.3)	57.1 (23.2)
SGRQ activity,		50.1 (27.8)	50.0 (23.0)
SGRQ impact,		34.2 (19.9)	32.1 (15.8)
Microbiology data (year before consent)			
Pseudomonas organism	None	64 (72.73)	70 (77.78)
	One	12 (13.64)	11 (12.22)
	Two or more	12 (13.64)	9 (10.00)
Haemophilus organism	None	77 (87.50)	75 (83.33)
	One	7 (7.95)	6 (6.67)
	Two or more	4 (4.55)	9 (10.00)
BACI score	None or one	72 (64.9)	50 (45.9)
	Two or three	21 (18.9)	37 (33.9)
	Four or more	18 (16.2)	22 (20.2)
	Median, IQR	0 (0-3)	3 (0-3)
LINQ score,		12.75 (2.50)	12.58 (2.40)
Disease knowledge		3.04 (0.73)	2.99 (0.70)
Medicines		2.34 (0.67)	2.37 (0.66)
Self-management		3.51 (1.53)	3.42 (1.60)
Smoking		0.14 (0.61)	0.00 (0.00)
Exercise		2.33 (1.06)	2.18 (1.13)
Number of sputum samples		1.82 (2.17)	2.25 (2.89)

FEV1: Forced expiratory volume in 1 second, FVC: forced vital capacity, SEMCD: Self-Efficacy to Manage Chronic Disease Scale, SGRQ: St George's Respiratory Questionnaire, LINQ: lung information needs questionnaire; BACI: Bronchiectasis Aetiology Comorbidity Index. Other than gender and smoking status, where data are represented as number and percentage, all data are represented as mean and standard deviation.

Table 6 Change in outcome measures base to 12 months



Change in outcome measures from baseline to 12 months follow-up

	n	Control	n	Intervention	Mean difference (Intervention - Control)	p-value	Mean difference (adusted for baseline values). (Intervention - Control)	p-value
		Mean (SD)		Mean (SD)	Mean (95% CI)		Mean (95% CI)	
SEMCD	67	-0.2 (1.6)	60	-0.2 (1.4)	0.01 (-0.51,0.53)	0.96	0.14 (-0.37,0.64)	0.59
SGRQ								
Total	61	1.3 (11.7)	54	1.6 (11.5)	0.27 (-3.98,4.52)	0.9	0.24 (-4.01,4.49)	0.91
Activity	63	4.7 (17.8)	56	4.1 (14.3)	-0.60 (-6.48,5.27)	0.84	-0.73 (-6.49,5.02)	0.8
Impact	66	-1.0 (11.9)	59	0.1 (12.0)	1.21 (-2.95,5.37)	0.57	1.16 (-3.00,5.32)	0.59
Symptoms	68	0.6 (18.8)	60	-1.0 (21.2)	-1.54 (-8.48,5.39)	0.66	-1.47 (-8.03,5.09)	0.66
LINQ	57	12.18 (2.73)	49	11.45 (2.19)	-0.75 (-1.71,0.21)	0.124	-0.48 (-1.32,0.37)	0.265
Disease knowledge	50	-0.12 (0.92)	44	-0.14 (0.90)		0.894		
Medicines	47	-0.15 (0.62)	40	-0.30 (0.72)		0.303		
Self-management	47	-0.28 (1.36)	40	-0.10 (1.57)		0.854		
Smoking	52	0 (0.0)	42	0 (0.0)		NA		
Exercise	54	-0.07 (0.87)	44	0.18 (1.26)		0.238		
Sputum samples provided	93	1.48 (2.52)	95	2.09 (3.10)	1.54 (1.00,2.35)	0.048	1.29 (0.88,1.89)	0.197
Exacerbations					IRR (Intervention / control) (95% CI)		Adjusted IRR (95% CI)	
Exacerbations 0-12mths	34	3.6 (4.8)	21	6.3 (8.4)	1.64 (0.87,3.07)	0.12	1.57 (0.85,2.87)	0.15
Hospital admissions or A&E attendances	84	0.73 (1.12)	87	1.07 (1.84)	1.36 (0.85,2.18)	0.206	-	-

SEMCD: Self-Efficacy to Manage Chronic Disease Scale, SGRQ: St George's Respiratory Questionnaire, LINQ: lung information needs questionnaire, A&E: accident and emergency. Intention to treat analysis. IRR: incidence rate ratio (intervention/control) ASD: Standard Deviation. CI: confidence interval. n: number with data available for analysis.

Table 7 Patient self-evaluation of knowledge and confidence

Patients self-evaluation of their knowledge and confidence with bronchiectasis

	number		number		
		Number (percentage)		Number (percentage	P
I do NOT feel confident in deciding when I need treatment	53	5 (9.4)	43	3 (7.0)	0.727*
I know which bacteria grows in my sputum/phlegm	48	18 (37.5)	41	15 (36.6)	0.929+
Sputum sample sent for testing…	50		41		0.111*
..when I last had a flare up		25 (50)		28 (68.3)	
..within the last 6 months		3 (6)		0 (0)	
..within last 12 months		22 (44)		13 (31.7)	
Home supply of antibiotics	48		41		0.969*
I have a home supply & know when to use them		38 (79.2)		32 (78.1)	
I have a home supply but I don't feel confident starting them		3 (6.3)		2 (4.9)	
I **don't** have a home supply but would like to have some.		3 (6.3)		4 (9.8)	
I **don't** have a home supply but I don't want the responsibility		4 (8.3)		3 (7.3)	
I feel confident that I understand my condition, how to get it treated when necessary and explaining it to family or friends.	41	37 (90.2)	29	29 (96.6)	0.395*

The analysis was conducted by * Chi-squared test and + Fisher's exact test.

The cost of 2 hours training was estimated at £176. It took an estimated 15 minutes per participant to arrange the phone calls and an average of 10, 7, 5 and 2 minutes for the four telephone education sessions. Three participants had no sessions, two had 3 sessions and 104 had all four sessions. The total cost of the booklets (printing) was £245.00. After summing these costs, and apportioning them across all 109 intervention participants, the cost of the intervention was estimated to be £40.11 per participant. Table 8 summarizes the mean QALY scores. After conducting multiple imputation for the other NHS costs and EQ-5D-3L scores, the regression analyses estimated the mean incremental cost for the intervention group, compared to the control group, to be £355.94 (95% confidence interval (CI) –£444.97 to £1156.85) and the mean QALY score to be 0.006 higher (95% CI –0.042 to 0.053). This resulted in an incremental cost-effectiveness ratio (ICER) of £64,223. According to the Cost Effectiveness Acceptability Curve (CEAC) there was a 36.3% probability that the intervention was cost-effective at a λ of £20,000 per QALY Qualitative evaluation of acceptability demonstrated that less than half the participants of the focus groups utilised the BET document. Seven of eight, felt the need for support, not necessarily in the form of BET. Most participants already had their own techniques for monitoring their condition. One of them said

> ‘*A lot of the things in there I already knew, but not everybody would, particularly the newly diagnosed wouldn’t’.*
>
> Another said
>
> *‘(…) what I would do is make it slightly simpler, I felt that sometimes I was repeating things. When you are filling it in, you are not well at the time and that makes it more difficult. I think that if someone could have reviewed my progress with me and guided me it might have been even more successful’.*

Those that used BET reported having gained a clearer and better insight into the presentation and duration of their symptoms.

> “*Without that [meaning BET] I would have been lost]… [I was able to take the BET booklet with me to appointments and let them know what worked effectively and what wasn’t]…[when I went to the hospital I was able to say Meropenem and Tobramycin IVs to Dr R*.]”

the importance of self-management facilitating treatment because it would be "*good not to wait until things are an emergency*". "*I think that support is my biggest issue*" Support in self-management is limited due to low specialist resource "*currently there is much more demand than specialist nurse time*". The need for individualised interaction was discussed

Table 8 Quality adjusted life years for intervention and control

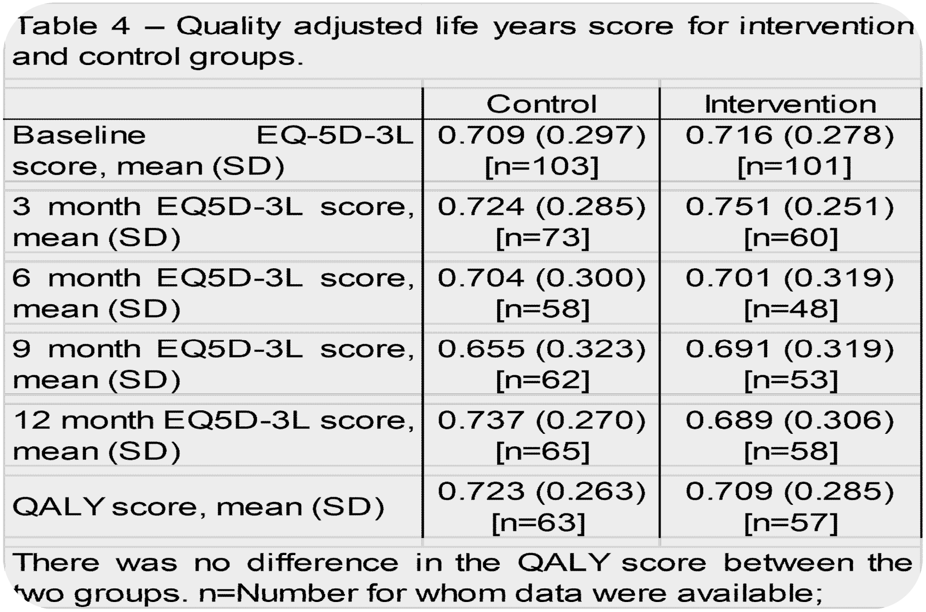


Table 4 – Quality adjusted life years score for intervention and control groups.

	Control	Intervention
Baseline EQ-5D-3L score, mean (SD)	0.709 (0.297) [n=103]	0.716 (0.278) [n=101]
3 month EQ5D-3L score, mean (SD)	0.724 (0.285) [n=73]	0.751 (0.251) [n=60]
6 month EQ5D-3L score, mean (SD)	0.704 (0.300) [n=58]	0.701 (0.319) [n=48]
9 month EQ5D-3L score, mean (SD)	0.655 (0.323) [n=62]	0.691 (0.319) [n=53]
12 month EQ5D-3L score, mean (SD)	0.737 (0.270) [n=65]	0.689 (0.306) [n=58]
QALY score, mean (SD)	0.723 (0.263) [n=63]	0.709 (0.285) [n=57]

There was no difference in the QALY score between the two groups. n=Number for whom data were available;

Discussion and Conclusions

The BET intervention did not improve self-efficacy. Enthusiasm for participation confirmed the need for self-management support and coinciding with the patients' and carers' research priorities published in 2016 by the EMBARC Clinical Research Collaboration (310). The intervention was in written format, as suggested in the BTS Bronchiectasis Guidelines 2010 (1), delivered with telephone education, these methods kept costs low and created an easily transferable intervention within existing technologies and established healthcare. The telephone education, personal and easily individualised to knowledge and support needs, was appreciated by participants and permitted efficient delivery over a large geographic area. Telephone contact may also help combat the isolation frequently reported in chronic disease (311) and provide opportunity for encouragement (312) .

According to the CEAC there was a 36.3% probability that the intervention was cost-effective at a λ of £20,000 per QALY but there is insufficient data to apply this with confidence. Unfortunately, the study was underpowered due to higher than expected withdrawals. Possible reasons for withdrawal include the burden of literacy represented by the intervention (313) and also by the multiple patient reported outcome measures in their many different original presentations and scoring systems (314, 315). Only one bronchiectasis specific quality of life questionnaire was available when the study was conducted and our patient and public advisors felt that the language (not yet translated for the UK) was inappropriate. The validated questionnaires used, may be a poor fit for evaluating bronchiectasis particularly when completed repetitively (baseline and then quarterly). Initially, participants found the one page action plan guidance on seeking professional help reassuring, however, for some, appointments were not obtainable within the timescales suggested due to NHS capacity issues. This discrepancy between advised action and what is available may have confounded the empowerment and self-efficacy that the study sought to nurture.

Traditional healthcare is conducted in face-to-face consultations, contrasting with BET guidance in written format with only a small amount of telephone education (24mins), designed to fit with existing services without encumbering an already financially stretched NHS. Conflicting messages regarding antibiotic use are a particular barrier to this patient group where media messages, specialist secondary/tertiary care advice and primary care delivery may differ. This research was inclusive, representing the real-world heterogeneity within people affected by this disease (51). Co-morbidities were not excluded although these are likely to affect the quality of life outcome responses (56). Generational health attitudes may affect empowerment. Both the intervention and treatment as usual groups received the BLF patient information and the BTS physiotherapy guidance for bronchiectasis. During enrolment procedures all participants reviewed their routine medications with a respiratory nurse who also clarified awareness of respiratory physiotherapy services and pulmonary rehabilitation. This high quality information and optimised treatment might minimise differences between the groups. The Bronchiectasis Empowerment Tool consistent with guidelines, forms a coherent foundation for future research.

Challenges for future research:-

- Intervention and evaluation adaptation to methods requiring less literacy.
- Reduction of the evaluation burden presented by multiple, different, patient reported outcome measures.
- assessment of the impact of co-morbidities on the well-being of the whole person and hence their self-efficacy, mood and quality of life.
- Intervention that dovetails with the self-management of other chronic co-morbidities
- Increasing the support and follow-up for bronchiectasis self-management as part of a life-long adaptive process - diabetes standards suggest greater than 10 hours of support (276)
- Consideration of how the intervention would be utilised in a fully integrated and collaborative person-centred care environment – preparatory sub-studies to evaluate the opportunities and pitfalls for this although the diversity of healthcare provision within the UK NHS make this a difficult task.
- Integration with existing multi-disciplinary services (avoided to prevent cross-contamination between the intervention and control group during the study) are necessary to re-enforce self-management skills coherently throughout all aspects of care. Measuring this re-enforcement may throw light on important mechanisms and processes to encourage this.
- Investigating the influences of age/generational disparities on submissive or collaborative attitudes to health.
- A stepwise building-block approach to the provision and acquisition of skills for the self-management of bronchiectasis is necessary to accommodate a variety of cognitive abilities, personal circumstances and disease severities. Knowledge acquired early may reduce fear and help inspire the individual's health promotion activity to limit disease progression. When the disease has progressed and symptoms become more troublesome the individual is more likely to be receptive to learning self-management skills and engaging collaboratively in self-management actions to minimise symptoms. This engagement is a personal burden that must be balanced to provide that individual with maximum quality of life whilst minimising the impact of disease and treatment

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Chapter 4

Qualitative aspects of BET

Participants’ self-management insights

Chapter 4

Qualitative aspects of BET: Part 1

Participants' self-management insights

Qualitative Part 2

FOCUS GROUP EVALUATION OF THE ACCEPTABILITY OF BET

Qualitative Part 3

Health professional interviews

-

Qualitative Part 1 -

Background

Though only randomised controlled trials, systematic reviews and meta-analyses were considered in assessing quantitative evidence for self-management the papers evaluated below provide useful insight into the need for self-management in bronchiectasis from a patients' perspective.

Table 9 Paper evaluation matrix

3	Medline and Pubmed	Paper Ref	**Lavery K, O'Neill B, Elborn J, Reilly J, Bradley J. Self-management in bronchiectasis: the patients' perspective. European Respiratory Journal. 2007;29(3): 541-7.**
		Design & Participants	Qualitative study recruiting 39 participants from Belfast City Hospital, 32 attended four focus groups.
		Aims	To assess the physical & psychosocial impact of bronchiectasis to determine whether patients with bronchiectasis are receptive to self-management & to identify obstacles or sources of support for a disease-specific self-management programme.
		Data Collection	Videotaped focus groups conducted by experienced moderator.
		Key Findings	Bronchiectasis has impact on patients physical and psychosocial wellbeing. Obstacles to self-management included lack of information & confidence.
		Strengths	Displayed clearly that the patient group studied are receptive to self-management. The iterative nature of the study data reviews and debrief sessions was particularly strong.
		Limitations	A well-presented study that might have benefitted from a comparative group from community based practice.
4	Medline and Pubmed	Paper Ref	**Hester KL, Newton J, Rapley T, De Soyza A. Patient information, education and self-management in bronchiectasis: facilitating improvements to optimise health outcomes. BMC pulmonary medicine. 2018;18(1):80.**
		Design & Participants	Expert opinion with literature review and evaluation of grey literature related to bronchiectasis available to the general public .
		Aims	Draws attention to the lack of information provision available to people with bronchiectasis in comparison with other respiratory conditions
		Data Collection	None - Literature review
		Key Findings	The need for evidence based information resources for people with bronchiectasis
		Strengths	Draws attention to the need for information resources
		Limitations	Expert opinion is low on the evidence pyramid. No data considered. Did not consider how to make information inclusive and reduce barriers of literacy

The qualitative paradigm pivots on the unique nature of each person's experience relative to their social environment, knowledge and previous life experiences. Combined quantitative and qualitative research provides opportunities to examine vivid personal perspectives that give insight into the acceptability of proposed interventions, the impact of research methods and the lived experience of how both affect or are affected by personal circumstances and understandings.

Lewin suggested in 2009 that mixed methods randomised controlled trials of healthcare interventions were uncommon (299). It seems counter-intuitive to neglect evaluation of the acceptability of healthcare interventions and their feasibility to the individuals using them. Ignoring the informative value of human response in the development and implementation of health interventions shows a disregard for the diversity of populations in personal, social, financial, psychological and physical terms. Qualitative evaluation provides an opportunity to view the complexities of self-management from an individual perspective. Health itself affects human experiences, behaviour and the social world they inhabit (316). Seeking to comprehend the resulting opinions, attitudes and behaviours is crucial to addressing the self within self-management. Diversity and complexity of illness experience and of self-management action and strategy are reported by Moore *et al.* (317) and also Haidet *et al.* (318) who consider self-management worthy of further investigation. Greenhalgh (319) suggests that self-related discourse and narrative accounts contain explanatory features such as what happened and what was done, cognitive progress and burgeoning understanding that sheds light on what was expected or unexpected. Narratives frequently describe relationships and environments as well as trends of what happens. Personal and societal expectations are made more evident.

This qualitative evaluation is presented in three distinct sections. A thematic analysis approach unites all three. This flexible method provided an uncomplicated means by which to aggregate, interpret and illustrate the expressed responses of the participants in relation to their self-management. It permitted the analysis of a very large qualitative data set and two smaller ones obtained by three different methods (narrative jottings, focus groups and interviews) to arrive at combined explanatory detail relating to; the context of self-management, use of the BET intervention and NHS care for bronchiectasis in the East of England.

The identification of patterns in the data represented and discussed here provide a vivid understanding of the opportunities and pitfalls faced by people with bronchiectasis in their self-management. The reflexive methodology espoused by Braun and Clarke often associated with the exploration of social justice (301) proved particularly pertinent to seeking to redress the paucity of information and lack of equity in services available to this poorly served population.

In this chapter data the real-world perspectives of self-management experienced by people with bronchiectasis within the East of England and of health professionals tasked with the self-management of bronchiectasis derived from the BET trial are presented and interpreted. This compatibility of thematic analysis with a mixed-methods approach unites the quantitative and qualitative paradigms within this thesis enabling a blended interpretation of the opportunities and barriers to the self-management of bronchiectasis. Triangulation is presented by Mays and Pope (320) as a method with which to encourage a more reflexive analysis of data. By comparing two or more data sources or two or more methods of data collection triangulation provides different viewpoints from which to synthesise interpretation. Full methodological triangulation was not envisaged in the design of the BET trial but would be undertaken by the trial team in future research. This change in the researcher's theoretical and methodological outlook reflects the evolving development of qualitative research skills obtained through experience of the trial and concurrent doctorate of philosophy studentship.

Unfettered by the restrictions imposed by a quantitative approach the methodology embraced by Braun and Clarke is highly reflexive and qualitative in nature. They advocate use of thematic analysis as a flexible explanatory and interpretive analysis tool set firmly in the qualitative paradigm. It is used here to celebrate the subjective nature of human response and inherently in researcher interpretation.

Researcher reflexivity

Reflexivity is an awareness of the influence of researchers on assumptions made, methods used, research processes, and their effect on the conduct and interpretation of research (320).

A post-positivist (321) approach in which the influence of the researcher on the research is adopted here in combination with aspects of social constructivism (322) in which resource and social construct affects the path of research. In these paradigms peoples' realities are thought to be socially embedded (323). When verbal qualitative research data is collected and analysed it is impossible for the researcher to erase their own previous knowledge and preconceptions. Acknowledging these is the object of reflexivity, allowing the reader to evaluate the influence of the researcher on the design and ultimately on the findings and interpretation of the piece.

Far from seeking the objective distance prized in quantitative research the researcher is openly presented here for evaluation (324).

Figure 6 on the following page together with the narrative below is designed to summarise this researcher's experience to give insight into formative events influencing point of view. Inviting the reader to consider the researcher's influence as well as the findings and analysis presented.

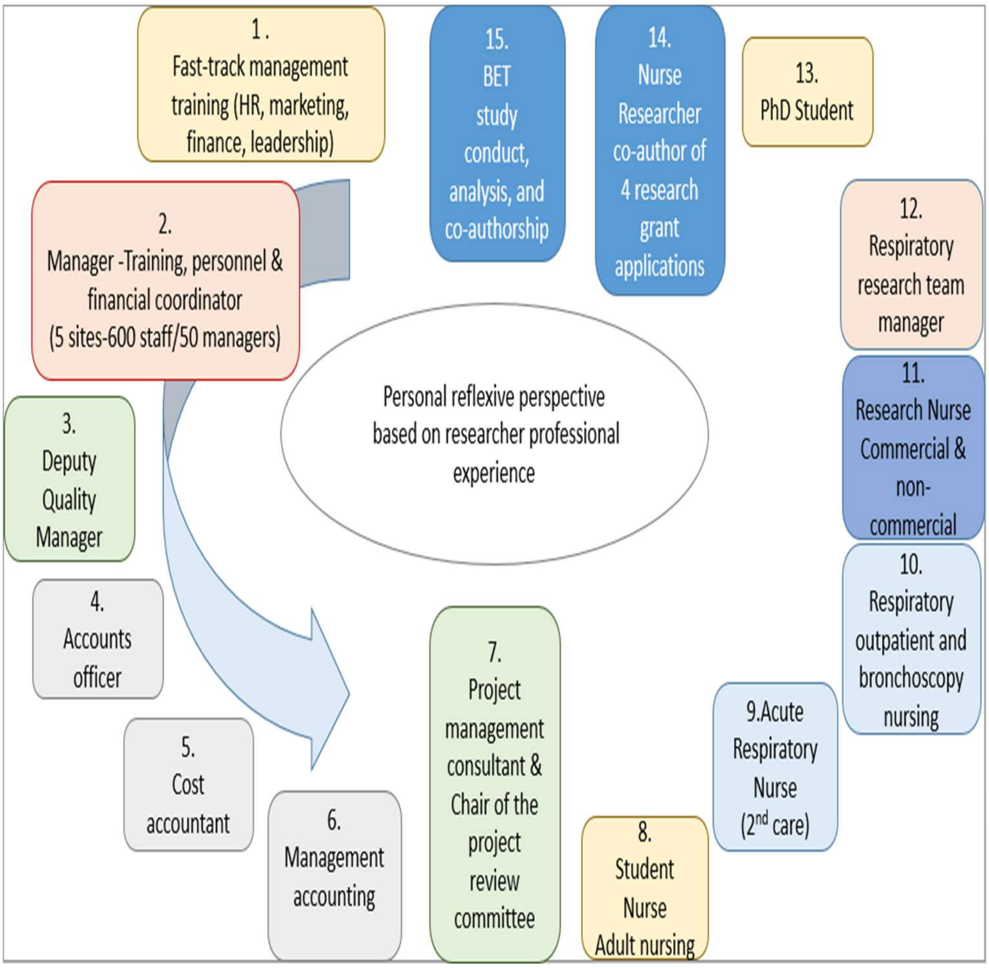
In childhood, discussion and verbal debate were encouraged. Schooling reinforced reasoned thought in written format and further education emphasised the derivation of thought and the source of evidence.

My employment provides an overview of my opportunities build knowledge and skills and experience in different environments. As a teenager whilst studying for 'A' levels I was employed part-time in various customer facing roles in which problem-solving, communication, professionalism, teamwork and meeting people's expectations were important.

In the figure (next page) an employment history commences (1. and 2.) within a work-based training programme blending psychological aspects of personnel recruitment, support, motivation and management, planning, communication and organisational skills provided by an international organisation with a lean operational and financial model and strong strategic direction. Communication, leadership, coaching, public image and interaction in the local community and promotion of quality and brand identity were integral to this role in which I became responsible for the training, personnel and financial coordination of 600 staff and 50 managers within a highly governed environment.

(3.) The role of deputy quality management involved process engineering, standard operating procedure documentation, quality assurance and audit design, conduct and review. This role has many parallels with the design and conduct of research.
(4. to 6.) My various roles in accounting and finance involved largescale data and financial management to meet statutory requirements and inform strategic direction. The alignment and transfer of data between systems and companies to arrive at integrated high quality information and robust results.
(7.) As chair of a project review committee providing support to innovators preparing original proposals and following selection and funding assisting with project management support and monitoring to guide projects to successful completion.

Figure 6 Researcher characteristics and reflexivity



Key to diagram	
Numerics	Represent the chronology of work experience lowest earliest and highest most recent
Central Elipse	Represents personal perspective based on work (and personal) experiences
🟨	Education/ learning
🟧	Management
🟩	Quality/Project management
🟦	Nursing
🟦	Research
⬜	Finance/Accounting

(8 to 10) Training as a nurse and nursing practice involved assisting individuals with their physical, mental and to some degree social needs by applying anatomy, physiology, psychology and pharmacotherapy skills with problem-solving and interpersonal competencies to provide high quality healthcare as part of a multi-disciplinary team in an NHS acute hospital environment.

(11 to 12) The clinical research environment has been formative in my development as a researcher. Particularly conducting commercial trials, developing research proposals, protocols, study materials and grant proposals.

(13) Academic education undertaken during my PhD (masters modules on the following topics: introduction to research methods; further qualitative methods; further quantitative methods and promoting health through behaviour change) with guidance from my supervisors and advisors have aided my theoretical and practical researcher knowledge development and the conduct and evaluation of BET.

Methods

1. A plentiful sample of 1386 ‘jottings’ relating to the self-management experiences of 64 participants receiving the BET education and therefore relating to their own experiences of self-management prior to their use of the intervention. These experiences are aggregated into ten emergent themes. Less than 1% of the participant quotes are used to illustrate each code.
2. Two focus groups with semi-structured format were conducted with eight participants to appreciate the feasibility and acceptability of the BET intervention from the participant point of view. These are aggregated as barriers and opportunities for self-management and experiences with BET.
3. Two health professional interviews were conducted to seek the dual informed perspectives of these BET steering committee members with insight into the design of research into self-management in combination with their professional roles as consultant with specialist interest in bronchiectasis and community matron supporting patients with complex chronic disease needs with their self-management.

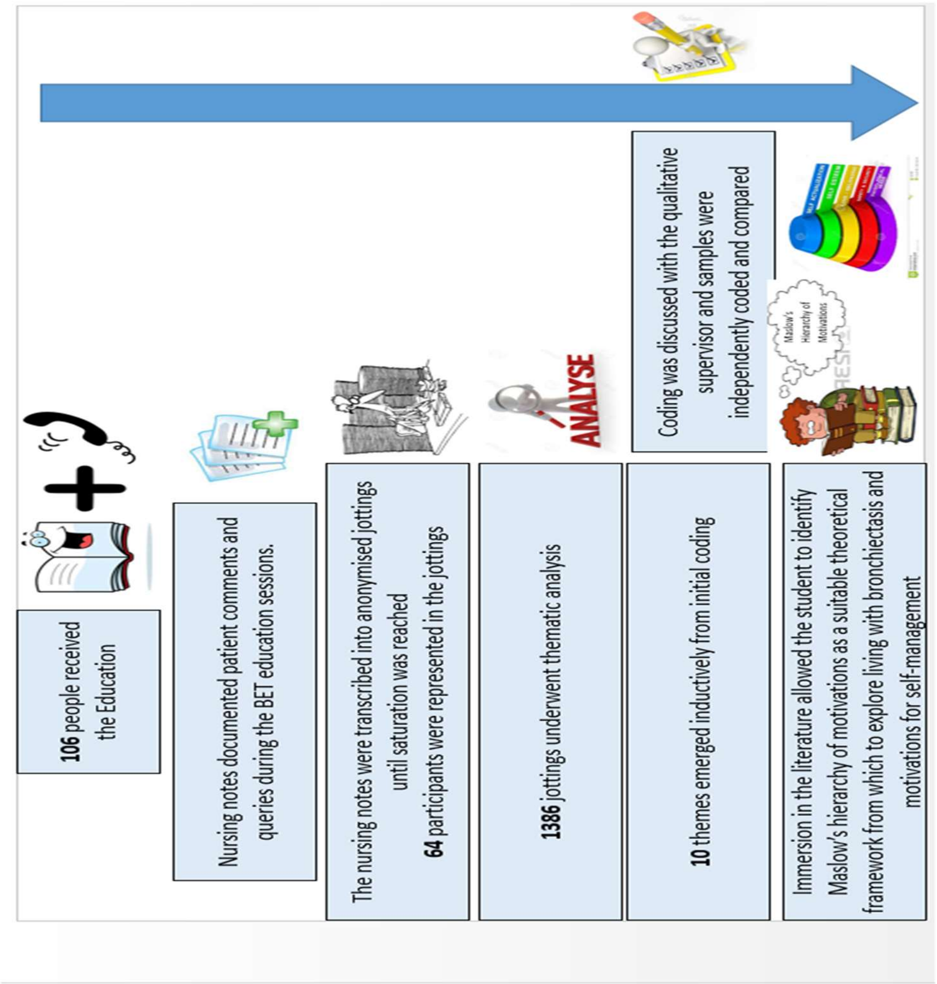
Context

As individuals we react to our environment. The goal of qualitative analysis is to observe, analyse and build an understanding of individuals and their interchanges, considering the physical, and emotional context of any data. Environment, timing and perception of control affect receptivity to information (325, 326).

The participants of BET were identified and invited to take part by their respiratory secondary care consultant (outpatient clinics provided the greatest numbers of potential participants). Patients who had expressed an interest in participation were then formally invited.

Participants were mailed a detailed patient information document on hospital headed paper (24 pages) in written format stating the aims, risks, benefits and requirements of participation. People expressing an interest after reading the information were invited to attend a face-to-face appointment at their usual hospital to further discuss the study with the researcher (a nurse in uniform) with a view to deciding whether to take part, known as informed consent.

Figure 7 Thematic analysis of jottings



Following informed consent a medical history was taken and evaluation of whether the individual met the study inclusion and exclusion criteria (detailed in the quantitative evaluation chapter) was made by the researcher. If the participant met these criteria the study questionnaires were given to the participant with a reply paid envelope and encouragement to telephone with any queries relating to completion. Some preferred to complete them in the waiting room.

Subsequent questionnaires were mailed at three month intervals to their home address with reply paid envelopes (brown first class).

The telephone education was arranged on consecutive days when possible and timed to suit the participant, with early morning, late evening and weekends chosen by some participants. Most participants' voices sounded more relaxed during the telephone education when at home in their own environment.

The exception to this relaxed and empowered reception of arranged telephone calls was a young mother who found it difficult to concentrate with small children around. She disclosed however, that if the education had taken place in clinic she would not have had the time to attend.

Sampling strategy

Participants enrolled in the BET trial were a purposive sample of people with a diagnosis of bronchiectasis (computerised tomography scan evidence) meeting the inclusion and exclusion criteria listed in the quantitative chapter and having suffered from one or more exacerbations within the past 12 months. The demographics tables on the previous two pages show the details of the 64 participants who provided qualitative jottings, eight of these individuals also attended the focus groups. Of the 109 BET participants randomised to the intervention 106 received telephone education. Nursing notes in the form of jottings were made to record what participants said about aspects of their self-management during the education. Figure 7 shows the process through which the jottings were collected and analysed. The notes helped guide and personalise the education permitting focus on the aspects of self-management that the individual was least informed or confident about and the brief and consecutive calls allowed practice and internalisation of the topics discussed. After the first education the first minutes of the following sessions began with a review of the previous topic to allow questions check understanding. These nursing notes – ‘jottings’ were transcribed in anonymised format in chronological order. Some participants said little during the interaction and these interactions were not transcribed. Nursing notes from over sixty individuals were transcribed before information became repetitive and saturation was deemed to have been reached (figure 7). Glaser and Strauss (1967) suggest that saturation is when new data does not shed further light on the issue studied (327).

Table 10 Patient Demographics – qualitative (2 pages)

Initials	Study No	Gender	Smoking status- never, ex, current	Age	year of diagnosis	<4 exacerbations	≥4 exacerbations	Co morbidities	1. Highest qualification	3. Total number of people in home	4. Marital status 1. SINGLE, 2. MARRIED, 3. SEPARATED/DIVORCED, 4. WIDDOWED
JS	1001	f	never smoked	70-80	8 years ago	y	0	3	GCSE	1	Widowed
JD	1003	F	never smoked	60-70	2001	y	0	3	NONE	0	
JRS	1023	m	never smoked		1998	y	0	1	NONE	3	Widowed
CRM	1025	f	never smoked	70-80	33 years ago	y	0	5	RSA	2	Married
NP	1026	f	ex smoker	50-60	0	y	0	5	MA	1	
NT	1032	m	never smoked	60-70	2011	y	0	6	NONE	2	Married
GJA	1033	m	ex smoker 1968-1993	60-70	2013		y	4	ENGINEER	2	Married
KWJ	1035	m	never smoked	70-80	2012		y	5	NONE	3	Married
PBS	1037	f	never smoked	60-70	0	y		3	NONE	2	Married
ST	1038	f	never smoked	50-60	2003		y	3	DEGREE	3	Married
CH	1043	M	ex smoker-started at 19 and stopped 2 years ago	50-60	2011	y		1	NURSE, TEACHER	2	Married
LS	1047	F	never smoked	70-80	2010	y		6	NONE	2	Married
NS	1050	M	ex smoker	70-80	2012		y	4	A LEVELS	2	Married
SKD	1051	F	never smoked	60-70	2012		y	2	GCSES	1	Separated/ Divorced
JW	1054	f	ex smoker started age 18 stopped 34 yrs ago	70-80	2010		y	5	NONE	2	Separated/ Divorced
DRE	1056	F	never smoked	60-70	2011		y	2	GCSE	2	Married
MN	1059	f	never smoked	70-80	2007		y	3	GCSE, HNC	2	Married
SM	1064	f	ex smoker	70-80	2012	y		6	GCSE, TEACHER	2	Married
MH	1069	f	ex smoker	60-70	2012	y		4	GCSE	2	Married
POC	1072	f	ex smoker	60-70	2013	y		5	NONE	2	Married
SGC	1073	f	ex smoker started 17 stopped at age 30	70-80	2013	y		7	NONE	1	Separated/ Divorced
SJ	1074	m	ex smoker started aged 16, daily 20	70-80	2013	y		2	ENGINEERING	2	Married
KAM	1075	m	never smoked	60-70	2010		y	3	NONE	2	Married
SLKL	1079	f	never smoked	40-50	2004	y		4	GCSE	4	Married
MB	1091	f	0	70-80	2003	y		1	NONE	2	Married
MON	1093	f	ex smoker started at 17, stopped 4 years later	70-80	1987	y		3	GCSE, NURSE/TEACHER,	1	Single
SAS	1094	f	never smoked	60-70	30 years ago		y	8	NVQ 1	2	Married
DL	1098	f	never smoked	60-70	0		y	3	NVQ, NURSE, TEACHING	2	Married
JD	1099	f	never smoked	70-80	0	y		5	NONE	2	Married
JCL	1103	m	never smoked	90-100	0	y		4	DEGREE	2	Married
MH	1110	m	never smoked	70-80	0		y	5	MSC	2	Married
PB	1116	f	never smoked	80-90	0	y		1	NONE	0	Single

Initials	Study No	Gender	Smoking status- never, ex, current	Age	year of diagnosis	<4 exacerbations	≥4 exacerbations	Co morbidities	1. Highest qualification	3. Total number of people in home	4. Marital status 1. SINGLE, 2. MARRIED, 3. SEPARATED/DIVORCED, 4. WIDDOWED
MCR	1120	f	never smoker	70-80	0	y		7	NVQ	2	Married
MJB	1123	f	never smoker	70-80	0		y	2	DEGREE	2	Married
JC	1128	f	ex smoker	80-90	2013		y	3	NONE	2	Married
RB	1130	m	ex smoker	70-80	2008		y	4	NONE	2	Married
WR	1135	f	ex smoker	70-80	1971		y	2	NONE	0	Married
JM	1137	f	never smoker	70-80	2004		y	7	NURSE, TEACHER	1	Married
RAJ	1141	m	never smoker	60-70	1952	y		1	NONE	0	
KMC	1142	f	never smoked	70-80	0	y		6	NONE	0	Separated/ Divorced
LT	1144	f	never smoked	40-50	1953	y		2	NVQ	1	Widowed
MC	1147	f	never smoked	70-80	1995	y		3	NONE	2	Married
KH	1149	f	never smoked	50-60	1994		y	8	NONE	1	Single
BW	1152	f	never smoked	70-80	2014	y		2	DEGREE	1	Married
JW	1154	f	never smoked	50-60	2013		y	6	CSE, AAT ACCOUNTS	1	Widowed
PM	1155	m	ex smoker	60-70	2014	y		6	FACTORY CERT	2	Married
KG	1157	f	never smoked	60-70	1965	y		3	NONE	0	
AW	1159	f	current smoker	50-60	2014		y	6	NONE	2	Married
GS	1163	f	0	80-90	1998	y		3	NONE	0	
JF	1165	m	ex smoker	60-70	2012	y		0	GCSE	2	Married
MB	1167	f	never smoked	70-80	1995	y		3	NONE	0	
SB	1170	f	ex smoker. Started age 14 stopped in 2004	40-50	2014	y		3	a levels	2	Married
CB	1172	m	never smoked	70-80	2010		y	4	NONE	2	
SAG	1174	f	never smoked	60-70	2013	y		5	A LEVELS	1	Separated/ Divorced
MW	1175	m	ex smoker-started age 17 stopped age 26 (5 daily)	30-40	2008		y	3	NONE	0	
EG	2011	f	ex smoker	50-60	0	y		5	0	0	
MFT	2017	m	ex smoker	60-70	started age 16 and	y		5	NONE	0	
EB	3004	f	0	70-80	2013	y		3	NONE	0	
PA	3007	m	ex smoker	60-70	2010		y	4	GCSE	2	Married
SW	3009	f	ex smoker	70-80	2008	y		4	A LEVELS	2	Married
DKC	3011	f	ex smoker-started age 16, stopped 1984	70-80	0	y		2	NONE	2	Married
CW	3017	f	never smoker	60-70	2013	y		3	NONE	0	
JS	4003	f	ex smoker started 16 and stopped at 20	70-80	2012		y	6	NONE	0	

The patient demographics table shows participant initials, anonymised study number, gender, age, smoking status, year of diagnosis, exacerbations (less than 4 or 4 and more), no of co-morbidities, highest educational achievement, number of people living at home and marital status. The demographics are for both the participant jottings and for participants of the focus groups. The jottings shown later in this chapter were purposefully chosen to illustrate the inductively developed themes.

Ethical issues pertaining to human subjects

Research ethics committees act in the first instance to protect the participants' safety, wellbeing and rights (328). The BET study received full research ethics committee approval and hospital research and development department authorisation before the study commenced.

Ethical issues considered were those of burden of questionnaires represented by the study, issues of privacy and confidentiality presented by the focus groups and ensuring that all participants in both intervention and control received existing 'gold standard' advice on self-management represented by the British Lung foundation information leaflet on bronchiectasis (329) and the physiotherapy guidance appendix to the British Thoracic Society Guidelines (290). The purpose of this practice is to test new treatments against the best of existing treatments so that decisions relating to comparable efficacy are possible and to prevent people with disease receiving less than the best care already available. In medicinal trials however, placebo controlled trials persist even when an already tested and licensed and advised drug regime is replaced by a placebo. This practice is criticised by A. Bradford Hill, he states that clinicians -

> *'will wish to know whether a new treatment is more, or less, effective than the old, not that it is more effective than nothing.' page 1 (330)*

His paper published in 1994 denounces what is in his opinion the continued unethical use of placebo controls. The study questionnaire burden was reduced following advice received from the ethics committee review. The Hospital anxiety and depression scale (HADS) (331, 332) outcome was removed from the planned study methods. We were keen not to overburden our participants.

The HADS questionnaire had originally been selected as a secondary outcome to evaluate the effect of anxiety and depression, known to be association with chronic disease (333, 334), with respiratory issues (335-337) and with bronchiectasis (338, 339).

Data collection method

The participants who were randomised to the BET intervention (randomisation procedure discussed in previous chapter) each received four brief telephone education sessions designed to introduce, explain and permit participants to practice utilising the Bronchiectasis Empowerment Tool. During these sessions nursing notes were made to document the progress of collaborative learning, questioning and information sharing. The notes permitted progress and educative momentum by summarising experiences voiced and issues raised by the participant. In this way each of the brief calls were honed to meet the individuals' specific questions and needs in a collaborative way that would not have been possible from pre-recorded standardised information. All the education was conducted with the same nurse to prevent contamination (leaked knowledge of BET) to participants randomised to the control and therefore receiving treatment as usual.

Data collection instruments and technologies

Source data was hand-written in patient notes. These were transcribed into anonymised qualitative jottings using Microsoft Excel, the jottings were evaluated and coded in separate cells.

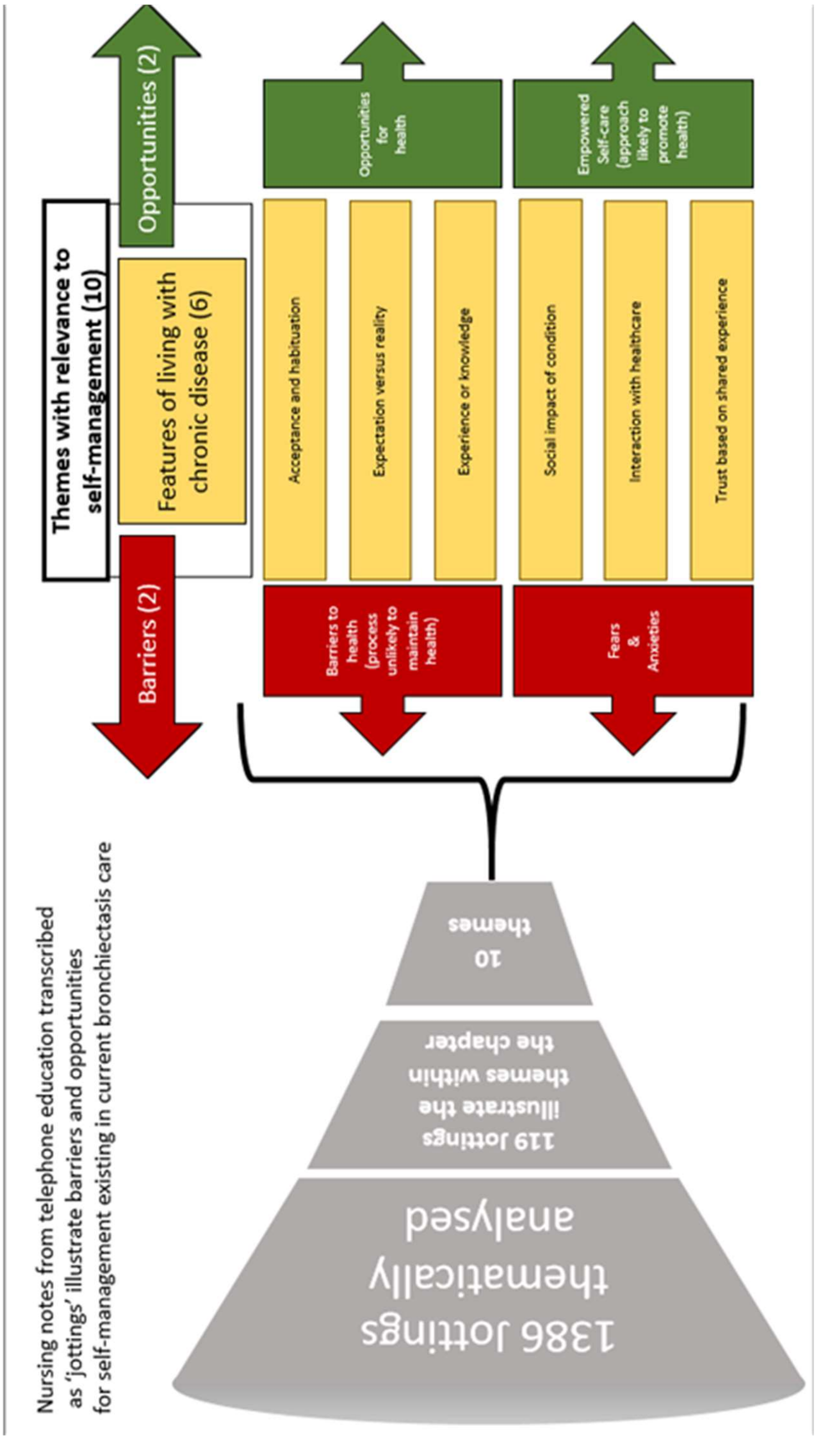
Units of study

Information expressed by participants on a topic were transcribed as sound bites or 'jottings' ranging from a few words to several paragraphs on a particular topic.

Data processing

Patterns in the data were identified and codes identifying these were then inductively grouped into explanatory themes which were then assigned to each sound bite, up to four codes were assigned where the data was relevant to more than one.

Figure 8 Thematic analysis theme identification



Data analysis

Microsoft excel was chosen as a database format to sort and categorise each of the themes codes identified. The advantage of using this software was that all the stakeholders and investigators were able to access the analysis. Nvivo qualitative software was considered but was not available to all the investigators and the system felt less flexible it was therefore rejected. Added to this the researcher had advanced Microsoft Excel data management experience. The ability to view the data succinctly and to perform multiple re-organisation and review of the data was also an advantage to the researcher. (Fig page 198).

Techniques to enhance trustworthiness

Samples of the source data and Excel transcription were checked for validity. To add rigour to the qualitative process (300) an experienced qualitative researcher with a background in social anthropology (primary supervisor to the PhD student) independently coded a randomly selected sample of the data. Both sets of coding were analysed and areas of disparity addressed, to enable the analysis to capture the essence of the data (340).

Analysis

Transcription (by the researcher) of the nursing notes to anonymised sound bites or ‘jottings’ (labelled with initials and their study number) was a labour intensive manual process of reading and re-iteration (typing).

Typing the jottings was engrossing and absorbing allowing immersion in the data, a term used in qualitative research to describe a deep engagement with data that fosters the identification of patterns and codes advocated by Miles and Huberman (341).

In the thematic analytical process (342) Vogt *et al.* (343) describe coding as a researcher-generated ‘*translation*’ using an interpretive approach (344). Downe-Wamboldt suggest that the goal is ‘*to provide knowledge and understanding of the phenomenon under study’* ((345)p.314). The inductive (346) linking of information, emergence of themes in thematic analysis is a framework that allows a clearer participant ‘*voice*’ and lends itself well to mixed-methods enquiry (347). Selltiz *et al* (348) warn against an overly quantitative approach which might limit the *‘character of the data available’*.

The framework is less philosophically complex than the Glaser and Strauss grounded theory who developed a method of systematically evolving theories of human behaviour within the social world based on symbolic interactionism (341).

The process of theme identification is illustrated in Figure 8 in which patterns were identified within the sample of over 1300 sound bites of information the data was assigned to one of the ten emergent themes. Two of which represented opportunities for self-management, six features of living with bronchiectasis and two themes likely to be detrimental to health and barriers to self-management.

Table 11 Summary of jotting themes

Opportunities	Empowered self-management, approach likely to promote health
Opportunities	Opportunities for health, process likely to support best practice
Living with bronchiectasis	Acceptance and habituation
Living with bronchiectasis	Experience or knowledge
Living with bronchiectasis	Expectation versus reality
Living with bronchiectasis	Interaction with healthcare
Living with bronchiectasis	Social impact of bronchiectasis
Living with bronchiectasis	Trust based on shared experience
Barriers	Barriers to healthcare or process likely to be detrimental to health
Barriers	Fears and anxiety

Where the jotting applied to more than one emergent code up to four were assigned see Appendix 13. In a process of induction observing specific instances and seeking to establish generalisations categorised as emergent codes was followed by a deductive process analysing the themes and illustrating them with specific instances discussed in the findings (349). The gradual refinement of themes was conducted using de-contextualisation and re-contextualisation of the data.

Following this period of immersion in the source data further context and understanding was sought through literature within health, psychology, sociology and anthropology. The work of Maslow in identifying a framework of five motivational needs resonated with overall barriers and opportunities for the development of self-management and provided a theoretical framework of requirements necessary for motivation to self-manage. Maslow identifies five overarching needs (229).

These motivations are commonly used to understand individual and group motivation (350). Self-management can be seen as self-actualisation. Figure 10 illustrates Maslow's motivational needs in terms of bronchiectasis.

Findings

The findings are discussed here by emergent theme. Each jotting is anonymised and labelled with participant study number.

Theme : Empowered self-care, approach likely to promote health

> *Having worked in the pharma I question things more and feel empowered to a degree. I push and prioritise my health using my experience. AW 1159*

This participant is clearly taking an active role in her healthcare. Her statement suggests a degree of involvement with and expectation of collaboration with health professionals. The first sentence suggests that her experience puts her on a more 'professional' footing vis-à-vis healthcare professionals. It is interesting that she feels that she must *'push and prioritise'* and takes responsibility and ownership of *'my health'* which might suggest either that her health is not already prioritised or that she feels that the demands on healthcare mean that she must justify and prioritise her needs.

The jotting suggests that skills are required to '*prioritise*' one's health within healthcare and that the confidence to '*questions things more'* and *'feel empowered to a degree'* have been acquired outside healthcare but within a specialist health related environment.

> *While I can breathe quite well I don't follow a physiotherapy ritual but when I crackle I do it (physiotherapy) two to three times a day, it doesn't take long to clear. MFT 2017*

This jotting exemplifies a flexible approach to airway clearance in which this individual has the self-confidence and ability to take action when needed, rather than maintaining a constant ritualised approach to airway clearance. *'While I can breathe quite well'* the impact of the disease is minimised and not encroached upon by ' a physiotherapy ritual'. There is an upbeat and confident ring to *'it doesn't take long to clear'* which speaks of positive experience and feeling in control. This jotting exemplifies disease self-management and may not be possible for all individuals. For some a physiotherapy ritual or routine reduces the need for making decisions and taking action. BET is compatible with either use.

> *I used to do my breathing exercises (airway clearance) three times daily: morning, daytime and night time. JF 1165*

The explicit timed regimen of airway clearance expressed in this extract is reminiscent of a medication regime and simply illustrates the commitment required (including time and space) to achieve this form of ritualised health promotion.

> *I do my breathing exercises each morning my huff n puff routine. CW 3017*

This illustrates a practical morning routine that permits staying well-enough to go about everyday life. Minimising symptoms first thing in the morning when symptoms are worst after being prone during sleep and at night to promote clear lungs and better sleep and minimising the interruption to life presented by airway clearance. Difficulty with morning appointments should be taken into account by services supporting self-management support. The flexibility and only brief record keeping in BET minimises its impact on daily life.

> *I have found a position that works for airway clearance. DKC 3011*

This hints at the individuality of participants and the need to evolve health promoting actions that work for them morphologically, psychologically and socially.

> *I love my flutter airway clearance device, I have had it for years. MH 1110*

This describes the use of an aid to airway clearance which is non-formulary and therefore not widely available to people with bronchiectasis in the area studied.

> *If I do postural drainage I can occasionally prevent a full infection. MH 1110*

Over the years a variety of airway clearance techniques have been advocated by specialist physiotherapists. It is interesting in this extract that the individual has learned that their chosen method can be a positive aid to avoiding *'full infection'* but that even in their enthusiasm for this technique the individual uses the term *'occasionally'* because despite this regime it does not always work in preventing infection.

> *I use active cycle of breathing and tipping. JD 1099*

A combination of approaches to airway clearance was performed by participants of this study although the most common appear to be active cycle of breathing and postural drainage as described in this extract.

> *I am very cautious with percussion due to osteoporosis it is a last resort for me and I use gentle pats*

The ability displayed in this extract to understand and evaluate risk is intrinsically a more difficult one for patients than for their clinicians who make their evaluation based on a larger sample and greater availability of evidence. Remaining objective about a treatment that affects one directly may be difficult. However, experience of individual reaction to and preference for specific treatments can guide the care team to deliver tailored treatment options more likely to be adhered to.

> *I exercise as much as possible but have to have frequent rests. JD 1099*

This extract alludes to the determination required to continue activity even though it requires more effort and energy than for peers and affects social interactions involving exercise due to pace and necessity for *'frequent rests'*. Social isolation caused by change of habits and more effortful social interaction can add to the already negative and depressing aspects of ill-health. A strong social support system provides greater resilience for all members of society. The BET study did not envisage social support, the overwhelming positive response to the telephone contact for education within BET hints at this being a way to both combat isolation and support self-management.

> *I do Pilates once a week and cough up so much more sputum on the way home that I feel that I can then take a deeper breath. DRE 1056*

This extract shows that the participant has come to terms with the fact and is even pleased that exercise helps her clear her airway, although this behaviour is taught and re-enforced by health professionals it is unusual for the message to be internalised in this way. Much more commonly embarrassment with uncontrollable coughing and cooled air-conditioned environments are described as disagreeable. The embarrassment caused by coughing and sputum sometimes lead to suppression of cough which is likely to encourage the growth of infection.

> *I hope to be back to exercising soon, I go to a GP referral gym. I haven't been going due to the ligament pain caused by the antibiotics. NP 1026*
>
> *A hill is a good test of how I feel, if I can get up the hill then I am fine. DRE 1056*
>
> *I clear my airway better when I stay active JS 1001*
>
> *Put the radio on and have a hop around the kitchen. EB 3004*

> *I go to a GP referral gym where they have assisted walking machines for people with spinal injuries so that you can walk supported it is marvellous.NP 1026*

Keeping active is acknowledged in health and disease as being beneficial to both physical and mental health. Despite this, it is difficult to maintain this benefit without a ritualised approach particularly when interruptions presented by exacerbations further inhibit maintaining healthy habits.

The jottings above show a selection of ways in which people with this condition approach keeping active to suit their lifestyle, goals and preferences. Keeping track within the BET booklet can aide both the person affected and health professionals to identify opportunities for greater activity. The social prescribing described above is becoming more widely accepted as part of chronic disease management.

> *I will take up the issue of reserve antibiotics and same day visits with my GP. JW 1154*

People with bronchiectasis rarely meet others with the same condition. BET self-management telephone education allowed participants to enquire about aspects of self-care that they were not already familiar with and have frank discussions within a framework of what is recommended in the bronchiectasis BTS guidelines of 2010 (1). It is clear in this jotting that BET has promoted an empowered stance in the participant.

> *I know the name of what I am colonised with KWJ 1035*

When sputum is sent for analysis it is useful if the name of the infection is shared with the individual affected. Although the jotting above is a positive example, many participants in this study reported that it was not common to be informed of the name of the infection. Although continuity with health service personnel may be increasingly low, supporting empowerment and growing patient knowledge provides a more active role for the person affected and inevitably at the centre of all health interactions encouraging truly patient-led collaboration.

> *I am good with routine ST 1038*

Lifestyles and learning styles are individual, this quote in the context of receiving BET education hints at the ease with which this individual can integrate note-taking for BET into a regulated life. It may be easier to ritualise and therefore incorporate positive health promoting habits into already steady regulated contexts.

Evaluating what is possible within the reality of people’s lives requires trust from the individual affected to promote sharing personal details of their life or allowing a health professional into their homes. Community matrons tasked with promoting self-management develop plans for health maintenance within the home, where it may be easier to assess the opportunities and threats presented in the everyday living environment. In contrast health professionals creating plans with their clients in a clinical and time-pressured appointment may have fewer clues and cues to what may be feasible. Tailoring of self-management to the individual translates the theory into practice and also permits a process of adjustment and honing so that the self-management as a process is under continual development (351-354).The BET intervention was not formally integrated with existing services because the provision of services is so variable that the intervention conducted in this way would not have been standard. BET participants were encouraged to discuss the intervention with their multidisciplinary health team if they wished to do so. A few did this with very positive effect as illustrated by

> *Our local arts centre has started a science cafe that is proving very popular with a programme such as antibiotics and resistance, genetics it attracts a mixed age audience and the people presenting are a mixture of conventional experts, holistic practitioners and artists. It is reasonably priced at 3 pounds and always packed, it allows me to explore information and satisfies my curiosity. NP 1026*

Services tailored to encouraging a positive interest in health woven into everyday life are unusual. The jotting above provides an unusual and refreshing example of what is possible.

BET by recruiting within a hospital environment, with outcomes requiring literacy skills and minimal face-to-face interaction may have discouraged participants with less confidence, lower literacy, fear of hospital environments or housebound. An ethics amendment allowed us to perform telephone consent (potential participants found attending the hospital a barrier to participation).

> *I have used a flutter device for 20 years. I use it when my ordinary clearance isn't working, if the flutter doesn't work I nebulise with 7% hypertonic saline. MJB 1123*

The jotting above provides a positive example of self-management expertise and empowerment. The individual’s personal knowledge and access to a variety of treatments allows flexibility and adaptation to needs and severity.

A knowledge of options and ability to cope avoid unnecessary anxiety, minimise need for displacement and disruption and relieve pressures on healthcare. A strategy and experience of outcome make meeting the challenges of the disease possible.

Theme : Acceptance and habituation to health impairment

Defined by the NHS a chronic condition is

> *"A Long Term Physical Health Condition (also known as a Chronic Condition) a health problem that requires ongoing management over a period of years or decades.] [Not currently curable but can be controlled with the use of medication and/or other therapies."*

Adjustment to symptoms and treatment affects quality of life and wellbeing (355). The relationship between pulmonary function measurements and individuals' functional ability in everyday life is weak (356). Questionnaires are used as a proxy to evaluate Quality of Life in the absence of objective measurements of bronchiectasis or quality of life, however, the paucity of questionnaires specific to the condition cause problems (357). Many questionnaires offer a narrow range of responses that risk de-personalising health information to the extent that it poorly portrays or evaluates the quality of life as lived by the individual. Participant comments made in response to the BET telephone education illustrate vividly their lived experiences.

> *I last had antibiotics Dec then Jan then Feb then March this is a pattern pretty much every year. 4003*

Overall there is a startling lack of self-pity or emotional language used by the individuals taking part in the BET education. Is this because by minimising discussion of distress they minimise personal acknowledgement of the impact of disease on their lives? What impact might this have on self-reported outcomes? Does it attenuate and minimise symptoms experienced? Patients diagnosed are advised that bronchiectasis is incurable, part of their emotional adaptation relates to accepting and enduring. Sympathy may be much shorter lived than the duration of chronic disease.

This jotting reveals the frequency and impact on life of repeated chest infections (exacerbations). At the minimum this person has lost a week in each month for four months, the detrimental effect on social interactions during the festive season are implicit.

There is both an acceptance that this is what life holds for the future and an understanding that this has been a pattern and life and survival will continue. The effect of these repetitive infections on work, personal and social life are inherent. The word *antibiotics* as treatment both suggests that the individual is taking an active role in seeking and obtaining medicinal treatment but also suggests that side-effects common to these medications are likely to have been experienced and these range from mild to severe gastric upsets, oral and vaginal thrush, lethargy and lack of appetite and a variety of other less common effects.

> *How I feel every day, I could say I feel breathless every day, I feel unwell everyday but I make sure to only ask for help when things change. KH 1149*

The impact of symptoms were eloquently described in the jotting concerning the influence on everyday life of this chronic condition for this individual. There is a suggestion that symptoms are minimised. Obtaining assistance from others relies largely on making a case and this may have implications on whether symptoms experienced daily are shared with others. The social and health interactions with others may be affected by the repetitive nature of suffering. This recalibration could affect self-reported questionnaires measuring quality of life (358).

> *I produce sputum daily nearly all the time. KH 1149*

The simplicity and lack of dramatisation in this jotting highlights the inescapability of this symptom though socially it is frequently seen as repellent both by the sufferer and the observer. People who have bronchiectasis take precautions arming themselves with handkerchiefs in order to manage the sputum production. Fear of unexpectedly expectorating is a frequently shared worry affecting self-image and causing embarrassment and shame in social situations.

> *I have increased urinary continence issues with respiratory infection. JC 1128*

As longevity increases the chance of experiencing chronic disease increases and for some multiple chronic disease (359) (comorbidities). Symptoms can also create physiological damage that present themselves in the form of other chronic health issues. Chronic coughing can weaken the pelvic floor muscles and lead to stress urinary incontinence secondary to bronchiectasis.

Self-image and social interaction already affected by bronchiectasis are additionally burdened as is the case in this jotting, these symptoms and diseases are likely to enhance distress and increase isolation attributable to ill-health (311).

> *I grew up with bronchiectasis so it doesn't bother me. PB 1116*

This concerns the ultimate habituation to bronchiectasis in which the person affected has grown up with the symptoms since early childhood (360). This does not necessarily minimise the effect that bronchiectasis will have had on childhood, sense of self and development. However, people who have experienced ill-health for a protracted period may have progressed or repeatedly progress through phases of grief and loss (361) in the oft repeated classic phases of grief demonstrated by Kubler-Ross (denial, anger, bargaining, depression and acceptance).

> *Where does all this sputum come from? I keep myself up as late as I can at night. If I fall asleep in the chair (my nights are so bad) my chest fills up. Put my book down 11.30ish 2 hour sleep and up again getting rid of the sputum and so the night goes on. ACB extract from Appendix 24*

This extract highlights the impact on quality of life of severe disease. This participant reported feeling encouraged to seek help by taking part in the study. Building the confidence (empowerment) to self-manage and to seek help when symptoms become overwhelming was a key aim of the study.

> *If my airway clearance routine doesn't go well I can't function later. KH 1149*

When symptoms become severe, reliance on treatments to achieve some quality of life increases. This jotting demonstrates the pivotal role of airway clearance on quality of life. As severity of disease progresses treatments become an integral part of daily living. Figures are designed to display the overshadowing of life by bronchiectasis symptoms and treatment.

> *I get very tired when infected, the coughing wears you out. JC 1128*

This illustrates the reason for apathy, lethargy and disinclination for further exercise during exacerbations. It also sheds some light on the difficulties of making decisions and feeling empowered when adversely affected by chronic disease.

The transition between necessary dependence and empowered independence is an individual one that requires excellent communication and trust between the individual, their social circle and care team. This excessive tiredness may have affected responses to questionnaires within the BET study or led to attrition.

Theme :Barriers to healthcare or process unlikely to support best practice

> *Sometimes you don't realise how ill you are. MON 1093*

Evaluating a worsening condition when affected by symptoms all the time may be quite difficult, especially when change is gradual and with the added issues of when severe infections and hypoxia affect cognitive skills. This issue, causing fear and uncertainty is illustrated in the next jotting below. Spotting change and taking action are essential to recovery. For people who live isolated or alone a support system, social or health based (such as community matrons) can help support decision making when acute illness makes sufferers housebound.

> *I can’t process information when I am too tired or too ill. KH 1149*

This jotting expresses even more explicitly the issues of information processing and decision making when unwell. The forging of buddy systems or encouragement in bringing carers or family members to appointments are likely to provide support needed for self-management in this vulnerable population. This may also explain why participants may have struggled with the outcome measures (questionnaires) within the BET evaluation and with identifying health changes as part of BET self-management. The comment below related to the completion of multiple questionnaires within the BET study.

> *I think I do understand what is required but forms, oh no, I'll do what I can! MB 1167*

Patient reported outcomes are in written format and may discourage people with poor literacy, learning difficulties and dyslexia. These issues would be difficult to overcome within the small budget available for the evaluation of BET only permitted creating educational materials in the simplest format which included written and pictorial formats. Using emerging technologies to reduce the need for literacy may hold possibilities of greater accessibility and greater interactive learning. For instance a large proportion of UK residents have embraced the usage of ‘smart’ mobile phones.

Habituation to troublesome symptoms may create an even greater need for education, support and motivation in order to form a foundation for behaviour change to maintain or improve health. Engaging family, friends and the multi-disciplinary healthcare team to help identify health changes and support self-management skills and knowledge development as part of supportive environment.

> *I haven't really studied how my sputum changes, I have had bronchiectasis for so long that you don't notice. KMC 1142*

Although BET was designed to draw attention to and assist people in identifying health changes requiring action, for those unable to internalise and apply this aspect after the brief education, lack of follow-up and integration with other health services may have limited the opportunity to drive home this message so improvement may have been short lived or non-existent.

> *It is very difficult to get transport to my surgery, we have to invest £14 taxi for each appointment. DL 1098*

For an ageing population who may no longer be able to drive or have modified their driving habits to daytime only driving (362) access to healthcare appointments are more difficult or more expensive as illustrated above. This added consideration when seeking help may lead to delay that permits infective exacerbations to worsen before treatment minimising the aim of BET which was to achieve prompt, efficient treatment without delay.

> *If I am unwell at the weekend I hang on until Monday KAM 1075*

Other reasons for delay may be the lack of out of hours provision of healthcare or difficulty obtaining it (363). The British Thoracic Society guidelines for bronchiectasis suggest that some patients may be prescribed reserve antibiotics to be kept at home, this enables expedited treatment.

> *It is difficult to see a named GP in under 3 weeks LT 1144*

Previous chapters have stressed the importance of collaboration in health management. Building a trusting understanding and positive momentum to manage health may be more difficult when continuity of care is threatened as described here. Hill *et al.* highlight the variable standards of bronchiectasis care in the National BTS Audit 2012 (8).

Difficulty in following the advice within the BET intervention due to unavailability of services may have discouraged participants taking part in the intervention.

> *It can be hard to see a GP promptly you have to convince the receptionist that it is an emergency, it is the luck of the draw. KWJ 1035*

The increasing pressure of demand for healthcare means that operations and ancillary staff have increasing difficulty matching patients with clinical availability as revealed in this jotting. For the person who is ill and already burdened by symptoms, fighting for an appointment may be even more of a struggle. There are opportunities here for technological flagging so that reception staff are aware of urgent needs. The fact that if they ask for an emergency appointment these are allocated to whatever physician is available is likely to make it more difficult for both the patient and the physician to achieve the trust necessary to collaborate in decision making. Further self-management intervention development should consider training of reception staff so that they can triage and prioritise needs where possible (this was not undertaken within BET).

> *My GP has not updated my prescription so it lists an antibiotic which is no longer effective for me. Also it shows Colomycin not the current Gentamycin. DL 1098*

As pressure on healthcare increases and the complexity of treating individuals with multi-morbidities and complex needs escalate so do demands on clinicians. These issues demand novel solutions. The jotting illustrates the potential risk to safety of a failure to update information relating to treatment. It illustrates the fragility of a system that relies so greatly on largely manual and human interactions.

> *My GP never comes out (makes home visits). When I called the out of hours service I was told the GP was not available. MCR 1120*

For people affected by chronic disease the arbitrary and historic territorial enclaves represented by primary, secondary, tertiary and emergency care are meaningless. The requirement for safe, expert, advice spans all of these, however, there remain disconnected services with differing strategies and funding. In particular, out of hours care is difficult to obtain when severely but not life-threateningly ill. Home visits are difficult to obtain and community matrons where they are available are in greater demand than they are able to supply.

> *I have never been taught airway clearance by a physiotherapist. EB 3004*

Airway clearance is a key element of bronchiectasis self-management. Although the quality of specialist respiratory physiotherapy advice regionally is excellent there is a scarcity of provision. This means that people with bronchiectasis are usually limited to obtaining airway clearance training when they are first diagnosed and then when they are acutely ill in hospital or specifically request a referral.

> *I don't send sputum for analysis. PB 1116*
>
> *I have to chivvy for sputum results a feedback process and timescales would be useful. AW 1159*

Sputum analysis generally doesn't provide clear-cut binary answers about the next step in treatment: it is important in building a picture of disease progression. Regular testing helps guide and support clinical decision making.

There are several reasons that patients do not send sputum for analyses: difficulty getting the sample to the collection place: misunderstanding that no significant growth means that there is no further need for testing: poor communication of results and a poor understanding of the reason behind testing. The lab report that poor labelling also means that not all samples are processed.

> *I don't have reserve antibiotics PM 1155*
>
> *I am allergic to Penicillin and Doxycycline gives me pain in the chest. KG1157*
>
> *Ciprofloxacin made me tired/lethargic and things, now I take doxycycline and don't have side effects with it.* GS 1163

To reduce delays in receiving treatment (transport, appointments) a reserve of antibiotics kept at home can be prescribed (referred to in the BTS 2010 guidelines (1)). Building confidence in when to initiate antibiotic treatment is one of the aims of self-management in bronchiectasis. Assistance with medicine monitoring such as appropriate documentation of allergies (for safety) and seeking alternative treatment that minimises side-effects is essential. If side-effects are too severe a natural aversion and delay in commencing treatment is likely to occur. Media messages suggesting that antibiotics are a last resort can be confusing for people who rely on these medications for their continued health.

> *I hate oxygen, I need 3 cylinders when I go anywhere by wheelchair to have sufficient. EG 2011*

To enable hypoxic patients to continue with everyday living they may be prescribed oxygen. As described in the jotting above this can cause logistical issues. There are no guidelines for buses, coaches, trains or taxis with regard transporting personal oxygen supplies so this can cause added difficulties. This highlights the need for the community and wider environment to be inclusive and supportive for people with chronic disease as illustrated by the chronic care model described in chapter one.

> *Extremes of temperature particularly cold are terrible for me, if I have to I go out with a scarf over my mouth but it is bad. GS 1163*

Although keeping active and interacting with others is encouraged for mental and physical good health many people with respiratory problems report issues with low and high temperatures in addition to wind and fog.

Gymnasium temperatures are frequently kept cooler than is comfortable for people with bronchiectasis and external environmental conditions during Summer and Winter act as an added barrier to keeping active. Pulmonary rehabilitation and lung clubs run from community centres are easily accessed by the communities who need them.

> *I find myself depressed, it came on quickly and I was refusing to go out. EG 2011*

Depression is very common in chronic respiratory disease (364), the jotting above illustrates the added isolation that this may cause. Depression is also likely to inhibit self-management. Improved confidence in self-management can reduce depression (107). Evaluating depression through a patient-reported outcome was originally planned as part of the BET evaluation, however, the ethics committee felt the burden of outcomes was too great and it was removed before the study was approved. The prevalence of depression in chronic disease and the success of cognitive behaviour therapy (CBT) in addressing depression may mean that access to, or referral to these services should be made widely available and integrated with self-management support.

> *The pain in my neck from] another condition [sometimes makes it difficult to clear sputum. MFT 2017*
>
> *In the past I was very active now my activity is limited by bilateral knee replacements. BW 1152*

Co-morbidities can act as barriers to self-management. The complexities of more than one chronic condition make the need for innovative support even greater and also coherence between disease management programmes.

> *I feel tired all the time and more breathless when infective. BH 1149*
>
> *I can't settle at night, can't sleep at all. I feel lethargic and demotivated, I feel flat. MH 1110*

Exhaustion is often reported by people with bronchiectasis (365). Infection is fatiguing and coughing continually is a calorie sapping muscular work-out of itself. Ensuring adequate and healthy food intake is difficult when lack of appetite and breathlessness make food intake unappealing. Poor and interrupted sleep is also frequently reported by people with respiratory problems, laying down exacerbating symptoms and coughing causing waking (366, 367).

Feeling exhausted affects motivation and hence is likely to impair self-management, particularly decision making, and engagement with health promoting activities.

> *I have had bronchiectasis since I was four when you are younger you think that you don't need the airway clearance. LT 1144*

In lifelong disease difficulty in inculcating the importance of health promoting actions whilst the optimism of youth still makes the individual feel invincible. Similarly, although it would seem intuitive to teach people self-management in early or mild disease, the motivation to utilise the lessons is unlikely to be internalised until symptoms require and underpin the need for action. Understandably taking care of ones' health does have impact on everyday life. This means that BET may be more greatly adopted by people with moderate disease.

Theme : Experience or knowledge

> *I wonder how you control the environment and all the factors that affect a person? On the farm we can control/impose the environment and change one thing at a time. I am convinced that it may be difficult to use a 'one size fits all' approach for this intervention because poverty, education and depression are likely to affect how it is received and absorbed. There may have to be more frequent reminders for some people. You can't make people do things and you can't control the environment in human beings JF 1165*

This participant used his farming experience and curiosity to think ahead and propose his own questions and predictions about the trial methodology and future translation into practice.

> *It would be useful to have a measure on the inside of sputum pots. KWJ 1035*

Although often asked by their healthcare team to evaluate the amount of sputum that they are expectorating sputum pots do not usually have graduated measures on the side and the universal containers provided for sputum analysis have a narrow opening making collection more difficult.

> *I don't exercise first thing in the mornings when I am at my poorest and give myself an hour and a half to ease round. CB 1172*

Entirely avoiding symptoms may not be possible, so using personal experience to best schedule the day is a way to enhance quality of life. This sometimes becomes problematic when it comes to healthcare appointments people with respiratory symptoms frequently don’t feel well until mid-morning.

> *I am permanently colonised with pseudomonas MH 1110*

Maintaining a positive attitude to self-management when burdened by disease can be a challenge. With increased knowledge can come an understanding of the challenges and limitations of a health situation both frustrating and depressing to the individual.

> *The antibiotics needed to treat my condition are the enemy they make me feel very low JN 97*

This is a view held by many people with bronchiectasis who really have very little choice but to utilise antibiotics but find their use unpleasant. Contrary to fears raised regarding over-use and discussions regarding antibiotic stewardship, this cohort who require antibiotics are often reluctant based on their experience of side effects. BET encourages individuals to keep track of whether the antibiotics they are prescribed are effective in reducing their symptoms during exacerbation. The knowledge that if and when oral antibiotics become ineffective and the potential of having to seek intravenous treatment may make this cohort more wary.

> *I have coughed up blood since I was 14 but it is now more frightening because I am on warfarin. KMC 1142*

Although habituation to symptoms since childhood have mitigated the fear of coughing blood, the medication warfarin does put this person at risk of continued bleeding. This illustrates the complexities of managing multiple chronic diseases. The flexibility of BET make it compatible with the self-management of other chronic health issues.

> *Sometimes the thickness of sputum in my throat makes the sputum difficult to cough. SGC 1073*

Difficulty expectorating sputum is not unusual. Methods to improve expectoration such as regular hydration and inhaling saline under physiotherapy supervision may be of benefit to this individual and could easily be integrated to their self-management routine.

> *Things can get much worse quickly. By the evening my chest can be tight and sore. By the next morning I can be very infective. WR 1135*

Personal experience of the rapidity of infection development can make the necessity for home antibiotics of greater necessity and utility. As disease progresses and there is greater lung impairment the effect of infection is likely to affect quality of life more quickly and impact the body's adaptive homeostasis.

> *I got to a stage where I was hardly ever well. JW 1054*

This sentence although brief highlights the impact of bronchiectasis on this person's life. Using BET to relate a history of events helps the individual communicate and health professionals react.

> *The pattern of me becoming ill has changed, I used to get a sore throat or head cold but now I just get increased cough. SGC 1073*

This comment highlights the need for continual education and collaboration during the chronic disease process.

> *I feel that I always have a slight infection. JD 1099*

One of the difficulties for people with bronchiectasis can be that they continually fight infection and therefore identifying when one exacerbation ends and the next begins may in practical terms present a dilemma in recognition, communication and treatment that is important in making BET useful.

> *My symptoms vary quite a lot on a daily basis. MH 1110*

For those participants who really engaged with the intervention increasing their self-observation made them aware not just of bigger variations in sputum or health requiring treatment but also of the variations caused by the disease throughout the day, such as sputum colour and volume. The repetitive self-evaluation required within the BET study to measure outcomes may also have highlighted the impact of symptoms.

Acceptance and habituation to chronic disease may have relegated impact of symptoms to a less prominent awareness. Re-examining their impact on quality of life is unlikely to have lightened their mood and may have mitigated the positive effect of increasing confidence in self-management.

> *I am so busy with other things and life and other conditions that I don't associate other symptoms with bronchiectasis. SLKL 1079*

Now that suffering from more than one chronic condition has become more commonplace it may be difficult for those affected by symptoms to attribute them to a specific cause where there is potential for more than one cause, as in malaise which might be attributable to various causes and even to the side-effects of medications. In these cases regular record keeping and a process of elimination are enabled by BET.

> *If I don't take antibiotics promptly the colour of my sputum becomes very dark. LT 1144*

Noticing the changes that occur and the consequences when treatment has not been possible re-enforces confidence in the necessity of treatment and recognition of when action is required. This is a learning curve for each individual to be encouraged that is possible within the simple format of BET.

> *I am aware of the interaction between Clarithromycin and statins. MH 1110*

The value of building knowledge of medications and their interactions is central to reducing individual risk. Self-knowledge of previous medication experiences, exposures and interactions can provide an additional check of value from a safety point of view. This guidance is valuable to clinicians who may be hampered by lack of continuity or knowledge of the individual patient.

> *I know that my diabetes and bronchiectasis are closely related, when my sugars are up I have learnt to realise that it is likely infection and that my lungs aren't well. NP 1026*

It is interesting in this instance that the person concerned observes changes in the monitoring of another chronic disease from which they suffer as more rapid markers of change than those attributable to bronchiectasis directly. This may be because they have been encouraged to self-manage diabetes for a significant amount of time and learned to observe change just as it is expected that they would learn self-management of bronchiectasis.

> *I have understood what this education is trying to achieve. JN 1097*

This individual makes this declaration with confidence after receiving the telephone education. There was no follow-up education devised in the BET intervention and maintaining confidence may have been enhanced by continued support or follow-up training.

> *When I am brewing an infection I usually feel breathless, my appetite decreases and everything is an extra effort. PBS 1037*

This self-knowledge gives the individual a time advantage with which to increase airway clearance and to plan the use of reserve antibiotics.

> *I start my reserve antibiotics before I get my sputum result. MN 1059*

This individual has correctly interpreted the self-management advice to begin reserve antibiotics, although sadly, some participants who pay for their prescriptions describe waiting because they feel that their initial antibiotic may be changed and do not want to incur two prescription charges. This may delay treatment contrary to best advice.

> *I learned physiotherapy airway clearance several years ago. MH 1110*

The ability to perform airway clearance is an important aspect of self-management in bronchiectasis. Many people with this condition only receive this training when they are first diagnosed or when acutely ill in hospital. Funding for refresher courses may reduce exacerbation rates.

> *Other symptoms that signal to me that I have an infection include increased mucous, wheezy, tight chested, stabbing pain in right side. JM 1137*

This self-awareness and knowledge of individual presentation of disease create an excellent starting point from which to plan actions and become confident (empowered with increased feelings of self-efficacy) in self-management

> *I don't usually send sputum for analysis but now I will.* SJ 1074

The jotting above shows an encouraging change in understanding and intention to take steps that are likely to enhance the shared knowledge on which this individual’s healthcare team will base treatment decisions.

> *I understand the process about writing down health changes now and what is being achieved here. AW 1159*

Reaching a point of shared understanding that justifies the need and purpose for self-management is essential to engaging and retaining the attention, responsiveness and awareness in the necessity for future actions.

> *Other symptoms: coughing constantly when I am infective, sleeping a lot nodding off during the day (usually I don't sleep). JW 1154*

This experience and self-knowledge shows that as well as symptoms such as coughing, exhaustion caused by the infection and also by coughing are likely to affect the ability or wish to carry out self-management actions when infected.

Theme : Expectation versus reality

> *I shall miss being able to talk to someone clinical about things are going.*
>
> *JN 1097*

Receiving information on the telephone and being able to ask questions where doubts or curiosity occurred (but wasn’t urgent enough to require a clinical appointment) was attractive to participants of the study, some suggested that a helpline would be of assistance. Some hospitals do provide helpline support and the British Lung Foundation bronchiectasis advice line is reported in glowing terms by people who have used it.

> *I don't have a reserve of antibiotics because they are no longer effective and I use intravenous antibiotics instead. JN 1097*

In people for whom oral antibiotics are still effective there is an advantage of saving time by starting reserve antibiotics. Unfortunately, this is not possible with intravenous antibiotics due to the need for a venous canulla for administration. There is a diversity of provision throughout the UK in terms of services for home administration of antibiotics. The pressure on beds at the lead hospital make it difficult to electively book antibiotic therapy.

> *If I don't have a form when I see my GP then the receptionist is unsure what to do with my sputum. JS 4003*

Sample identification is pivotal to accurate reporting. This jotting suggests that providing testing forms to the patient, training for the receptionist or the ability to take details and then refer the issue to a colleague would create a more positive and reassuring response to the patient.

> *If I am able to drive I can get help quickly. SGC 1073*

For the severely unwell and the elderly obtaining transport can be difficult. Providing enhanced access to transport or a system of collection of samples might help. Although BET encouraged participants to send sputum for microbiological analysis no enhancement of current systems were proposed within the study.

> *I was treated with Intravenous antibiotics and it was a revelation, I felt better for the first time in ages. AW 1159*

The introduction of intravenous antibiotics when oral antibiotics have ceased being effective is illustrated by the jotting above. This decision is not taken lightly by clinicians or their patients, the need for venous access and the training, knowledge, dexterity, environment and supervision to achieve this treatment whether at home or in hospital and the knowledge that antibiotic resistance may eventually follow and reduce treatment options are evaluated, risks and benefits weighed against each other.

Theme : Fears and anxieties

> *I was very unwell once on holiday and the experience was very frightening. GS 1163*

The isolation caused by periods of sickness when away on holiday far from colleagues or family can be compounded by the difficulty involved in managing exacerbations away from familiar environments. This can act as a deterrent causing anxiety about spending time away from home and usual support systems.

> *I have to really do some work at the gym over the summer to keep myself well this winter. I need to protect myself and keep my immune system strong. NP 1026*

There is a note of fear in this jotting. Although the intention is a positive one the anxiety of being unable to exercise at present is a clear issue and burden of the disease. Whilst it is helpful for people with bronchiectasis to feel increased feelings of control, burden of responsibility and self-demonisation may also increase depression and be unhelpful.

> *On the bus once I couldn't get my breath and feared I was going to die. SGC 1073*

This jotting clearly identifies the fear and isolation caused by bronchiectasis even in a busy public place when symptoms become acute.

> *I feel I don't understand what would happen if I stop taking drugs I get side-effects from. SM 1064*

Coming to terms with the fact that bronchiectasis can’t be cured but merely managed makes the role of medications including the long and short term side-effects even more important. Negotiation and collaboration between prescribing clinicians and their patients relating to medication choice are likely to encourage adherence.

> *The antibiotics make me very low. JN 1097*

Although there is no other alternative but to take antibiotics to treat infective exacerbations the side effects reported mean that as well as being fearful of exacerbations there is also a fear of the treatment and resulting symptoms. Inhaled antibiotics provide the possibility of fewer side effects and more topical treatment in situ within the lungs.

> *I feel that I am getting resistant to antibiotics. AW 1159*

The repetitive use of antibiotics does result in resistance so this is an understandable fear and reality. Collaboratively discussing plans for the future may help relieve or rationalise some of these fears. BET can be a good starting point to review sputum and physiotherapy

> *I am lucky I am not on the horse tablet (large) antibiotics. JS 4003*

Difficulty swallowing tablets can make oral antibiotic treatments an added chore. The size of certain antibiotics make them even more worrying for some. Trials with gel swallowing aides may provide a way of overcoming this issue in the future.

> *I am not sure that I want to be trusted with antibiotics but maybe I could PM 1155*

For people who have grown up in an era where only health professionals were thought qualified to manage medications it can be hard to switch readily to a greater responsibility without delaying or seeking approval from professionals.

> *I don't think that Intravenous Antibiotics at home are really a reality. JD 1099*

As in the previous jotting it can be difficult for people to assume the responsibility of intravenous antibiotics at home after having viewed them as a specialist treatment in hospital. Follow-up has been documented as important in building confidence with home intravenous self-administration.

> *I worry but I don't think that I am panicky.* KMC 1142

Feelings of anxiety with breathlessness are not unusual but feeling short of breath frequently can lead to more frequent anxiety and depression. Depression is common in chronic disease.

> *I do not have a reserve of antibiotics and do not believe in keeping medications, my Doctor will advise me, I feel confident in her ability.* JF 1165

When exacerbations are infrequent a reserve of antibiotics may not be necessary. This jotting suggests a reluctance to take responsibility for health. It may not be appropriate for all people to self-manage. Learning to self-manage is highly likely to take a variable amount of time depending on individual wish to do so, other life responsibilities and stability of disease. It is likely to be an ongoing process involving growing experience integrated with support from a variety of multi-disciplinary professionals and services facilitating treatment either at or nearer home.

> *In the past I have been told I don't have an infection when I know I have.* MC 1147

Confusion regarding sputum analysis is not unusual. The complexity of the lungs means that infections located in one lobe of the lungs may not be throughout and therefore sputum from a sample may not reflect the whole.

> *I had a really frightening episode unable to cough sputum this morning - I couldn't clear it and couldn't breathe.* CB 1172

Currently there are only support lines for bronchiectasis in a few localities. Instances like the jotting above show how being able to share experiences would be helpful.

> *Through experience I have now been reduced to recognising the dreaded deterioration and being admitted to hospital via my consultant's secretary* JN 1097

This jotting shows the dread of deterioration, experience of worsening symptoms and fear of hospital admission.

> *The inherent unpredictability of bronchiectasis make it even more frightening when what you feel you are relying on is unpredictable.*
> NP 1026

This participant's comment was made after a discussion regarding sputum analysis. She found it difficult that sputum analysis does not give a binary response but rather helps build a picture from which treatment can be planned. At the time that the study was conducted there wasn't a service level agreement to guide patients with regard timescales for processing and expected results. This creates uncertainty over and above the inherent uncertainties of the condition.

> *I am concerned re Cdiff. I am reluctant to take 2 antibiotics concurrently.*
> *DL 1098*

Clostridium Difficile is the commonest cause of antibiotic associated diarrhoea accounting for 15% to 30% of all cases (368). For patients who have an exacerbation of bronchiectasis this added burden of ill-health is unwelcome and can create fear and reluctance to take antibiotics when required.

> *"I am so depressed at present…I am not exaggerating when I say I have over 20 things wrong – some major some minor. If I was able to dispense with one it would be the bronchiectasis.* ACB Appendix 24 extract

This extract from this participant's letter in appendix 24 illustrates the impact fear and anxiety caused by bronchiectasis and the interaction of multiple morbidities on quality of life. Self-management for bronchiectasis has the potential to mitigate some of these fears.

Theme : Interaction with healthcare

> *I would like to use a nebuliser but I don't know how to get one are the NHS providing these? MCR 1120*

Although nebulisers have been made available on the NHS, local budgetary constraints mean that in the region studied for BET (the East of England) they are non-formulary and therefore not available to local prescribers unless they can justify exceptional circumstances.

> *I do not have a respiratory specialist nurse at my surgery MFT 2017*

This suggests that the individual feels a need for this support. Unifying standards of care and support are necessary to reduce inequalities in healthcare.

> *The hospital environment discourages responsibility on the part of the person who is ill, it encourages dependence and a child-like no questions attitude, otherwise you are seen as troublesome JN 1097*

When resources within hospital are tight there may be less time for education, support and the encouragement of good long-term habits that require greater supervision and provide a risk management challenge in the short term.

However, this attitude reduces trust and creates an uncomfortable power gradient in which the patient may be disempowered, discouraged and frustrated.

> *It would be good to go to community hospital for Ivs and less acute treatments, I would feel worried about Ivs (intravenous antibiotics) at home. I need to relax when I am receiving treatment, I couldn't do that if I was at home and was responsible. JD 1099*

The demise of cottage hospitals in favour of acute centres is a strategy that has put greater pressure on community services and social services.

> *Although I can access other GPs within the practice in less than 2 weeks they are unsure because they don't know me or my symptoms. JS 4003*

BET provides a record of patient treatments and progress that has the potential to increase the confidence of healthcare professionals less familiar with the individual. Patient confidence in their wishes and care preferences can help reduce this uncertainty through empowered self-care and collaboration. Time and economic pressures make communication skills ever more important and the methods for achieving and recording these might benefit from innovative approaches.

Theme: Opportunities for health: process likely to support better practice

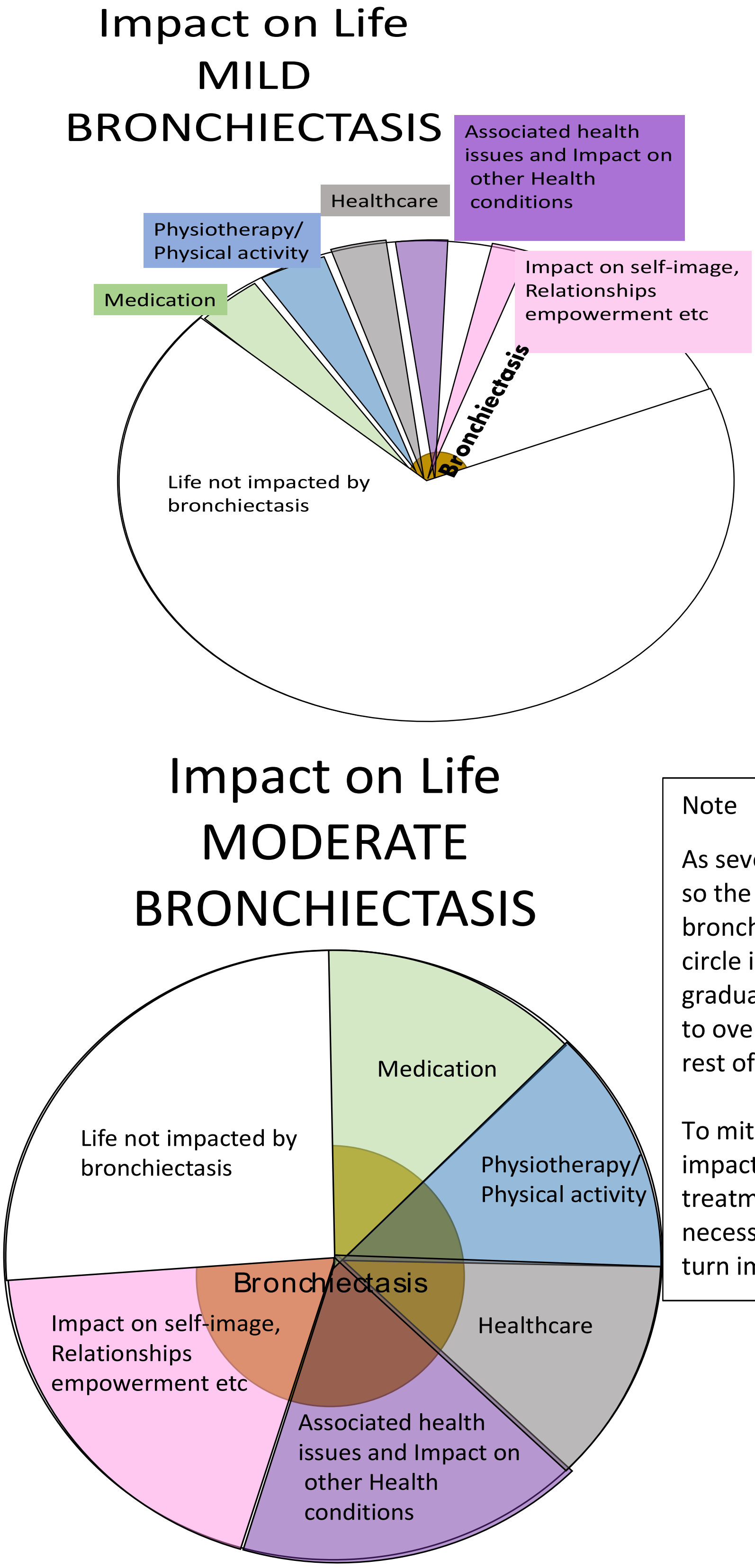
> *I've learned things already from this trial which I hope will be beneficial to me. KG 1157*

The four brief telephone education sessions were well received by participants. A low cost efficient mode of communication and education able to reach a large geographically dispersed area. Perhaps receiving calls at home at a pre-arranged time chosen by the participant and relaxed in their home environment increased feelings of comfort and control. When compared with the bustle of a clinical environment contact at home may be preferable and involve less inconvenience from displacement. Follow-up was perhaps the missed opportunity of maintaining this positive momentum in BET (that trial funds did not allow).

> *I use a wedge for postural drainage, cost £75 but good investment. JN 1097*

Taking positive steps to support their own health is an empowered attitude, if this results in improved health as in the comment above it cements good habits a mental investment in self-health and self-management for the future.

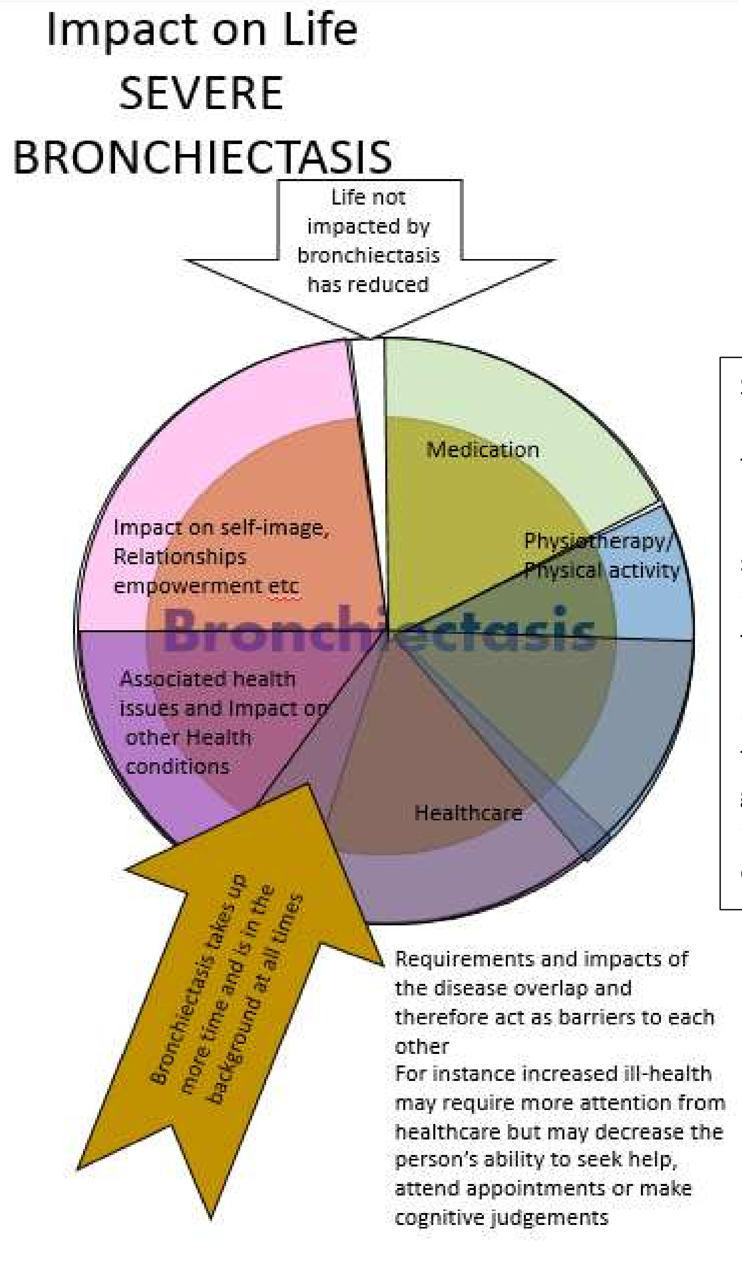
Figure 9 Impact on life of bronchiectasis severities



Note

As severity increases so the impact of bronchiectasis (the circle in the middle) gradually increases to overshadow the rest of life.

To mitigate the impact of severity treatment is necessary, this in turn impacts on life



Requirements and impacts of the disease overlap and therefore act as barriers to each other
For instance increased ill-health may require more attention from healthcare but may decrease the person's ability to seek help, attend appointments or make cognitive judgements

See also previous figures p244

N.B. As severity increases so the impact of bronchiectasis (the circle in the middle) gradually increases to overshadow

> *I use the flutter in the mornings it is easier to remember with medications. MH 1110*

Utilising personal strengths and weaknesses and integrating health needs into the practical structure and fabric of everyday life makes tasks more achievable. Personalising care is more likely to make it acceptable.

Theme : Social Impact of bronchiectasis

> *You need your health back in order to live JN 1097*

This succinct jotting shows the barrier that symptoms can pose to everyday quality of life and social interactions

> *You can be old at thirty sitting around and feeling sorry for yourself. EB 3004*

This illustrates the impact of mood on ill-health and shows insight (and possibly personal experience) into how easy it is to feel low with bronchiectasis.

> *Do people look/stare or do you imagine them looking at you? I'm not sure, are they thinking why is he on the bus with his germs? CB 1172*

> *The TV advert suggesting that when you cough you might have cancer has been a real nuisance neighbours and people who don't know me suggesting I consult a doctor. MON 1093*

> *Sometimes if I am out and I choke then I am embarrassed about my chesty cough. KMC 1142*

The three jottings above illustrate the social impact of having symptoms that are evident to others and how even kind concern can be troublesome.

> *I do feel the isolation sometimes, I would be very interested in telephone support groups or a telephone 'buddy' system. JN 1097*

Breathe Easy is a respiratory support group but people who have bronchiectasis rarely attend partly due to the inconvenience of displacement but also some feel that meeting others with chronic infections may lead to infection.

> *I mix very little apart from Sundays …careful to avoid personal contact. Thus I keep clear of infections…* ACB extract from Appendix 24

This extract speaks of isolation and the social impact of fear of infection.

> *Explaining bronchiectasis to relatives is difficult. POC 1072*

> *My family text my wife to ask how I am. MFT 2017*

Both the jottings above show the difficulties of communicating ill-health to family members without causing upset, the feelings of care and worry regarding loved ones health blended with fear of making them feel the object of pity.

> *I don't avoid quiet places such as church GS 1163*

This declaration acknowledges the social impact of coughing whilst this individual does not let it dissuade them from attendance at church it might well discourage others.

> *People say thoughtless things to you such as last week when the lady on the cash desk said "my Grandad coughed like that before he died" EG 2011*

This jotting shows how simple thoughtlessness can affect those burdened by chronic ill-health.

> *I am denigrated for being too well or too poorly. MH 1110*

It is difficult for people with bronchiectasis who are affected by symptoms but are seen more frequently clinically and in terms of research when present with severe symptoms that are less controlled and are discharged from secondary care with an associated loss of support when exacerbations become less frequent.

> *It can be difficult to find somewhere to empty sputum, I usually find a toilet for the privacy to clear my airway MFT 2017*

Although coughing and airway clearance are important to maintain health in bronchiectasis, these actions are not socially acceptable. People affected by bronchiectasis report suppressing these actions in public and finding the privacy to cough or perform airway clearance can be problematic.

Theme : Trust based on shared experience

My GP collaborates with me. For me and people with chronic illness we want to minimise medicines taken and therefore want to explore natural options. NP 1026

Building trust and understanding with healthcare advisors allows people burdened by chronic disease to make decisions about their health with confidence (feeling supported). Fear and anxiety caused by poorly communicated treatment options are unlikely to support the effort needed to make treatment recommendations fruitful.

> *My community matron has given me confidence KH 1149*

The majority of patients attend healthcare rather than healthcare treating them in or near to home. The community matron role has become increasingly important to those too unwell to leave home for regular follow-up. Specialists in self-management these individuals help support people in their chronic disease management to reduce acute admissions to hospital. By providing care at home community matrons also become aware of the home environment, caring arrangements and preferences in a much more direct and contextual way.

These Senior specialist nurses communicate and interact with multiple multidisciplinary colleagues and health agencies so that the individual receiving treatment has one point of contact and a coordinated package of care.

> *My partner drove me to hospital when I was acutely ill, it was useful someone else taking over and telling me that I had reached the point of needing more help. LS 1047*

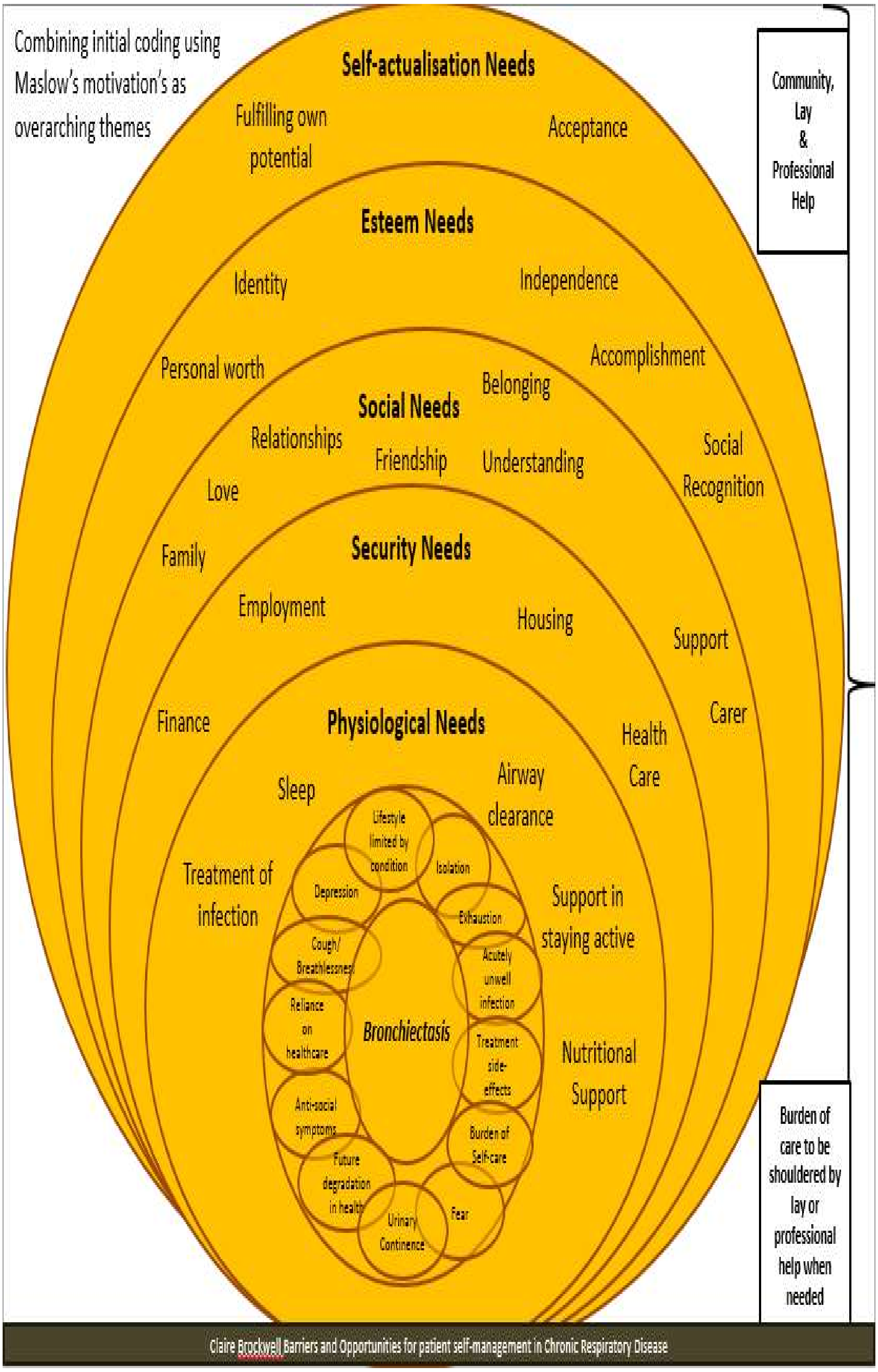
Partners, husbands, wives, children, carers and important others play an important role in assessing and reacting to changes in health. Habituation to chronic disease means that symptoms are very familiar to the individual affected. This combined with the stoic attitude needed to stay positive in adverse conditions and the fatigue, physical and cognitive effects of severe symptoms can make it difficult to seek help.

> *I have no doubt of the value of these education sessions, I was pro-active and checked on my sputum result at the GP yesterday, I have started prioritising checking things since we spoke. NP 1026*

In this jotting the participant describes the positive effect of the education sessions. It is unclear how the education sessions were positive but they appear to have motivated and supported this individual in performing self-management.

The jottings illustrated here outline aspects of living with bronchiectasis that present challenges to health and happiness. These participant sound bites have been organised into a framework of themes. Two of these represent barriers to self-management, two demonstrate opportunities for self-management and the remaining six embody what it is to live with bronchiectasis. To honour the generosity of the participants who shared this information it is necessary to seek a unifying theory to provide structure for and underpin the formulation of solutions or enhancements to care tailored for the self-management of bronchiectasis.

Figure 10 Maslow's hierarchy of needs and bronchiectasis



Maslow’s motivational needs (229)

Key to the figure previous page

Beginning with basic needs and culminating in self-actualisation.

Physiological needs: sleep, mental and physical wellbeing, nutrition, respiration.

Security Needs: employment, finance, healthcare, housing.

Social Needs: belonging, caring and being cared for, family, friendship, love, relationships, support, understanding.

Esteem Needs: accomplishment, identity, independence, personal worth, social recognition.

Self-actualisation: acceptance, fulfilling own potential.

Discussion

Maslow’s motivational needs can usefully be used as a theoretical framework linking the information received in the patient insights as illustrated above. Considering the participant motivation within this psychological framework makes addressing motivation needs in a coordinated fashion with materials aimed at clearly defined areas of health and social care to form a foundation for empowered self-management of bronchiectasis (self-actualisation).

Brief but positive directed telephone conversations were undertaken during BET, those randomised to the intervention were able to share their hopes and fears during the patient education. Taking part in the research also encouraged some to ask questions and collaborate with their health workers, using the driving force and motivation of being a participant to keep track and also increase their understanding of bronchiectasis. It is not unexpected, due to social response to coughing, to read that weddings, baptisms, funerals, theatres, cinemas, gymnasiums and restaurants are problematic for those affected. This helps explain some of the isolation experienced by people with bronchiectasis. Encouraging independence in people with chronic disease requires stages of learning, support and supervision until health actions are safe, fully understood, prompt and efficient. Educating and supporting individuals takes time and attention. Where staff are over-stretched, activities may be reduced to component health-professional responsibilities. Managing a high demand with minimal interaction and collaboration may be an attempt to save time.

The role of specialist nurses in patient education, nurse-led clinic follow-up and self-management advice has grown. This allows physicians to redefine their roles, leading to better outcomes for chronic disease patients (369). Microbiology labs are unable to process samples unless they are labelled appropriately. Providing sample pots and Identified labels with only the date and sample collection time would reduce confusion and expedite the process.

A decision tree or decision flow-chart to help guide symptom management such as sputum clearance beginning with hydration (such as keeping a glass of water at the bedside and avoiding caffeine if possible). Followed by choices and guidance related to nebulising saline in conjunction with specialist physiotherapist advice on airway clearance (to reduce the viscosity of sputum and help expectorate it). Encouraging physical activity assists expectoration. Finally medication options such as mucolytic medications are effective for some individuals. As pressure on healthcare increases and the complexity of treating individuals with multi-morbidities and complex needs escalate so do demands on clinicians. This issue provides an opportunity to seek novel technical solutions in maintaining documentation regarding treatment strategy and results to provide an enhanced data picture. This data might inform decisions and provide a source of collaborative discussion for people with bronchiectasis and their healthcare teams to exchange and inform each other. Airway clearance is a key element of bronchiectasis self-management. Providing physiotherapist specialist training and regular refreshers would help underpin this skill development but funding for this is not currently available.

Sympathy and empathy can be limited and people with chronic disease minimise ill health in their social interactions perhaps because they wish to be identified for their personal traits and not defined by their ills. In order to survive and endure daily ill-health there is a re-adjustment of expectations in which self-management might help retain control and identity as illustrated by an extract from Appendix 25 below.

> *"…I do think there is so much people with bronchiectasis can do to improve their health. Having Diabetes has been a really good pointer in terms of self-management as I have found it far easier to influence than lung disease. And the increase in self-esteem I feel at being in the top 10 GOOD PATIENTS for diabetes makes me feel I can be more pro-active about my lungs"* NP 1026

Discussion Jottings

The participant feed-back within this chapter demonstrates obstacles and opportunities to self-care that exist in current bronchiectasis interactions with health. Exploring how to smooth the bronchiectasis journey may create a better foundation from which individuals can increase their self-management skills and hence self-efficacy. The useful categorisation of needs presented by Maslow (used here as higher order codes) provide an easily understandable approach and framework from which to interpret patient experiences to create self-management interventions in the future.

Qualitative Part 2

Focus Group Evaluation of the acceptability of BET

Introduction

The Focus Group evaluation of BET was designed to assess whether the BET intervention was acceptable and feasible from the participants' perspectives, exploring the barriers and opportunities for the use of BET as a self-management tool. Acceptability being the perception of whether a treatment is suitable, adequate, tolerable and satisfactory (370). The use of mixed methods enhances 'user view' participant perspective that helps highlight strengths and flaws of methodological approaches. It also elucidates potential facilitators or obstacles to the intervention and evaluation. These may be procedural, organisational, environmental, personal or social.

Method

A deductive thematic analysis was used within a post-positivist methodology seeking to evaluate approach was adopted to analyse the focus groups presented. Focus groups were selected as a method of evaluation that required little literacy skills from the participants. That represented the least inconvenience to the participants due to the relatively brief nature of the group discussions. The focus groups were semi-structured so that some direction relating to appraisal of the BET intervention and evaluative study was possible. The moderator was skilled in the conduct of focus groups patient and public advisors steering BET felt that grouping participants would encourage empowerment to voice opinion, reducing feelings of submission sometimes evident in 1 to 1 encounters with health professionals.

Our patient advisors also felt that digital audio recording would be less intrusive than combined audio and visual filming of the groups. The design sought to minimise inhibitors and encourage frank discussion of the intervention. Focus groups were chosen in preference to one-to-one interviews, in which participant awareness of the researchers' vested interest might lead to polite response rather than the more natural feedback triggered by fellow attendee exchanges.

The moderator for the focus group was known to the participants as co-author and conductor of the research, had experience of conducting focus groups and also of conducting group behaviour interventions (market research in 1992 and project management 2003, and health - related to group behaviour change evaluations 2013-2015). The moderator's PhD supervisor an experienced qualitative researcher attended the groups as an observer. For the researcher's reflexive statement please refer to the previous section (page 72).

The physical surroundings were light and airy, in a modern meeting room with a view (through large windows) of the hospital at which the participants attend their specialist bronchiectasis clinic. The seats arranged facing inward arranged in circular pattern to encourage engagement. Refreshments were available on a table at the centre and offered around in a welcoming gesture. Neither the researchers nor the participants were familiar with the room utilised.

Critical evaluation of the intervention by the participants had been encouraged during consent and throughout the study. The value of a continuing dialogue regarding personal impressions of the intervention were re-enforced during the education sessions (relating to the use of the BET document) and on compliments slips when follow-up questionnaires were sent. This engagement from the participants in deciding the future of the intervention was again sought when arranging and explaining the purpose of the focus groups (letter of invitation to the focus groups).

Purposive samples providing the greatest diversity of bronchiectasis severity and variation in treatment were selected in order to better understand the utility of the design.

As described previously BET had Research Ethics Committee approval. Great care was taken to avoid sharing the identities of the participants (to preserve confidentiality) by only introducing the participants to each other using a number (none of them had met before). Although initially the participants expressed social discomfort associated with not sharing their names, they laughingly united in berating over-regulation that assisted in encouraging their interaction with each other. Discussion flowed well within the focus group sessions may have been enhanced by the anonymity and shared experience of disease.

The data was collected using audio recordings, jottings and transcription. The transcription quality was checked by the observer and compared with her jottings. The two audio devices were obtained from the university (and double checked for deletion on return after transcription) the data transcribed to Microsoft Word and Excel software for data processing and analysis. The transcription was divided into chunks of dialogue and anonymised, identified only by chronology, participant initials, and study number. Emerging patterns in the data were analysed independently by the researcher/moderator and the supervisor/observer. Comparison and discussion enriched and confirmed interpretation.

Findings

Exacerbations – recognition and keeping track

Exacerbations of bronchiectasis are associated with higher mortality (57). Recognition and treatment of exacerbations are a key goal of self-management.

> *"Well I have a pretty good memory so I actually can remember since 2013 how many I have had." ML 1044*

She further elaborated:

> *"I remember mine because I know how ill I was at the time and I know, I mean sometimes I can be OK and other times I can be really, really ill ermm and especially if you get two together, you know I had one in March and April and they were two weeks apart but both times I was hospitalised. So that is memorable in itself." ML1044*

The comment above suggests that the burden of disease is such when exacerbated that in the short-term between appointments (which are likely more frequent during exacerbation) this individual feels able to relate events without the need to write things down (specialist consultant letters commonly summarise the number of exacerbations reported).

[re keeping track on a calendar]

> "No, I keep my hospital letters so that I know when I have been in (meaning into hospital for consultations or to be admitted). My consultant kindly always sends me a copy of what he also sends my GP. So that I can keep track." *ML 1044*

The hospital letters are clearly of benefit to this individual and a allow sharing of information between secondary and primary care.

> *"I just remember (exacerbations) because it is every time I go and see my grandchildren, seriously! They'll even lick you, you know. They always have colds (re children and infections). You have to see them (re children and infections), there is no choice there."*
> *SJ 1074*

This comment hints at the social implications of a vulnerability to infection and the personal conflict involved.

> *"I write mine down. I write them down so that when my consultant asks me I know. He always asks me. I just put a piece of paper in the drawer…with [my] hospital letters and I just put in what month I don't write the exact date but I put what month it happened….Sometimes I'll put if it lasts a long while, like the last one that I had it lasted about four weeks because it just kept going on and on and on and I couldn't get rid of it. I just write it down throughout the year to December and I do that every time I have my tablets (reserve antibiotics) so that when I see my consultant I can tell him, because it is usually one of the questions that he asks you." MB 1096*

This comment displays the individualised way that this person has responded to her learned knowledge "*I write them down so that when my consultant asks me I know. He always asks me."* The way that the participant describes putting this information and her hospital letters in a drawer suggests an organised approach to keeping information relating to her condition and perhaps practice and repetition in doing so. It also suggests containment, having the information in the drawer is both accessible and also away from view. This containment reduces reminders of disease on everyday life, this segregation may be important in maintaining mental as well as physical health re-enforced by the comment "*I just put in what month I don't write the exact date but I put what month it happened"*.

There is also a suggestion of a positive ritual to help remember to keep track "*I just write it down throughout the year to December and I do that every time I have my tablets (reserve antibiotics) so that when I see my consultant I can tell him, because it is usually one of the questions that he asks you*."

There is a clear response here to the expected structure of the healthcare interaction which through experience and knowledge has guided this individual to respond with their own strategy to enable to response during healthcare interaction.

In the second focus group the question was probed further:

> *"I would prefer to write things down on a daily basis because I don't like forms." JD 1104*

Moderator: Do you take your notebook or diary to appointments then?

> *"Oh no, I don't do it, I am just saying that is what I would prefer to do." JD 1104*

It is interesting here that although the participant chose not to use BET she does not actually utilise her preferred method either. Keeping a record requires a sustained effort which may be hard to maintain, the sections in BET were designed to make it easier to break down the issues into four main categories and hence take positive action relating directly and more specifically to those categories.

Empowerment

> *"I found that with the BET tool it was brilliant because I really, I was so distraught, that I couldn't and I didn't understand it (meaning bronchiectasis diagnosis). I didn't know what happened, I could tell you about asthma but erm I just didn't know about this bronchiectasis." ML 1044*

This quote suggests that BET was a place to start in understanding her condition.

> *"For me I became aware that I always had a chest infection following contact with someone who had a cold, it always started with someone else. Unfortunately a cold doesn't last for two to three days like for other people it last for weeks and always goes onto my chest. Fortunately I have a reserve of two week course of antibiotics at home. As soon as I cough up different coloure*d *stuff I start taking my antibiotics, it is very good because you know what it is like getting into a Drs anytime is always a nightmare although when I explain what is wrong with me I can always get into the Drs within a couple of hours. Having the antibiotics is great because if I take ill on a Friday or Saturday I don't have to delay treatment. Taking antibiotics promptly reduce the length of my infection,*

> *they always seem to drag on but the antibiotics make it manageable. I had a chest infection before Christmas and it is only now starting to clear." GA 1033*

This quote emphasises the impact that having reserve antibiotics has had for this individual and the fact that he has clearly understood the significance of changes in sputum colour for bronchiectasis management. He displays a confident and empowered stance in his self-management despite being the quietest member of the focus group, politely awaiting an invitation to speak. The physical and social impact of infections for this individual are explicitly voiced. He clearly has good communication skills evidenced by his ability to obtain prompt treatment from a practice who respond well to his requests.

> *"Whenever I speak to anyone they have never heard of it." JD 1104*

Suffering from a health problem that is debilitating but also not easily understood by others might make explanation of ill-health to others more difficult and perhaps have an isolating effect. The eager interactions between participants of both focus groups may well have been due to curiosity and some bonding over bronchiectasis as a shared burden.

> *"You don't know really what you have got, and my first thought is, am I contagious? I had a grandchild with asthma and I am thinking 'my goodness, do I have something that I can pass on to her?' But no I was told afterwards that I couldn't pass it on. It is all these things and I think that something like that (meaning BET) might help with. When you are first diagnosed would be very valuable." MB 1096*

The suffering caused by fear and lack of understanding of the condition in addition to the physical symptoms of bronchiectasis is illustrated above. This individual clearly sees bet as an opportunity for knowledge development. The BET booklet as it was designed documented only the basics of bronchiectasis management and did not have information about contagion or about any genetic links. So the BET booklet did not meet this person's expectation and yet still frustrated a focus group member who felt that the BET booklet was too much (below)

> *"I think that for me the book there is maybe too much there. I don't seem to be too unwell, I can cope with what I have got and I do the physiotherapy , I clear my lungs in the morning and I just get on with it. I keep exercising, one thing I do find is that if you sit around it is one of the worst things." SJ 1074*

This quote suggests that the participant is comfortable with the ritual that has maintained his health but is perhaps uncomfortable with a greater intrusion or responsibility in his life represented by BET.

> *"I was diagnosed in 2003/4 all my life I had asthma and I didn't realise that it was bronchiectasis. I have built up my knowledge relatively recently through the letters that I have received. I have had to be very clear about the different stages of my illness and what was diagnosed at each stage depending on what examinations I had undergone and the best thing for me was like you being told, yes you have asthma but you also have bronchiectasis and then recently I have been referred to see Professor W at the B Hospital (London) and he has been able to split the bronchiectasis into various different sub-diagnoses if you like, he has explained to me that where you have mycobacterium infection your bronchiectasis is also being exacerbated by aspergillus." ST 1038*

Understanding the cause and the diagnosis of bronchiectasis was an issue of importance illustrated several times by various focus group members as above. Of note, the specialist consultant in London has broken down and structured the information shared and how well this has been received despite being quite complex information.

> *"I was on antibiotics to knock the aspergillus on the head. Prof W explained that we are not too worried about the mycobacterium at the moment, we know that is rumbling away but that isn't our priority we are going to try and get the aspergillus infection and that's what is happening now, it has been really really great, being able to have this explained to me so that not only do I have all the clinic letters but um in my own mind I am so much clearer about the condition I have. I have managed to because it has been named for me I have managed to get more information from the internet. There is a really fantastic website called patient.com and if you really want the more in-depth explanation you can go to patientplus.com and the more information that I have learned about self-care and about good health and how you can really, really help your condition yourself, that has been very valuable. So it has taken away the fear and (chuckling) I strongly recommend just finding out as much as you can."*

A shared and fully understood plan of action is displayed here where clinician and patient utilise a collaborative approach and engage in shared goals, intentions, motivation and understanding. Also of note are the efforts made by this individual in seeking information from accessible sources, such as the internet, with which to understand and manage symptoms. Graffinga *et al.* suggest that seeking information in this way displays engagement (371).

> *"Certainly I think that it is important now that we have access to more information and access to our own records access to those clinic letters that we make use of them. In years gone by that wasn't possible we weren't sent clinic letters and were always kept slightly in the dark I feel whereas now physicians and health workers have to be a lot more candid so they have to tell you a lot more and you are able to ask more questions and gain knowledge that way. So certainly in the last ten or fifteen years I feel so much more enlightened and informed and I have got the letters as a support so I feel much better now than I used to I always felt as if I was never really being kept informed." ST 1038*

The detailed but stepwise approach taken by the specialist doctor and illustrated in this quote appears to reassure the participant. She goes on to explain how much she appreciates the increased availability and sharing of information with patients, discussing a number of sources that she finds useful including generic websites and personalised consultant letters. Her vocabulary and confidence in discussion suggest that she is an excellent communicator and highly literate.

> *"In the early days it was quite difficult but I have become quite good at it now, I have a little notebook, when it is particularly bad I make a note of it. I found that because I had allergy asthma and I had allergy tests which showed that I am allergic to trees, grass and nettles, nettles being the most severe for me of course I have specific times when the grass and the flowers are out and then the nettles come on, but having said that, I am into my two years and two months of being on long term antibiotics and that has got a grip of the recurring chest infections." SKD 1051*

This account shows the diversity of respiratory co-morbidity associated with bronchiectasis. It also shows through the careful recall of time how important obtaining long-term antibiotics has been to this individual in managing the disease.

> *"Well when my lot make too much fuss I say that it isn't when I cough that they need to worry it is when I stop coughing that it will be time to worry!" JD 1104*

This somewhat morbid quote although repeated in jest did echo the fear and anxiety which this individual clearly displayed throughout the focus group.

> *"I find the Potters capsules very helpful in the morning sometimes I can't lay down at night so I get up and sit on the settee I am a bit of a nightmare for getting up and down [poor sleep]." GA 1033*

Poor sleep is very commonly reported among bronchiectasis sufferers and adds to the burden of the disease, non-medicinal formulations unlikely to cause harm may be of comfort when little else is available.

> *"I struggle to sleep for seven hours." MB 1096*
>
> *"I find that all I can do is sleep, I sleep for seventeen hours." ML 1044*

Difficulty sleeping, exhaustion and lethargy are symptoms often reported by people with bronchiectasis. The added impact of infection and of medication side-effects can increase these issues with impact on quality of life.

> *"I also find that the sputum tests don't always show much. You can be ill and it still doesn't tell you so." JD 1104*

It is a frustration for patients and health practitioners that sputum tests help build an overall picture rather than giving a highly accurate result with an associated specific course of action.

> *"I use bronchoforce because that is what I was advised, they are nettle and ivy homeopathic drug 20 drops, I try and limit myself to once a day when I am bad." SKD 1051*

The search for alternate treatments can be attractive to a group of people whose treatment (antibiotics) commonly cause side effects.

> *"I mean most people know what bronchitis is but what is bronchiectasis nobody knows." MB 1096*

Isolation is common in chronic disease (311, 372, 373) Added to this suffering from a chronic disease that most people have not heard of and are unable to identify or sympathise with is an added burden of bronchiectasis.

> *"Yes I have [been able to drive] since I was 17, all my friends wanted to spend time smoking and I wanted to learn to drive. Although the assumption is when you have this cough that it is smoking induced. I am afraid that I have told lots of people off in healthcare because they ask- how many do you smoke? and I reply - how about asking me whether I have ever smoked? I find all sorts of people assume, Drs nurses, receptionist and I get fed up." SKD 1051*

This quote shows the frustration of making what are considered positive health decisions and yet still being burdened by disease and then the further insult of being judged incorrectly as a smoker by health staff who should know better than to assume.

> "I get like that sometimes, [fed up with people assuming smoking related ill-health] although I sometimes wonder about the passive smoking." *JD 1104*

This comment shows the impact of other people's assumptions compounded by an awareness of the damaging impact of smoking behaviours beyond the individual's control.

> *"Now it is much more pro-active the help we get which is wonderful when I saw the chart of declining lung function I thought that I am not going to take my good health for granted." ST 1038*

This deceptively simple comment highlights that health is only usually considered when it is lost, when symptoms are present, retrospectively. It highlights the mental difficulty in deciding to take preventative health actions and behaviours.

> *"Well I am always active because I always have lots to do. But for example parking the car a while away so that I have further to walk. To and from the car in the fresh air. Making sure that I do get out at lunch time and do have a walk in the fresh air, things like that. Just taking it seriously about being outside in the fresh air and getting oxygen and stuff like that and really expanding your lungs so doing the physiotherapy." ST 1038*

> *"Yes I walk and I swim, I used to play badminton but I can't do that anymore because I have arthritis in my hip." MB 1096*

Both the quotes above and many more throughout the focus groups suggest the positive integration of exercise into daily routine.

> *"I do find that being at an angle helps me, because I have a divan base and I got a piece of foam cut in a wedge and lay it under the mattress and that has worked for me." JD 1104*

Postural drainage following airway clearance is the method described here and is reported as effective by a number of people with bronchiectasis.

> *"I have discovered in our surgery a Dr who knows all about it yippee! ……………….. Dr…………………. but unfortunately she is leaving. Apparently she trained, on it (meaning bronchiectasis)."* MB 1096

This quote illustrates the participant's relief on finding a GP with specialist knowledge in bronchiectasis. Patients look to health professionals for guidance and if they find themselves more knowledgeable than the person from whom they are seeking help it reduces confidence and increases feelings of isolation and need for support.

> *"My GP seems very good you know. He also picked up on my reflux."* SJ 1074

In the UK primary care system it is relatively difficult to change GP so access to and satisfaction with the individual may be relatively difficult to resolve. This participant reports a good rapport and feels grateful for a diagnosis which affected his quality of life.

> *"You'll never get information unless you ask."* SJ 1074

This quote is interesting in that when questions are asked they may be more likely to be answered. However, in this scenario the pressure is on the individual to understand enough to formulate the question and favours better communicators.

> *"My Dr used to say to me the only thing for you is to go for a week skiing."* SJ 1074

This quote sounds like a joke but the participant has taken it very seriously. It illustrates how a brief communication and how it is delivered has impact.

> *"But you can't isolate yourself like that (meaning from infection)" SKD 1051*

The impact on quality of life of a chest infection for someone with bronchiectasis is significant and some participants try to isolate themselves from what they feel are sources of infection. This isolation has its own effect on quality of life as illustrated in the quote.

> *"You can try! Laughs (meaning isolating yourself from others and therefore infection)." GA1033*

This balancing of the risk of infection is a personal one with impact on daily life as illustrated by the last two quotes.

> *"A big problem is that since I have been diagnosed with this condition you have to declare it on your insurance and it costs." SJ 1074*

People with bronchiectasis are burdened by the disease, by the difficulty of planning engagements without knowing whether they will be well enough to enjoy them and by the financial burden exerted by insurance.

> *"I have stopped attending the exercise group because as soon as I am in the air conditioning I start coughing, I am embarrassed they are embarrassed and I get nowhere." SKD 1051*

Although exercise is advocated in bronchiectasis people affected by the disease cough more when exerting themselves and are affected by temperature (both hot and cold) as illustrated in the quote above.

Social embarrassment as in the quote inhibits exercise as a positive health behaviour. The recent introduction of lung clubs may mitigate this embarrassment but people with bronchiectasis may then also fear contagion from others who are very likely to have infection.

> *"My GPs are very much inclined to say 'go to hospital' and that is it." ML 1044*

This comment suggests the education and decision making support relating to the management of bronchiectasis may be helpful to primary care health professionals.

> *"Mine is worst first thing in the morning I have to have a glass of water at the side of the bed to help reduce it." SJ 1074*

This issue is frequently reported, the glass of water to hydrate and help loosen secretions seems a good idea.

> *"I check the colour in the morning every day and do something about it if the colour changes. Although recently for me in the nasal passages and in my sinuses and I try to clear those as well in the shower and keep check throughout the day, I know when to get myself moving and can feel the changes so I do something about it." SJ 1074*

This comment displays knowledge and the ritualisation of positive health behaviour.

> *"Eating well, keeping well hydrated, taking exercise. Going to the GP to seek antibiotic treatment. Complying with medication so it was the opposite to when I was younger when the GP often used to say to me you have got asthma there is nothing wrong with you, you just have to wheeze." ST 1038*

This individual has embraced a holistic approach to their health and also expresses the improvements to healthcare from her perspective where in the past there had been obstacles in obtaining treatment.

> *"I find it very difficult because the GPs surgery that I visit due to staffing issues (three GPs have left) are only running nurse staff led at present. So you can't see a Dr until you have seen a nurse. We have one particular nurse whom I have seen twice and I have said to her 'do you know that I have bronchiectasis?' and she has said yes I see hundreds and hundreds of people with bronchiectasis. So I think that she doesn't know what she is talking about." ML 1044*

> *"The only trouble is that if you are unwell this morning and you need an appointment today you have to go down at eight in the morning if you are not there by eight thirty by quarter to nine all the appointments are*

> *gone and you can't make one until next day. Then you have to go through the same thing next day." MB 1096*

Both these quotes illustrate issues of access to and provision of healthcare that may have presented a significant obstacle to self-management using BET.

> *"I think that if I had been given it (BET) when I was first diagnosed I think it would have been useful because you haven't got a clue really what you have got." MB 1096*

This quote seems to suggest that BET has a role to play in early information giving, although the focus group member with the mildest symptoms did not use it and felt the information was too much for him.

> *"Yes, I agree but I do think that they are good? Without that (meaning BET) I would have been lost. Because I was able to take the BET booklet with me to appointments and let them know what worked effectively and what wasn't for instance when I went to the hospital I was able to say Meropenem and Tobramycin IVs and she said to Dr R she told me what to give her before I even got there and I said it is the BET tool – here" ML 1044*

This quote suggests that keeping a record in the BET format was effective for this individual at this time.

> *"I think that you have to become proficient when you have a clinician asking you in a consultation what is going on? They really like it when you have kept a record of clinical measures. Quantifying in some way, for example your sputum volume, density, or colour. They are trying to make a clinical decision based on fact received in a small timescale. Of course it is a subjective evaluation and for example before a flare-up I will get a general 'malaise' which is difficult to explain. But you need to arm yourself with as much information to share in a brief timescale as you can." ST 1038*

This participant hints at the need for a shared language and information expectations in order to make the most of healthcare interactions.

> *"I know that it (BET) was tremendously useful for me." ML 1044*

This quote in addition to the others from this individual suggests that BET provided a structure from which she could approach self-management.

> *"A really good tip that you gave me was if I didn't want to write it all down to keep the inner leaflets from my medication and write the start and stop date." ST 1038*

Again this this quote hints at the fact that caring for oneself whilst minimising the intrusion of the disease into everyday life is important.

> *"With the antibiotics I find that if I take them sooner the exacerbation lasts less long but if I delay it can get a hold and last much longer. I do not like taking antibiotics so I fight taking them to the bitter end." MB 1096*

This ongoing internal battle for people with bronchiectasis illustrated above is a difficult one. On the one hand media messages advise reduction in use of antibiotics and side effects are often significant to the recipients and on the other hand most people with this disease are aware of the difficulty of treating a more severe infection and the potential of lung damage.

> *"At first I dismissed symptoms but now I try to piece together what aggravates or improves it, why today and not yesterday? We all know that exercise is good for most conditions but when you are coughing more and physically exhausted it is trying to keep motivated. I go to yoga and had to explain to the yoga teacher that when I lay flat I cough. I was so proud last time I went I only coughed twice! It is managing to control things." SKD 1051*

This quote emphasises the difficulty of remaining motivated against the physical, and social odds.

> *"Yes it is worse if you are still. When you lay in bed at night it is worse in the morning. MB 1096"*

Many respiratory patients are far worse when lying down, the need for rest and the frustration and anxiety of symptoms and sleeplessness in the early hours when thoughts and problems can often seem amplified.

> *"What helped me was when I was sitting in the waiting area of the hospital and there was an advert up showing that your lung function reduces as you age and that horrified me. Just as cardiac function reduces. This fact was really scary. I thought oh o I am really going to try and make sure that my lung function maintains as long as possible." ST 1038*

Fear as detailed in the comment above is frequently reported by male smokers as a motivation to quit. In this statement fear seems to be the trigger for even more positive changes in health behaviours.

> *"Sometimes people just back away from you [due to the cough]." JD 1104*

This lack of social acceptance may lead to an unhealthy suppression of cough (expelling sputum is important).

> *"Home IVs are necessary to avoid infection from others they must also be cheaper than sitting in hospital for two weeks? I have sent a letter suggesting that we need a bronchiectasis nurse five days a week (currently 6 hours weekly)." ML 1044*

The squeeze on healthcare finances make it difficult both to obtain in-patient beds for intravenous treatment and to provide support for intravenous treatment at home.

> *"Yes we need more of J (bronchiectasis specialist nurse)." ST 1038*

The need for specialist advice and support in self-management of bronchiectasis whether on the telephone or in person has been a repetitive theme throughout the BET study.

> *"I think that support is my biggest issue." ML 1044*

Again this amplifies the need for flexible solutions in providing support to people burdened by disease and who frequently find displacement an obstacle (ill-health, transport, parking, risk of infection, finance, impact of frequent health appointments).

> *"It was nice as I mentioned earlier to speak to a GP who was knowledgeable and knew exactly what I was saying. I do remember it was a yippee moment. But sadly that person is leaving." MB 1096*

The importance of knowledgeable or specialist support is evident in this comment.

> *"Just being able to pick up a phone and say this is going on is it ok? Is Colistin getting on top of it? I dread to think what will happen next." ML 1044*

The simple but reassuring aspect of an interpersonal telephone interaction provides a low-cost and practical support avenue that may also reduce the anxiety that many report in a clinical environment and reduce the need for literacy skills to reach a broader population. Can also reduce the burden when ill-health and exacerbation may reduce cognitive abilities or self-management motivation.

> *"So maybe one page per infection that would be brilliant. Simplified so that you don't have to think. I don't know about anyone else I think that many bits of paper can be a bore snippets would be great so that you can refer back when you wish." ML 1044*

This comment suggests a more structured and bite-size approach to providing and building knowledge and education

> *"I didn't use the book, I am rarely unwell because I keep my physiotherapy going I get up in the morning and do my physiotherapy and check my sputum in the shower. As soon as I learnt about that it kept me going "SJ 1074*

This quote emphasises the importance of access to and perhaps regular physiotherapy retraining with a specialist physiotherapist. In the East of England where this study took place, due to pressures on finance and staffing, specialist physiotherapy is only offered when first diagnosed, when admitted to hospital or through specific referral.

> *"From a personal basis not being able to pick up a phone and say to somebody do you think that it is alright? Do you think that I can do something to improve things? If you know someone who knows a lot about it that would be wonderful. A nurse to talk to." ML 1044*

Again the need for encouragement, explanation and advice on the telephone is made clear in this comment.

> *"We do have a nurse specialist for asthma but not for bronchiectasis" ST 1038*

The numbers of asthma patients per primary care practice justify employing a specialist nurse. A solution for delivering advice to people with bronchiectasis (thought to be up to ten per practice) is needed.

> *"Just someone to talk to. Would it be someone that was available on the telephone but could also be a satellite person to visit you at home because attending the GP might expose you to other bacteria or you may just be too poorly to get out. I know that at the moment there is really no choice and that everything is a risk assessment in life and that sometimes you just need the treatment and have to push past those risks and worries." ML 1044*

The telephone support could perhaps be triaged so that multi-disciplinary bronchiectasis expertise was available such as: coaching (in self-management), community matron, consultant, dietitian, exercise physiologist, nurse, occupational health support, physiotherapist, psychologist.

> *"I don't want to be pessimistic or anything, but, this self-knowledge is something that some people can't do and may also be something that is hard to write down. In the morning in the shower I sometimes think of I feel great today but that is something that time has taught me." SJ 1074*

Introducing peer 'health buddies' either for support by telephone or in person might allow people with bronchiectasis to support each other and to feel positive about assisting others who might face similar issues. This might also extend to attending health appointments as advocates.

> *"I can agree with you on that but you do need something written down because you can go to your GP and say this is what has been happening over the last few times using the booklet which gives them a better idea of what is going on and sometimes you just don't have the energy to tell them this or that happened. I think that you are saying SJ that you have this pretty mildly?" ML 1044*

This comment suggests that having some sort of record or aide memoire creates a good starting point for collaboration and discussion. There may also be an empowering effect to having been given a tool that is specific to the disease and hence justifies the individual in having knowledge of and requesting actions or services in line with national guidelines.

> *"A page that lists everything on one page like sputum colour, volume, etc and whether you have visited a health professional." ML 1044*

This comment and the quantitative and qualitative findings of the study suggest that further work on the formulation and presentation of the information and education is necessary. BET is a first step in meeting the self-management needs of the bronchiectasis population and further research is needed to develop a more acceptable intervention to meet their needs

Discussion

Social Impact of bronchiectasis

Bronchiectasis has multiple social impacts on people with the disease from the initial fear associated with limited knowledge when first diagnosed (MB1096) to vulnerability to infection eloquently established by SJ 1074 in relation to contact with his grandchildren. The difficulty faced through the isolation of not being able to compare symptoms with anyone else (MB 1096) and coping with the ignorance and erroneous assumptions of others (JD 1104) could cause frustration. Bronchiectasis symptoms such as coughing and airway clearance are often seen either by the sufferer or their peers as distasteful, as JD 1104 relates *"sometimes people just back away from you [due to the cough]"* SKD 1051 discusses embarrassment when attending exercise classes though keeping active is a core recommendation to keeping well. Coping with the disease and fear of its progression creates differing approaches to social interaction the vulnerability to infections (SKD 1051, GA 1033) which have an impact on willingness to interact. Unfortunately declaring bronchiectasis increases the cost of insurance premiums which adds a financial burden and barrier to social interactions. The impact of exacerbations on life are exposed by ML 1044. This theme of isolation is common in bronchiectasis, being unable to share experiences, fearing infection, suffering from symptoms that are embarrassing and not socially acceptable (coughing and unexpected expectoration) as well as the increasing difficulty of leaving home due to ill-health during exacerbations or as severity increases, create a need for support that should be carefully considered.

Specialist Knowledge

The second most discussed theme within these focus groups was specialist knowledge and support. The limited aspect of specialist knowledge with regard to bronchiectasis is described throughout the discourse beginning with the difficulty in obtaining and uncertainties associated with diagnosis (ST 1038).

The knowledge and ability to break down and explain complex aspects of the condition in order to engage and share a collaborative approach to treatment is shared by ST 1038 who goes on to explain that she finds the more open access to healthcare information helpful, increasing shared knowledge and trust.

Describing the health promotion aspects of health information (declining lung function) as preventing her from taking her health for granted.

The delight of MB 1096 in finding a GP with specialist knowledge of bronchiectasis and the envy of the other focus group members tells its own story. Also ML 1044's comment about her GPs deferring to hospital specialist evaluation may reflect the diversity and work-load of a growing patient population – re-enforced later in a discussion of GP staffing (ML 1044).

Difficulty of obtaining an appointment with the GP for those who are unwell or have caring responsibilities is illustrated by MB 1096.

The need for specialist support in receiving home intravenous antibiotic treatment is illustrated by ML 1044. There is an echoed requirement for specialist nurse knowledge from ST 1038. The disappointment is palpable in the quote from MB 1096 that the specialist GP that she has discovered is leaving.

Self-management support and BET

Keeping track of repetitive symptoms can be difficult. MB 1096 describes her expectations built through experience of what her consultant is likely to ask and her personalised method of keeping track, punctuated by the use and documentation of antibiotic use. It is interesting that JD 1104 talks of a daily diary but does not use one herself. ML 1044 clearly found some comfort in using BET. GA 1033 discusses the advantages of having reserve antibiotics on standby. SKD 1051 describes the difficulty of keeping track and describes how she became habituated and evolved her own method by utilising a notebook. Sputum testing results cause confusion, in particular the fact that the results are neither binary nor conclusive but rather provide information from which to base future decisions is illustrated by JD 1104.

For each individual maintaining motivation to self-manage is approached differently. Some are motivated by fear *"I saw the chart of declining lung function and I thought that I am not going to take my good health for granted…Making sure that I get out at lunchtime and do have a walk in the fresh air"* ST 1038. Others maintain a ritualised routine "*I check the colour in the morning every day and do something about it if the colour changes*." SJ 1074

When to introduce self-management is an interesting question. Although it would seem ideal to provide information and education materials to support self-management at diagnosis (as suggested by MB 1096) the focus group member who had the mildest presentation declared "I didn't use the book, I am rarely unwell" SJ 1074 .

There were suggestions on amending the format *"maybe a page per infection that would be brilliant"* ML 1044. Continued follow-up and easy access to self-management support and advice was discussed ML 1044 succinctly summarised this in the following request *"Just being able to pick up a phone and say this is going on, is it OK?"*

Conclusion

Severity, individual preference, motivation and habit all affect self-management. The need for specialist knowledge is evident. A self-management intervention for bronchiectasis with ongoing telephone support has the potential to help bridge this gap (and reduce social isolation) using existing accessible technology at low cost. Finding ways to individualise record keeping so that the BET tool or other recording device requires less literacy and associated burden requires further innovative design. The BET intervention was a step in the right direction in supporting people with bronchiectasis, it needs further development to more closely to suit their needs and preferences.

Qualitative Part 3

Health professional interviews

Background

Health professionals act as guides to patients in understanding and accepting their health issues and in maintaining and improving their health prospects. As part of the infrastructure delivering healthcare they are acutely aware of the opportunities and limitations inherent within their immediate health delivery system, wider NHS and social care and the logistics, education, financial impact for all involved.

Introduction

The following interviews explore the unique ‘insider’ perspective of health professionals exposed repeatedly to the realities of self-management navigated by individuals with bronchiectasis. The health professionals reflect on the barriers and opportunities to self-management in bronchiectasis. This part of the qualitative evaluation continues to utilise the post-positivist theoretical framework employed in the previous two sections. Advantage has been taken of the flexibility of the thematic analysis method used here in a simpler format more akin with the positivist methodology of the quantitative chapter. The aim being to seek exploratory and explanatory healthcare-centred insight into what may have obstructed or been missed opportunities in the development and evaluation of the BET intervention. Finally, this data is considered in order to obtain pointers to guide future bronchiectasis self-management development.

Methods

Below the Consolidated criteria for Reporting Qualitative research (COREQ) is a framework providing a checklist for reporting qualitative studies (374). The framework is used here to provide the reader with a detailed account of the interviewing of health professionals who were steering group advisors to the BET study to understand and explore their observations of the barriers and opportunities for self-management of bronchiectasis in this region.

COREQ is designed to provide a highly contextual view of the research conducted. The first domain evaluates the research team and reflexivity. The researcher/interviewer is female and reflexive aspects of occupation experience and training are presented earlier in this chapter. The relation of the researcher to the interviewees was of PhD student and junior colleague. The interviewees were specialist advisors to the BET study and as such had been highly attuned to the concept and evaluation of self-management and in relation to their patients with bronchiectasis. The steering advisors met six monthly to discuss progress of the BET study and self-management in healthcare and research literature. Both interviewees were aware of the interviewer’s goals, they had been involved in the BET protocol design which stated the objective of interviewing health professionals as part of the study. The interviewees were aware of the researcher/interviewers vested interest in the topic and appeared highly motivated to take part.

The theoretical framework employed in these in-depth interviews was a post-positivist one (321). Thematic analysis was initially used deductively to identify the barriers and opportunities for self-management.

The Participant selection was purposive. The two health professionals invited to be interviewed were uniquely placed due to their dual roles as specialists encouraging self-management of bronchiectasis and steering group advisors to the BET study. Their steering roles provided an extended period during which to consider bronchiectasis self-management and to observe what facilitated or obstructed their patients in being able to self-manage. Their healthcare roles, independently of the study, pivot on informing and supporting self-management and enhancing self-sufficiency in managing bronchiectasis to maintain quality of life. The specialist consultant is male aged in the range 40 to 50 and the specialist nurse/community matron is female and aged in the range 60 to 70. The method of approach for invitation was face-to-face at the conclusion of a BET steering group meeting. A convenient time was arranged by telephone to suit the interviewees. The interviews were conducted in the environment chosen by the interviewee (options offered were in a meeting room away from the healthcare environment, in an office at work or at the interviewees' choice of other venue). The interviews were digitally recorded, transcribed and transcripts reviewed by the interviewees (member checking) no changes in the form of redactions, clarifications or enhancements were requested and the interviewees felt that they had nothing to add. Only two interviews were sought to permit in-depth evaluation of possible moderators and confounders to the study and to consider future directions for research into self-management for this patient group. No further interviews were planned or conducted (recent university and hospital research studies shared during monthly updates reported the difficulty of obtaining feedback from health professionals particularly during flu season).

Only the participant and the interviewer were present during the recorded interviews. Both interviewees are senior clinicians with more than ten years specialist experience and are both prescribers. For data collection both interviewees were provided with the same interview question which was:

What is your personal opinion based on your interactions with patients of the barriers and opportunities for bronchiectasis self-management?

The interviewees were allowed to pursue this topic as they chose with minimal interviewer interaction other than a few requests for elaboration or clarification where needed. The interviews were audio recorded. No repeat interviews were felt necessary by the interviewer or interviewees. Field notes were made during the interview, both participants initially aware of the novel situation of being audio recorded but quickly relaxing when relating observed patient behaviours.

The duration of the interviews was very different, the consultant interview conducted during work hours lasted fifteen minutes and was interrupted by urgent requests. The community matron interview away from her workplace and outside working hours lasted fifty minutes and was uninterrupted. The interviews concluded at the convenience of the interviewee. Data saturation is unlikely to have been achieved. The purpose of these interviews was to explore bronchiectasis self-management in light of the quantitative findings of BET.

Data analysis was conducted by the researcher/interviewer. The data was deductively coded by the interviewer and codes reviewed by both interviewees. The coding is very simple and relates to barriers and opportunities for bronchiectasis self-management. Barriers and opportunity coding were applied deductively. Excel was employed to manage the data due to its accessibility to the interviewees and interviewer, its flexibility as a data-management tool and the familiarity and proficiency of the researcher employing it.

The interviewees provided feedback on analysis and were present when it was discussed at a BET steering update (individual quotes were not reported during the meeting though codes and themes were discussed).

Quotations have been used to illustrate important topics within the chapter and the barrier and opportunity codes used to explain these.

Findings

Training

Findings that were consistent to both professionals related to health professional training, both individuals being part of informal peer supportive specialist training groups for continuing professional development.

Multi-disciplinary health professionals undergo highly structured clinical training in order to qualify in their profession and to provide evidence based clinical treatment to health service users (375). Post qualification their knowledge and skill maintenance and improvement relies on individual practitioner motivation, opportunity and ability to select, fund and undertake continuing professional development whilst maintaining everyday practice. There is a lack of framework to guide knowledge acquisition for staff at all levels, generalist and specialist who are expected to seek information independently on a piece by piece. The National Institute for Health and Care Excellence (NICE) was established to help encourage equity of health delivery in the UK through high quality clinical guidance now recognised internationally. NICE provide easily accessible information to drive *'Quality, innovation and value for money'* (376) in the British National Health Service. The latest information relating to bronchiectasis represents guidance on antimicrobial prescribing for acute exacerbation published in December 2018 (377). In Bronchiectasis the British Thoracic Society guidelines both 2010 and 2018 do provide an excellent source of information (1, 20) the latest guideline consists of over sixty pages in a dense, information-rich written format with extra appendices. It is encouraging to see that a short course is taking place in May 2019 to *'ensure respiratory teams in the UK deliver optimal care to patients with bronchiectasis in line with the new BTS Guideline.'* The cost of the course is £320 for non-BTS members and lasts a day provided at one centre and date only in the UK. For primary care staff justifying the cost, travel and expenses and obtaining time away from work to attend may be challenging where training budgets are highly scrutinised. For secondary care the issues related to justifying training may be similar and depend on whether there is bronchiectasis specialist service able to send a representative. The programme content is perhaps aimed more at specialist hospital teams. No webinar, video-conference, or other online materials are available at present that might make the information more accessible to a diversity of multi-disciplinary, commissioning or patient support and education groups. A two page summary for the general public has been made available in a written format.

Empowerment or deference

Both interviewees noted that some patients remained submissive and deferent despite encouragement and support in engaging in empowered self-management.

This seems to agree with the generational hypothesis espoused by Tolbize (187) explored in detail in the introduction to this thesis, in which social environment has created marked differences in attitude toward self-management and relating to interactions with health professionals. With older generations more deferent and reluctant to impinge on what they feel is the health professional's territory.

It is important to note that though people with bronchiectasis are likely to build experience of their own symptoms they may find it more difficult to evaluate risk because they are not exposed to the patterns of repeated phenomena which help health professionals make decisions with confidence knowledge and experience.

Self-management support

The community matron focussed most on the psychological aspects of emotional and physical aide and assistance required in self-management. In particular the isolation of people who are housebound creating the need for a family member or other emotional mainstay to assist with physical and emotional needs. With depression inhibiting the will to self-manage.

Information needs and the new BTS public summary

The community matron observed that for non-specialist general practitioners providing patient information about bronchiectasis was a challenge maintaining specialist knowledge relating to bronchiectasis difficult when managing a large and diverse patient population with a wide variety of disease. The two page public summary within the updated BTS bronchiectasis guidelines are a tangible marker of progress for people with bronchiectasis. Advice from specialist respiratory physiotherapy at least annually and if a patient has more than two exacerbations per year will be welcomed. Respiratory physiotherapy input in the region studied during BET was highly valued by people with bronchiectasis and by their healthcare team although availability funding and staffing was limited and unlikely to meet the requirements in the public summary. Similarly access to the level of intravenous treatment suggested in the summary is not currently available within the region studied in BET at home or in hospital except as an emergency admission. Increases in funding required to provide this may be difficult to obtain in the current financial situation of most UK hospitals.

Agreeing self-management plans with the people tasked with self-management will perhaps encourage a more collaborative approach from both health professionals and provide information for plan enhancements. How agreement will be evaluated is a topic of interest. The point of contact to be referred to 'when things go wrong' warrants clarification. The term mucus is used in the summary and other NHS documents refer to Sputum and phlegm, consistency of language may help reduce confusion.

Processes within self-management

The specialist consultant (perhaps relating to his engagement with past guideline development) focussed on system and procedural issues that affected people with bronchiectasis detrimentally. Medication formulary incompatibilities between primary and secondary care causing patient confusion and reluctance to allow people with bronchiectasis to keep home antibiotics even when recommended by secondary care leading to delays in treatment. Other examples of delays to treatment related to incorrect interpretation of chest sounds or unnecessary delay to antibiotics whilst awaiting sputum microbiology. In terms of self-management the greatest challenge to the process was the recognition and timely treatment of exacerbations due to variation and individuality in person to person presentation and the likelihood of gradually declining symptoms at all times.

The following illustration of interview statements and their detailed evaluation into barriers and opportunities permits an excitingly detailed view of professional experiences and how these represent barriers and opportunities to the self-management of bronchiectasis.

Interview Specialist Consultant

greatest issue with self-management?

> *"it is effective management of exacerbations and there are a lot of issues linked to that, most people have a degree of background symptoms which they become used to and for most people it is managing the 'down times' drawing the line and making the decision that they are exacerbating." CONS*

Barrier - Distinguishing between the variability of background symptoms and change requiring treatment.

Opportunity- Learning over a period to recognise exacerbation means that treatment need not be delayed by awaiting health professional advice

> *"Some people are very confident feel they know themselves better than health care practitioners."*

Opportunity, improved confidence is viewed as an advantage by this healthcare professional.

> *"And at the other end of the scale there is your typical retired elderly person who won't do anything unless it is blessed by a doctor or health professional. If they are told by a health professional that they are not exacerbating, they totally accept it, where actually they are coughing up vast amounts of sputum and do have an infection."*

Barrier- the statement above suggests that despite excellent instincts patients can be misguidedly discouraged from their accurate recognition of exacerbation by health professionals with less than adequate knowledge.

> *"At the other end of the scale are people who are very confident i.e. my sputum has changed, I know that I have an exacerbation, I want this…"*

Opportunity – this healthcare professional clearly views the confidence displayed in the behaviour discussed above as an opportunity. Building the confidence described may take time for patients and their support networks because they have only their own exacerbations on which to build experience. In contrast, health professionals, particularly specialist health professionals in secondary care have a much larger bronchiectasis population on which to base repetitive experience and pattern spotting to support their growing experience.

> *"Patients are often attuned to the media and primary care culture that is wary of antibiotic use and therefore delay taking decisions about starting antibiotics until they come for their secondary care appointment (sometimes up to three weeks) because they want permission from an expert, where actually they are the expert on themselves."*

Barrier - Conflict with regard to antibiotics can leave patients confused. In addition side-effects make patients reluctant to start treatment. Inhaled nebulised antibiotics may offer much needed alternative routes of administration. These methods do not suit all and require a degree of dexterity and time.

Barrier – Providing education that resolves the conflicts displayed in the statement above are clearly necessary in order to encourage self-management and also self-management support.

> "Patients frequently report that their primary care health professionals have listened to their chest and it is clear therefore I don't need antibiotics."

Barrier – lack of congruent, consistent and accurate messages throughout healthcare.

> *"Sometimes the converse, crackles were heard therefore there must be an exacerbation, which can be equally untrue because crackles are often permanently there."*

Barrier – again poor or misunderstandings within health professional knowledge that causes confusion for patients.

> *"Another misunderstanding is that the sputum culture was negative therefore there is no exacerbation. Sharing with primary care colleagues that sputum culture is essential and very useful but more about what you do next time. The culture can be more about making informed decisions regarding resistance if antibiotics are symptomatically ineffective."*

Barrier - Both patients and health professionals seem to find it hard to understand that sputum results are much more complex than a binary result and that actually when nothing is grown it does not necessarily follow that there is no infection. Rather the sputum result gives clues on progress of the disease.

> *"Also waiting on sputum results is unnecessary delay."*

Barrier – delay due to waiting for antibiotic results before starting antibiotic treatment.

> *"If symptoms of sputum volume or colour or your key 'red flag' symptom changes for more than 24 hours rescue/reserve antibiotics should be commenced"*

Opportunity – this is a concise message, simple to deliver and receive

> *"It is an issue where secondary consultants and primary physicians disagree so that the person with bronchiectasis does not have a reserve of antibiotics and therefore have to wait to be able to get appointments and other related problems"*

Barrier - The availability of appointments both in primary and secondary care does not permit treatment of infection within optimal timescales so providing people with this condition with reserve or home supply of antibiotics and the understanding of when to start treatment is important to prevent delay.

> *"GP staffing and practice nurse staffing make getting appointments problematic."*

Opportunity - Nationally there is a shortage of GPs. Self-management provides a method to bridge this gap. However, support is still required.

> *"Definitions of exacerbation can be a bit woolly and a bit personal some people have some features and symptoms and others don't so it has to be individualised and therefore it is hard to be categorical."*

Opportunity - This individuality is something that makes teaching the individual to recognise their own particularities an advantage of self-management that might be difficult to learn for health professionals who may not meet the person regularly to build this knowledge.

> *"The question of feeling empowered enough to take antibiotics is a difficult one. Younger people have grown up encouraged to question things."*

Opportunity – this quote hints at generational differences in attitude to empowerment. The reticence of older generations might be achieved through peer support from younger people similarly affected.

> *"So the personal management of exacerbations for individuals is this complex mix of good information, poor information, doubt and confidence on everyone's part."*

Barrier – this extract hints at the pitfalls of trying to learn self-management skills in the current environment.

> *"The Cystic Fibrosis multi-disciplinary team meet and also review new literature available monthly as group learning"*

Opportunity – shared knowledge increases the information foundation for advice to patients and as group learning lightens the load and the effort to each seek information independently, it is time and effort efficient and promotes teamwork.

> *"There is a mismatch between what the patients are prescribed on consultant letters but actually receive something else."*

Barrier – Access to consultant letters from primary care practices is now easily obtained but not necessarily to home visiting health professionals due to information sharing arrangements. Primary and secondary care formularies are different which may represent a reason why different medications are received by patients.

> *"Cascade information – share information"*

Opportunity – an investigation into the mapping & cascade of information may be helpful alongside an audit of education, medication and sputum analysis and interpretation.

Interview 2 Community Matron

> *"Main need is a care-giver, somebody to support them when they are ill, for those who don't have someone to fulfil that they are more anxious than those with a supportive partner."*

Barrier and Opportunity - In discussing the greatest need or biggest issue in self-management this quote identifies the need for comfort and support.

> *"Moral support, mostly someone to be there when they are frightened."*

Opportunity – in identifying fear as a barrier to self-management this extract also identifies an important interpersonal need that should be considered as part of self-management.

> *"They have a need for a three o'clock in the morning role and there aren't resources for that that I can refer them to."*

Barrier – The lack of a helpline that would provide a sympathetic listening ear when fears seem at their most acute during the sleepless small hours or for people who are very isolated is a missing part of the support puzzle.

> *"Neither befrienders nor carers fulfil their needs which are to be supported when they are sick and afraid. A helpline if it were available around the clock would go some way to meeting their needs."*

Opportunity – clinical/psychological advice line.

> *"For those who can obtain a personal budget and make that system work for them then that is second best to having direct care. It is hard to find the right personal assistants to help you but if you can do it, it makes a massive difference, paid for out of social services personal budget."*

Opportunity – the personal budget is clearly viewed as an opportunity to exert choice and preference over care. However, the quote is tempered with caution suggesting that obtaining the right personal assistant is *'hard to find'*.

> *"When you are ill changes in personal support can be difficult in a particular instance I can recall the assistant has left during a period of severe illness so the individual was doubly handicapped."*

Barrier – it seems that obtaining and maintaining the staff obtained through a personal budget can be a struggle and seeking new help when hampered by ill-health poses an added burden. Since these are individual arrangements there is not necessarily a stand-in when the circumstances of the employee change unexpectedly.

> *"You only qualify for the support when quite severely ill so decisions must be made because they are the employer whilst poorly. It used to be Equal Lives that supported during this period but they are sometimes really unavailable and unfortunately it isn't anyone else's role either."*

Barrier – the quote above is not surprising under today's financial pressures on services. It represents an added burden and obstacle to the chronically ill who require these services.

> *"Equal Lives is a charitable group in Norfolk to support and back up people with disabilities, they give them access to these personal assistants and campaign on the behalf of the disabled."*

Opportunity – this charitable organisation clearly supports people with chronic disease in providing specialist knowledge of employment law, contracts and etiquette relevant to employing people to assist with activities of daily living.

> *"You have to pay to get the expertise from Equal Lives for employment rules and regulations and obviously if those arrangements breakdown and you have to restart the process you have to pay again it is not a one-off cost."*

Barrier – the quote explicitly explains the issue.

> *"Social services and internet services might support you but in terms of holiday pay, sick pay and terms and conditions for personal assistants you need the skills regarding the employment rights of the person that you are employing and this might not be your skill set and you are ill at the same time."*

Barrier – Again this quote explicitly highlights the pitfalls, intricacies and pressures involved to enable choice and control over everyday assistance whilst unwell.

> *"The greatest need when people with bronchiectasis are stable or managed at home with manageable infections is support and encouragement."*

Opportunity – this quote highlights the importance of encouragement and support during periods of bronchiectasis stability and speaks of the isolation and psychological needs of this group of patients when largely housebound.

> *"My patients are wary of taking antibiotics, most of them, no matter what you say -won't start their antibiotics without you agreeing that it is the right thing to do. And most of them have picked up on the message of over-use of antibiotics and are frightened that they will do so."*

Barrier – overcoming this reticence is an important step in acting fast to treat infection and engaging the self in self-management. This statement is worrying, it may be harder for a generation who in the past had been discouraged from self-motivated action to feel confident in taking action.

> *"Although I care for a variety of people and some seem quite assertive they will all ask my opinion."*

Opportunity – mutual respect is necessary for collaborative health

> *"I have to seek updates through personal choice and development."*

Barrier – the fact that training is mostly self-motivated means that it is an extra burden at the end of already over-booked clinical time rather than a guided development along semi-structured pathways.

> *"There is no easy flow of information or updates to patients, they get nothing."*

Receiving regular updates and direction on where to find reliable sources of information might be both reassuring and develop knowledge.

> *"I am not sure that people with bronchiectasis would welcome updates about the condition, it is something that they don't want to make the main focus of their lives, one or two would and are hungry for information."*

Barrier – perhaps the encroaching nature of chronic disease already overtakes more of their daily lives than these people would like and they may therefore avoid re-enforcement or reminders of their ill-health.

Opportunity – for those seeking information it is important to capitalise and provide good quality, accessible information.

> *"I would say that 3 out of 8 know how to do their airway clearance. One does it religiously the other two would know how but only do it when they need to."*

Barrier – Five out of eight of the patients described here need physiotherapy advice and education in the home for which there is little provision.

Opportunity – the people who perform their airway clearance ritualistically and those who do it when needed have both adopted methods that are acceptable and work for them.

> *"The other five have not seen a physiotherapist."*

Barrier - Access to this specialist advice is of importance to this patient group.

> *"If it were financially possible I think that a physiotherapy update offered every year would be comforting because then they would feel in touch but not overwhelmed."*

Opportunity – beyond initial training, refresher training would be helpful but is not available in this region.

> *"A newsletter that informed people with bronchiectasis of innovation that they could then discuss with whatever their support network is (so also informing healthcare workers and support teams to provide an extra opportunity for discussion)."*

Opportunity – providing a basis for shared knowledge and discussion

> *"Each CCG decides on the model and whether they need community matrons and how many so it is a postcode lottery whether you can obtain one."*

Opportunity - Providing guidance for CCGs on care required for bronchiectasis and the importance of reaching this and other chronic disease populations in their own homes.

> *"Some of my patients with family who also have bronchiectasis in other parts of the country do not have community matron support."*

Barrier - For this population who become more bound to their homes as severity increases, having support for their self-management and specialist advice within the home on addressing physical and psychological needs helps maintain stability.

> *"Community matrons have to cover all chronic care needs and therefore are often not specifically respiratory trained."*

Opportunity – A growing population of patients with multiple co-morbidities mean that helping these people achieve self-management using validated methods could help guide both the patient and their health professional along a best practice pathway.

> *"As community matrons we meet once a month and motivate each other with our learning needs."*

Opportunity – Providing bronchiectasis information and updates in an easily accessible and regularly reviewed format might make learning opportunities more fruitful.

> *"I find it difficult to find a journal that meets my learning and work requirements."*

The NHS does not provide role-specific materials or websites guiding knowledge development.

> *"People who are at home are bombarded by calls for commercial services and are therefore often reluctant to receive calls and find it difficult to leave the house due to fatigue and effort so they are careful about saving their energy either for family special occasions or important hospital appointments and are wary of committing to other activities."*

Opportunity – The telephone is one of a number of methods that can reach people largely confined to their homes, planned and timed interactions may help reduce intrusion and anxiety.

> *"Transport for the elderly and getting places can be difficult, buses might mean two buses and they often can't afford taxis. Timing of appointments can also feel quite early to them even when it is ten O'clock."*

Barrier – Starting the day and getting washed and dressed can be very effortful for people with severe respiratory issues who may find it difficult to attend early appointments. In addition government-subsidised travel on public transport for the elderly begins at 09:00 in the morning so in a geographically spread area time taken to travel to appointments can be an obstacle to early appointments

> *"This patient group are generally quite poorly informed because they get little information from their GP."*
>
> *"Diagnosis by referral for HRCT can take a long time."*
>
> *"Patients can often wait between 3 and 6 months for a diagnostic appointment."*
>
> *"Referral to Older People's Medicine can be attractive for GPs who know that patients receive a good holistic assessment including cognition, falls etc. which are targeted nationally where there are not the same requirements for respiratory care. All the GPs are overstretched in my area things are critical and patients are often redirected to walk-in centre for emergency appointments. Routine reviews can take up to two months."*

Barrier – The past twenty years have seen repeated warnings that a growing elderly population and chronic disease demands were outstripping healthcare supply and the quotes above illustrate these issues and make it increasingly difficult for people to engage in self-management if they can't access healthcare when they require it.

> *"If patients are low in mood we can ask for anti-depressants to be prescribed or ask them to refer themselves to the wellbeing service but this can take several weeks due to resources. Social services can be asked for a carer's assessment but that can also take weeks."*

> *"Once you have assessed someone's mental state needs attention the only thing that you can speedily do is medication and understandably people are often quite resistant to receiving more medication and they worry about taking medication for anxiety and depression."*

Barrier – depression is highly prevalent in people with chronic disease and undermines engagement with self-management. The quotes above highlight the limitations of support available.

> *"Concordance among my patients are hugely varied, and it is a very individual thing, they need to be in control, and they need to figure it out, so you need to discuss it with them when they will allow, a bit at a time."*

Opportunity – this quote highlights the opportunity presented by health professionals who are able to provide continuity of care and hence assess when opportunities present and moderate the burden of information to what is manageable.

> *"Their last bit of control when chronically ill can be refusing to talk about anxiety and depression and keeping everything pleasant and controlled rather than discuss they deny - which sometimes paradoxically appears to work for them and they continue against the odds, and it is their choice which must be respected."*

Barrier – although this quote clearly illustrates a barrier to providing support, it also provides reassuring evidence of respect for patients' wishes. The natural psychological defence mechanism represented by denial may, as the quote suggests, sometimes be beneficial.

> *"For a majority of my housebound patients they do not get regularly reviewed by either a GP or a hospital consultant."*

Barrier – Self-management requires guidance and support and access to healthcare. It is hard to imagine, relating to the quote above how professional guidance and advice is obtained where access is similarly scarce and community matrons do not exist.

> *"If I were to train another community matron I would advise starting with checking the guidelines for bronchiectasis where things are summarised, usefully organised and systematic."*

Opportunity – The BTS bronchiectasis guidelines referred to above are successful in providing specialist knowledge, information and guidance to frontline health professionals to support people with bronchiectasis.

> *"Measuring sputum volume, teaspoon, tablespoon, egg cup or teacup, makes people cringe but is actually very useful to evaluate change."*

Opportunity – This simple method of evaluating sputum volume makes communication effective and meaningful.

Discussion

These interviews illustrate the reality of day-to-day healthcare interactions. By categorising these insights into barriers and opportunities for self-management it is easier to consider how best to provide care for people with bronchiectasis.

Barriers summarised

A variability of background symptoms mean that it takes time to learn to self-manage and to recognise exacerbations.

However, this individuality highlights the importance of becoming expert in one's own symptoms to avoid less accurate generalisations applied by health professionals who (due to healthcare funding issues) may be seen relatively infrequently. Receiving different health messages from primary and secondary care are highly likely to cause confusion. Media messages discouraging antibiotic use increase the reluctance to utilise antibiotic treatment effectively. Funding of medications is not standard so formulary availability causes issues where specific treatments advised by specialist consultants are not provided (because they are non-formulary) by primary care general practitioners. Although airway clearance training is pivotal in the care of bronchiectasis there was not enough physiotherapist staffing in the region studied to provide initial training or regular refreshers/updates

For the severely ill seeking to maintain autonomy by using personal health budgets guidance and support is required for employment purposes. A lack of infrastructure surrounding continuing education for all multidisciplinary health professionals in the UK means that maintaining knowledge is a personal burden in excess of continually mounting clinical responsibility and reduced training budgets. This means that training is neither standard nor supported in practical and meaningful ways.

Opportunities

Building personal knowledge of symptoms and being able to start treatment appropriately provides opportunities of individualised care. The confidence required to make health decisions could be addressed as they have been in other chronic diseases through cognitive behavioural approaches. Exploring and unifying health messages and providing a framework for sharing information should increase collaboration and confidence in both health professionals and people managing bronchiectasis. Actively identifying social and generational information may help facilitate culturally and socially acceptable engagement and dialogue. Peer coaching and support present opportunities to reduce isolation and bridge the gap between self-management support required and healthcare staffing available. The growing trust and social change in clinical support from paternalistic to more collaborative, allowing patients to keep a reserve of antibiotics, though not universal, does allow prompt treatment within 24 hours of change of symptoms.

Addressing depression and isolation as a barrier to health and to self-management common in chronic disease transcends disease barriers and therefore would benefit from a universal strategy including telephone or mobile support. The ability to discuss issues of self-management using a helpline would avoid displacement issues and allow triage of requirements to the wider multi-disciplinary team enabling a broad spectrum of appropriate support and advice.

Table 12 Evaluating BET using Pinnock et al Reflections on asthma model

Evaluation of BET self-management using the Pinnock *et al.* BMC Medicine (2015) 13:127 Table of Study authors' reflections and lessons learned in asthma self-management implementation	BET intervention	BET Evaluation	Future Bronchiectasis self-management interventions	Future Bronchiectasis self-management evaluation
Effective patient self-management education needs to be supported by regular reviews, underpinning a partnership with patients. In addition to education, aligning with patients' perceived needs and preferences.	The BET intervention was brief and without supported review and follow-up, this is likely to have limited its value.	Outcome questionnaires required self-motivation to complete (they were sent to home addresses) the burden of literacy, or of frequency (questionnaires completed at five time points in a year) added to the fact that the questionnaires were designed for other respiratory	Regular reviews necessary	Less literate and onerous form of evaluation should be considered. Perhaps less frequent measurement too
Only a proportion of people accept the offer of self-management education, and all studies reported an attrition rate. For many interventions, especially those delivered in deprived communities, recruiting and retaining patients was a major challenge. Financial incentives (free access to care, free prescriptions, favourable insurance premiums, free patient resources) were potential strategies for increasing engagement	BET recruited the target 220 people but the attrition rate was high only 127 participants completed the study.	No face-to-face follow-up and no integration into community as proposed in the chronic care model	Intervention should address all aspects of the extended chronic care model.	The use of more volunteer and peer support and use of technologies to reduce the need for literacy and burden of evaluation.
The use of telephone interventions may overcome some of the practical barriers to participation in self-management programmes.	The use of telephone education in BET seemed acceptable to the participants randomised to the intervention.	No telephone evaluation was made for outcomes	Telephone interventions should be considered although alternatives are required for the hearing impaired	Telephone evaluation may be possible if the questions are brief and not multi-choice
Achieving change is a challenge, even in well-motivated teams. There is a need to support professionals as they integrate new behaviour into practice. Promising approaches include collaboratives, and plan/do/study/act (PDSA) cycles, and introduction of self-management support as a component of improved chronic care.	Integration was not envisaged within the scope of the BET evaluation study. Though education is an important aspect of maintaining an informed and well-motivated health professional team this thesis shows the lack of guidance and framework for continuing professional development.	Integration was not within the scope of BET	If integration with existing services is proposed within the research study a totally different methodological study design will be required compared to BET (COHORT)	Consider positive examples within the business sector
There is a need for regular oversight and frequent reviews to ensure intervention fidelity and respond to evolving situations. Frequent staff turnover can be a particular challenge which needs to be addressed, to ensure that skills are not lost.	The positive influence of clearly articulated guidance and regular audit evaluation is highlighted by the British Thoracic Society examples of these for bronchiectasis.	Issues of intervention fidelity were minimised in BET by using scripts and one researcher delivering all the intervention education	Should consider Pinnock et al. warning and provide regular support and evaluation.	Engage with governance and audit stakeholders to benefit from expertise
Professional training in supporting self-management, collaborative multidisciplinary working, with good communication and referral systems between professionals, and involving existing staff members in the design and implementation of interventions are potentially important ingredients of implementing self-management support.	Government investment in the National Collaboration for Integrated Care and Support is likely to form a more cohesive foundation for self-management than was available to the participants of BET.	Was not in the scope of BET	Consider external support in coordinating and creating motivational environment	Needs careful consideration
A team approach involving the community was seen as essential to the success of projects in deprived, minority communities.	Not within scope	Not within scope	Team approach with community congruent with chronic care model	Complex needs careful consideration
A key facilitator highlighted by several authors is the commitment of the healthcare system and/or local practice or clinic, with on-going evaluation.	Continuity plans are difficult in current economic environment	Continuity plans are difficult in current economic environment	Continuity plans are difficult in current economic environment	Continuity plans are difficult in current economic environment
There are practical barriers if on-going funding or resources (including time) are insufficient to enable complex interventions to be sustained.	Low cost due to funding	Low cost due to funding	The nature of short term funding for research is unlikely to change	
Technological solutions (such as computerised cognitive behaviour therapy programmes, automated telephone calls) show some promise.	Only telephone technology used	Not in scope	Exciting opportunity	Exciting opportunity

Conclusion

The issues surrounding the bronchiectasis care pathway during the conduct of BET may have been too great to be resolved by self-management. The National focus on integration of chronic disease care discussed in the introduction is likely to enhance the coherence of services making collaboration with health services less onerous for the patient. The process of continual improvement in bronchiectasis care led by updated guidelines (BTS) and regular audits are also likely to improve the quality and delivery of bronchiectasis health services through the unification of methods resolving disparities of treatment to provide a stronger foundation from which to foster individual self-management skills. Though BET did not meet the participants' needs, the table in the discussion section comparing BET with the Pinnock *et al.* reflections on the implementation of asthma shows opportunities for future bronchiectasis self-management intervention development.

Chapter 5

Discussion, Conclusions and Future Directions

Opportunities for and barriers to self-management in bronchiectasis

Chapter 5

Discussion, Conclusions and Future Directions

Opportunities for and barriers to self-management in bronchiectasis

Design of the BET intervention

BET Action plan (Appendix 20)

Action plans for chronic illness are designed to help identify change requiring treatment in diseases that have periodic worsening called exacerbations (378). These exacerbations mark decline in health, reduction in quality of life and often increased demands on health services (379). In bronchiectasis an exacerbation manifests with a variety of symptoms depending on the individual: subjective and persistent (≥48 h) deterioration in respiratory symptoms including cough, dyspnoea (breathlessness), increased sputum volume, change in sputum texture, change in sputum colour, haemoptysis (coughing blood), chest discomfort or pain, fever and also systemic symptoms such as fatigue, nausea, difficulty concentrating and general malaise (380). In order to be of assistance to individuals and their families when an exacerbation strikes, the information must be concise and easily understandable, requiring as little interpretation and literacy as possible. The BET action plan consisted of a one page 'at a glance' guide to support people with bronchiectasis in identifying health changes and supporting actions in response to those changes (Appendix 20 page 2). The British Thoracic Society template for self-management has the advantage of being easy to complete for health professionals, low in cost (it can be sent to any printer) and only a few pages long. Its minimalist approach to information might make it easier to individualise. However, it is all written with no diagrams to help reduce literacy issues or increase visual appeal. It is also quite sparse and therefore provides little guidance or support to navigate the multidisciplinary environment for health professional completing it or for the person using it. The onus is on the health practitioner to create the detail. Documents supporting people with asthma (another chronic respiratory disease) have been in existence for up to twenty years, these advocate utilising between two and four action points (286). The BET action plan had three action points:

1. Sputum colour change.
2. Sputum amount change.
3. Signs of worsening health

In addition, urgent medical attention is advised for severe breathlessness, chest pain or fever.

Baker *et al.* (381) advocate a logical presentation of information in sequential chunks to allow learners to apply cognitive skills to a section at a time and ask questions

Visual representations were used within the BET action plan to reduce the need for literacy (382-384), widely acknowledged as a barrier to health information use and to facilitate use during acutely ill episodes when cognitive function may be affected (385). The action plan is designed to guide decisions and provide an agreed pathway and evidence of advised action for participants who are requesting what are sometimes scarce and therefore difficult to obtain healthcare resources such as same day GP appointments.

BET Sputum - section 1 (Appendix 20)

Retention of secretions in bronchiectasis make airway clearance necessary in its management (386). British Thoracic Guidelines recommend that where possible people with bronchiectasis should be encouraged to take an active independent role in using their chosen form of airway clearance technique (1). The active cycle of breathing is a method that can be utilised for airway clearance. A summary of this clearance technique is illustrated as an aide memoire within BET. Specialist physiotherapy training to learn an airway clearance technique appropriate to the individual is recommended (387) (and advised within the booklet). The sputum (blue) section of BET has two note-taking sections the first allows the participant to keep track of changes in colour, consistency and volume of sputum, whether they sent a sample for testing, the result and whether the hospital or GP requested the tests. The following section tracks the use of antibiotics and whether they were effective with a space for two words only, the first being the name of the infection and the second the antibiotic used. An understanding of the necessity of regular sputum analysis in helping healthcare professionals build a picture of the progress of bacterial colonisation is one of the aims of BET.

BET Health Changes - section 2 (Appendix 20)

The causes of bronchiectasis are referred to by Suarez-Cuartin *et al.* as many and varied (51) it is therefore unsurprising that people affected evince a variety of symptoms in addition to those of increased sputum production discussed in the previous section. It is important for those who, either for physical or psychological reasons, have difficulty expectorating sputum to watch for other signs of an exacerbation

These other symptoms of exacerbation may include breathlessness, cough, chest pain or discomfort, fever, loss of appetite, malaise, apathy, fatigue, and symptoms secondary to the effects of the disease such as depression, difficulty sleeping, stress urinary incontinence and headaches. Change in these symptoms can be a useful marker of when to take action and also a measure by which to collaboratively assess progress when collaborating with health professionals. In the same repetitive formula as with the other BET sections the (red) health changes section has a crib sheet with a variety of common symptoms and then a variety of actions that can be taken such as; health change; increased breathlessness and to action - increased airway clearance.

BET Medications - section 3 (Appendix 20)

The increasing complexity of patients' healthcare needs mean that frequently people take a number of medications (polypharmacy) which have the potential to interact. Maintaining a record of medication as an aide memoire, creating a fuller picture of when changes occurred e.g. sensitivities, allergies and resistance (particularly to antibiotics) was designed to inform a more active role leading to increased feelings of control. This record may also better inform decisions regarding acceptability and an extra check from a safety perspective in collaboration with the clinical team. The medication section explained the difference between the unwanted side-effects of medications which should be reported to healthcare and the signs of an allergic reaction where prompt action in contacting healthcare and in discontinuing the medication are necessary. This section within BET also contains a list of antibiotics and whether these are orally or intravenously administered. When BET was developed inhaled antibiotics had not yet been licensed or become formulary for bronchiectasis at any of the hospitals involved. Changes in guidance would have required regular updating of the booklet to reflect these advances not necessitated during the study.

BET Contacts with healthcare - section 4 (Appendix 20)

As previously described, self-management is frequently referred to as a collaborative process. In BET the patient was encouraged to maintain information about past and future visits to healthcare designed to encourage self-management by making it easier to spot patterns and prioritise needs with healthcare professionals.

The (yellow) healthcare visits section began with (the now familiar) crib sheet describing whether the visit was Monday to Friday, Out of hours or emergency services call out. What speciality was attended e.g Practice nurse and the reason for the visit e.g. regular check up

Naming the intervention

The steering group were keen that Bronchiectasis be prominent in the title of the self-management information booklet. The aim of the document in supporting people with the condition by providing them with information that was designed to support and give them confidence in self-management was embodied by the word empowerment. Finally, the steering group felt that what we were trying to develop was a support tool. The document was initially called the Bronchiectasis Empowerment Support Tool (BEST). Patient and public advisors approved of the title, however, our potential funders criticised the title as potentially misleading, therefore amended to the Bronchiectasis Empowerment Tool (BET).

The visual design and structure of BET

Our patient and public advisors were keen that the use of colour and space would help direct the user within the document. Images were used as visual cues within the action plan and coloured borders to assist navigation through the four sections within the booklet (blue Sputum section, followed by red for health changes, green for medication and finally yellow for interactions with healthcare). When we canvassed our bronchiectasis advisors they felt strongly that the use of cartoons or clipart was patronising and off-putting so a photograph was used for the cover page, the photograph agreed upon depicted three individuals of different ages and sexes (both sexes and different ages are affected by bronchiectasis). The photograph shows the individuals outside interacting in an active format without showing any specific formal exercise. Our advisors felt that human interaction and enjoyment or 'quality of life' were important messages.

Keeping track – barriers and opportunities of BET

The concise and organised nature of the sections within BET were designed for simplicity of use and approved by our patient and public advisor (during feasibility testing) to felt that the format assisted keeping track of events in a format that aided collaboration with healthcare.

Our specialist consultant was keen that

"BET should not be a burden to those who are ill or an encumbrance reminding people of their ill-health during periods of stability and health. It should assist in self-management and health communications in the briefest and least complicated way possible." (388)

The notes sections (in tabular format at the end of each section) were designed to be used only when change occurred and hence minimise the burden or focus on disease and effect on quality of life. There was a risk that if the participant remained well for some time that they may forget to utilise the notes sections (this issue may have been mitigated if the intervention were adopted due to multi-disciplinary contacts and requests for information as reminders). Keeping notes may be more difficult for people with low health literacy.

BET Telephone education – barriers and opportunities

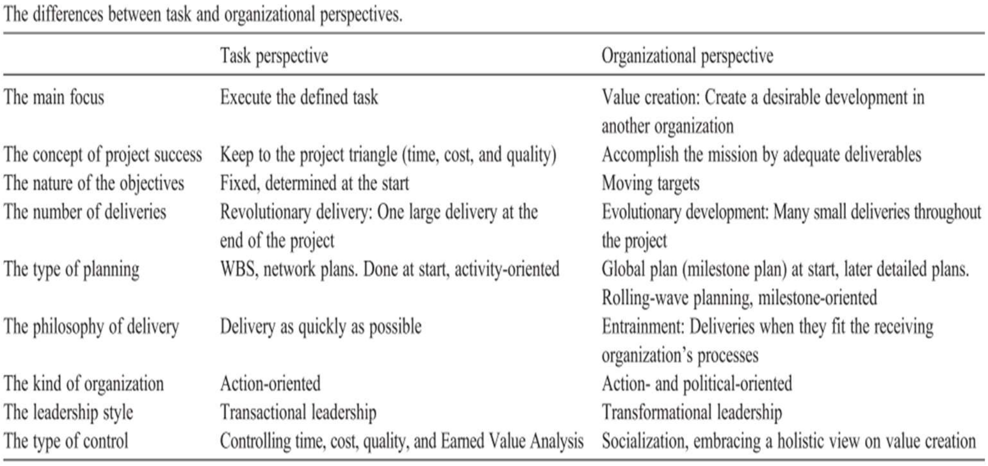
Appendix 21

Conducting the education sessions regarding the use of BET on the telephone permitted the greatest scheduling efficiency in terms of nurse time and effort. This method also represented the least displacement to participants and reduction of risk of contact with other infected patients within a busy outpatient respiratory environment, less travel with associated costs to the participant or the research study and also less competition for clinical space within an acute hospital environment. When the telephone education was tested (pilot, feasibility) with our patient and public advisor she reported feeling more at ease in her home environment and more inclined to discuss issues that caused her emotional and physical pain; she also appreciated the ability to choose a time that suited her. She reported that her confidence increased after day two when she had experienced two sessions in a similar and repetitive format and had been able to ask questions.

Opportunities and obstacles.

A combination of the cost of conducting clinical research and availability of participants may account for the lack of randomised controlled trials for self-management interventions. The British Thoracic Society guidelines for bronchiectasis 2010 provided the information foundation on which BET was constructed (1). In addition the increased availability of Computerised Tomography (CT) scanning provided a robust diagnostic confirmation of symptomatic diagnosis (39). Funding for this research provided by the NIHR and portfolio adoption facilitated the development and clinical testing of this intervention for patient benefit. The small fund available for Research for Patient Benefit limited the design of BET to a written format which was both simple and low-cost and similarly to questionnaire completion mailed to home addresses rather than face-to-face visits by the researcher to participant home addresses. Physiotherapy training for participants was not possible as part of the intervention due to lack of specialist staff resource. The governance and infrastructure surrounding research provides protection for patients and improved quality and standards for data collected. It also represents a significant necessity for specialist knowledge, expertise and administrative, time and cost burden for researchers, hospitals and universities. This research project was conducted from a task perspective rather than an organisational perspective. The risks and advantages of an organisational perspective are outlined in the table presented by Andersen (389) below.

Table 13 Factors affecting project success



The differences between task and organizational perspectives.

	Task perspective	Organizational perspective
The main focus	Execute the defined task	Value creation: Create a desirable development in another organization
The concept of project success	Keep to the project triangle (time, cost, and quality)	Accomplish the mission by adequate deliverables
The nature of the objectives	Fixed, determined at the start	Moving targets
The number of deliveries	Revolutionary delivery: One large delivery at the end of the project	Evolutionary development: Many small deliveries throughout the project
The type of planning	WBS, network plans. Done at start, activity-oriented	Global plan (milestone plan) at start, later detailed plans. Rolling-wave planning, milestone-oriented
The philosophy of delivery	Delivery as quickly as possible	Entrainment: Deliveries when they fit the receiving organization's processes
The kind of organization	Action-oriented	Action- and political-oriented
The leadership style	Transactional leadership	Transformational leadership
The type of control	Controlling time, cost, quality, and Earned Value Analysis	Socialization, embracing a holistic view on value creation

In addition the Santos *et al.* make a useful summary of factors affecting project success (390)

Implications for bronchiectasis care

Although government funding of research provides the means with which to evidence the treatments of the future, these are limited by the capacity and capability of the NHS clinical research environment, and by what is acceptable to participants. Clinical research relies on being able to recruit and retain sufficient participants to meet power calculations and enable clinically significant change to be detected. Although modern technology supports communication between sites, the staffing, regulatory burden and competition between research and everyday healthcare for clinical space and staff make the conduct of multi-site clinical trials effortful. Finding ways to formulate research hypotheses, interventions and clinical testing methodologies that are acceptable to patients, feasible within the NHS clinical environment and constructed to the highest ethical, quality and governance standards is a positive challenge that provides the basis for high quality, research evidence with relevance to people with bronchiectasis. The use of mixed methodologies should allow the simultaneous measurement of an outcome of relevance using a validated tool (an instrument of measure for which there is already research evidence) and the insights of participants who take part

Bias and Confounders of the BET study

The value of evidence-based healthcare is now almost universally acknowledged (391, 392). Bland, in his introduction to medical statistics suggests that ‘*it is often from the flaws in a study that we can learn most about research methods’* (393). In clinical trials the lower the variability between participants the greater the chance of detecting a treatment difference if one exists (393). A greater variability of participant is more likely to represent the diversity seen in everyday clinical practice hence the increasing popularity of pragmatic trials in which interventions are evaluated under real-world conditions (394). The BET Self-management education was designed to reach as many individuals with bronchiectasis as possible, inclusion and exclusion were hence broad and inclusive of people diagnosed with bronchiectasis and at least one exacerbation within the past year. Clinical trials often have upper age limits even though we are frequently reminded that there is a growing ageing population (395). Patient reported outcomes have grown in popularity due to their perceived ability to capture the patient ‘voice’ required by medical decision making (396). There were no objective measures of disease-progress or severity when the BET study was designed. Our patient and public advisors let us know that added visits to healthcare related to taking part in research would discourage participation owing to the burden of disease, geographical dispersal relative to the hospital and time already spent visiting healthcare for bronchiectasis or comorbidities. This was confirmed when potential participants interested in the study were asked to visit the hospital to discuss the study and decide whether they wished to take part. An ethical amendment to the study was made to allow telephone consent if necessary. Dang *et al.* report the influence of literacy, emotions, attitudes, socio-economic status and cultural beliefs on perceptions of well-being and sickness affecting patient reported outcomes (397). In order to ensure that all participants received the highest standard of available care both groups received the British Lung Foundation information leaflet on bronchiectasis and the British Thoracic Society Physiotherapy Guidelines for Bronchiectasis.

Methodology for the evaluation of BET was created with advice from NIHR research design service and reviewed and approved by a research ethics committee.

Conducting the study provided insights into the efficacy of the methodologies employed and both the limitations and opportunities presented by the BET evaluation study.

This is a critical analysis of the BET study and intervention to identify possible reasons for bias or confounders. The BET evaluation was developed based on the knowledge and publications available at the time. It is important to note that a trial designed today (2018) based on contemporaneous knowledge would not have the same methodology owing to the understanding represented by this trial and publications in the field of bronchiectasis. Aliberti and Blasi (310) report a 70% increase in publications relating to bronchiectasis between 2013 and 2016 and 113% increase between 2011 and 2016. This represents a significant positive momentum in better understanding of this disease.

There were no patient reported outcomes specific to bronchiectasis and validated in the UK when the evaluation of BET trial was designed. The SEMCD multiple, validated and frequently used patient reported outcome measures were used. A recently published (2016) protocol for a feasibility study to evaluate a novel information resource for patients with bronchiectasis (398) benefits from a bronchiectasis specific questionnaire but has an even greater burden of questionnaires, diaries and follow-up visits. The burden of completing each section contained written information and tabular forms to keep track of events.

Bias and Confounders

Heterogeneous disease

The BET study had broad inclusion criteria in order to reflect the bronchiectasis population from which it was recruiting. Bronchiectasis itself is diverse in cause and outcome (45, 57, 399, 400).This may have resulted in too great a variety between participants to measure changes in the outcomes. The introduction of measures of severity is likely to make it possible to better characterise bronchiectasis participants in recruitment to and analysis of future research.

Co-morbidities

McDonnell *et al.* explain that people with bronchiectasis frequently have comorbidities and the impact of these *'on disease severity and outcome is poorly understood'* (56).

This variability in bronchiectasis presentation may have attenuated the chance of detecting a treatment difference with non-specific quality of life outcome measures. In their 2016 paper McDonnell *et al.* suggest that the Bronchiectasis Aetiology Comorbidity Index (BACI) complements the Bronchiectasis Severity Index (BSI) in assessing disease outcomes this may clarify the impact of co-morbidity in future research concerning the self-management of bronchiectasis.

An informed and experienced cohort

Our steering group was advised as part of ethical research design to ensure that all participants of the study had received information already available and relevant to bronchiectasis. To comply with this, following consent a discussion of respiratory medications reviewed individual understanding and technique to promote optimal use. Both groups received the British Lung Foundation information leaflet on bronchiectasis (401) (further developed since study completion in their 'Living with Bronchiectasis' document (292)) and the BTS guideline on physiotherapy for bronchiectasis (290). The contemporaneous delivery of this high quality information may have reduced the difference between groups of receiving bronchiectasis education and hence affected the patient-reported-outcomes.

This theory is supported by a treatment as usual participant who felt that she had learnt *'lots about bronchiectasis through taking part in the study'*. In addition, none of our participants fell into the newly diagnosed category (less than one month), most had lived with bronchiectasis for many years and had evolved their own ways of keeping track of the disease in a way that they may have preferred due to habituation (median years since diagnosis 5, mean 11 years).

Availability of recommended health services

During the trial participants unfortunately experienced problems in obtaining GP appointments as recommended in the one page action plan. Our focus group feedback illustrated that obtaining GP appointments has become increasingly difficult due to staffing issues. Rather than increasing confidence and self-efficacy in caring for themselves the BET intervention may only have increased frustration when participants were unable to access the care recommended. The need to unify the bronchiectasis treatment pathway and hence support for patients requires further research.

Literacy

Literacy is a matter of importance within BET and its evaluative study. Minimising displacement for participants meant using patient reported outcomes (PROs) in the form of written questionnaires. The patient-held information within BET was also largely written with tabular tracking sections to complete. Illness and wellbeing beliefs affecting patient reported outcomes are explored below. The level of literacy of its participants was not evaluated in the BET cohort. Participants were asked, as part of the collection of demographic information for their highest level of academic attainment.

One hundred and ninety three participants (88%) responded to the question of the two hundred and twenty participants who consented to take part in the study. Of those respondents fifty-five reported no qualifications (25% of participants). One in six people in the UK have literacy below that expected of an eleven year-old (402).

In addition to issues of literacy the questionnaires (PROs) had multiple different measures and formats that our patient research ambassadors noted to be confusing. This may have contributed to attrition (Appendix 18).

Culture

Self-management is about adopting behaviours to promote health. Behaviour is culturally informed but there is a paucity of information relating to the impact of culture on health research (403). People with chronic disease frequently minimise symptoms, through habituation, in order to accept and move on with every-day life and to adapt psychologically to living with disease (404). Adaptation to bronchiectasis and habituation to physical and emotional hardships may minimise the impact on quality of life reported using patient reported outcome measures (405). Refusal to take part in trial measurements during a trial visit is unusual. However, we live in an 'evaluation' culture where all services seek feedback, this overwhelming demand may result in rebellion and refusal to complete mailed questionnaires.

Emotions

People with chronic respiratory symptoms commonly suffer from anxiety and depression, these in turn affect outcomes of educational interventions (406). Depression has impact on motivation which may assist in explaining attrition rates and failure to return questionnaires.

Attitudes

Attitudes to research affect patient choices to participate in clinical trials. An Irish paper published in 2016 (407) described a paucity of evidence available on the topic after identifying that at the local research facility two hundred and ninety one participants only were recruited from a catchment area of 1 million. Two hundred and fifty thousand of which had attended hospital once within the past year, meaning less than a half of one percent participated.

The local hospital site from which the greatest number of participants were recruited for BET provides tertiary care for a catchment of 822,500 (408) and recruited 4933 (409) research participants in the year 2016 to 2017 representing less than 1 percent. Patients living in Norfolk receiving information relating to research frequently 'ask permission' of their General Practitioner or secondary care consultant.

In the BET trial there is a steep withdrawal of participants after their initial consultation. This may be the point at which participants internalised the personal effort involved in completion in comparison with the small amount of inter-personally delivered education received.

It is not known why, though it may be due to a realisation of what is actually involved, a feeling that they have discharged their responsibility merely by agreeing to take part or due to an underestimation of the burden of their disease and its effect on their ability to complete trial requirements. Attitudes to individual responsibility within chronic disease vary widely (410) these also affect people's perceptions of whether they are able to change their health behaviours illustrated in the diversity of observed behaviours discussed in chapter 8 relating to roles and interaction with health professionals (411).

Socio-economic standing

The fact that deprivation and low literacy are linked is substantiated by Baker *et al.* (412). Aaartsen *et al.* go further in establishing the influence of socio-economic position and health in which lower economic standing is a predictor of reduced longevity and poorer health (413). Lower levels of educational attainment frequently mirror economic standing acting as a barrier to research participation.

Data treatment

It is viewed as good practice to apply intention-to-treat principles to clinical trials in order to reflect more closely the uptake of the actual population if the intervention were to become practice.

Name of the intervention and cover photo

During the education some participants shared their fear that the ‘tool’ part of the Bronchiectasis Empowerment Tool might be a drill or other painful medical implement.

This surprise finding had not occurred to our patient and public advisors (perhaps due to oral introduction preceding document review). In addition the participants did not identify with the cover photo (Appendix 20).

Types of bias

Attrition bias

This bias with relevance to BET may have occurred if the more literate and moderately burdened by disease remained in the study and continued to complete outcomes. To compound this people with mild bronchiectasis may not be symptomatic enough to require, accept, integrate or obtain much noticeable benefit from the adoption of BET.

Those choosing to remain in the study may have been well informed, literate and engaged with health and may have begun the study with confidence and ability to care for themselves and hence have shown little change in the primary outcome of self-efficacy. Participants cognitively affected by severe ill-health or lack of self-confidence due to low health literacy levels may have eliminated themselves through attrition (when faced with the questionnaires) despite their need to build disease knowledge, increase self-efficacy and develop self-management skills.

Power

The attrition rate meant that we did not receive the number of completed primary outcomes to meet the power calculation. We expected 154 patients to complete the six item Self-Efficacy to Manage Chronic Disease Scale (SEMCD) at twelve months which would have given an 80% power to detect a treatment difference (two sided 5% significance) of 1 unit of the questionnaire with a standard deviation of 2.2 units [14]. Only 127 completed the primary outcome at 12 months. Sample size or power calculations are designed to allow you to detect a significant difference i.e. one not exhibited by chance alone and based on the minimum clinical important difference of the primary outcome measure used (the smallest difference considered worthwhile by a patient (414)) .

Missing data can be a threat to the validity of the data on which trial interpretations are based (415, 416). Decision to withdraw may be linked to the intervention or evaluation (statistically termed 'missing, not, at random') and hence provide important insights that should not be overlooked (415).

Missing data represents a reduction in power, there is less power to detect a treatment difference. In an intention to treat methodology missing data has to be accounted for. If, in contrast, only the data collected is considered, this is termed complete case analysis. However, complete case analysis may present a smaller and less representative sample. If there is something fundamentally different about those who choose to complete the study it can introduce bias. Accounting for missing data can be approached in several ways, by conservative estimate using the sample mean of the data collected, by using last observation carried forward or by using simple imputation to estimate a single data point from the other collected data. Multiple imputation is used when more than one data point is missing at random using chained equations, fully conditional specification or sequential regression multivariate imputation methods. All the methods for dealing with missing data can be confounded when the progression is hard to predict. People with bronchiectasis have variable patterns of stability followed by single or multiple exacerbations which may confound imputation. For these reasons missing data was not imputed in the statistical analysis of BET.

Patient reported outcomes and questionnaire bias

Most patient-reported questionnaires undergo validity testing alongside a commercial trial this means that participants are attending visits. During visits researcher support staff are there to answer questions, encourage completion and check for missed data. Where questionnaires are mailed to a home address the motivation to complete them may be reduced because assistance in understanding the requirements is not available (the BET trial had a helpline number for this purpose but nobody used it). One participant who had acknowledged his difficulty in completing questionnaires sought family support rather than call. Data supplied by subjects relies on their individual interpretation of the questions (417). As previously mentioned the lack of bronchiectasis specific questionnaires may have meant questionnaire options poorly matched the participant's disease presentation.

Our patient research ambassadors noted that the requirement to use validated questionnaires for the evaluation had resulted in multiple presentations and scoring systems that could cause confusion (appendix).

Intensity of the intervention

To increase the likelihood of translating trial evidence to NHS clinical practice, it is important to consider making the intervention simple enough to embed into existing systems and processes and inexpensive enough to be considered within budgetary restraints. The intervention could be tested at different intensities of communication, support and follow-up to see whether a difference is detected. In this intervention the brief 24 minute telephone education without follow-up may not have been enough to make a difference. Current financial pressures on health providers meant that an integrated, multi-disciplinary approach was not possible.

Qualitative bias

Qualitative measures are by their nature contextual and subjective. The context of a meeting in an academic environment within view of the hospital may have affected participants' views with regard healthcare. Participants with less confidence and less literacy are more likely to have declined taking part in a focus group (418). Qualitative evaluations during BET were only sought in the intervention arm, interactions with the other group would not have been treatment as usual.

Only participants who remained in the study and had responded at twelve months were invited to take part in the focus groups which may mean that participants with lower literacy had already been lost to follow-up as mentioned previously with regard to literacy burden and attrition. Care was taken within the BET trial to promote rigour and validity using recommended frameworks to describe all aspects of the collection, analysis and interpretation. The trustworthiness of qualitative research can be subdivided into credibility, dependability, transferability and confirmability (300). There are conflicting opinions on whether increasing dependability is reasonable. Guba and Lincoln (419) consider member checking (participant transcript checking) critical, whereas Sandelowski argues that forced consensus is contrary to the highly contextual nature of qualitative information (420, 421).

Member checking was used for the health professionals but the self-doubt, self-criticism and embarrassment of one of these individuals discouraged the researcher from the possibility of causing similar reactions via member checking of the focus group feedbacks.

Generalisability

Peer quantitative researcher review of BET suggested that having all the sites within a region might limit the generalisability. This is a consideration. However, the variability of health approach and delivery per region is even more likely to have added heterogeneity and confounders, raising more questions than it answered.

Recruitment

Success of recruitment in BET was largely dependent on the engagement of the Principal Investigator (PI) leading the recruitment strategy at each site. In BET the sites that recruited best were the ones where the nurse researcher was able to visit and conduct informed consent and review progress. Sites who recruited best either had a very engaged PI identifying potential participants or a similarly engaged research nurse performing this role. The three sites that were furthest afield yielded only a few recruits despite the burden of approvals (regulatory and NHS) in setting up and starting the study at each site.

Contamination

Only the Nurse Researcher leading the study provided the BET booklets and the telephone education. In this way contamination between groups would only have been possible between patients themselves and this contact was deemed unlikely at all sites. This approach to the research did however unfortunately eradicate the possibility of coordinated multi-disciplinary support for the participants in their self-management. An integrated multi-disciplinary approach would have involved greater complexity not possible within this timescale or fund.

Repetitive outcome measurement

People with chronic disease go through a physical and mental adaptation to their symptoms and disablement. It seems likely that if patient reported outcome measures of quality of life are measured too frequently that this may heighten awareness of symptoms and disablement.

Thus the frequency of questionnaire outcomes may have a confounding effect in masking or reducing any subjective improvement in quality of life obtained through the BET self-management intervention.

Describing bias and confounders within this chapter emphasises the value of employing a mixed-method approach:

1. Positivist quantitative methods to evaluate statistically whether the precise question asked has been answered i.e. Did the BET intervention increase feelings of self-efficacy as a patient-reported outcome documented using the SEMCD questionnaire?
2. Flexible thematic qualitative explanation and exploration of patient and health professional interactions.

In both the quantitative and qualitative approach using frameworks and guidelines such as those described in appendix two assisted the shared communication and coherence of the research by making the detail more easily understandable, reproducible and allowing a more comprehensive evaluation by the reader of what took place.

Quantitative evaluation is designed to be focussed and specific; like a litmus paper the test displays a change or not. With the addition of qualitative aspects we are better able to evaluate the landscape within which the question is situated and the face-to-face interactions that are an essential part of healthcare.

By systematically considering all the bias and confounders for the quantitative and qualitative research it is possible to evaluate the research and formulate improvements in future methodologies. The advances in bronchiectasis research since BET was designed (2010) mean that it would now (2017) be possible to stratify for severity using a validated measure and similarly use a bronchiectasis specific questionnaire less likely to be frustrating to participants. Reducing the burden of literacy both in the written intervention plan and in the multiple and frequent questionnaire outcome measures may reduce attrition. The qualitative aspects revealed that healthcare was not available when sought as advised in BET, differing messages from a variety of health professionals and varying availability of sputum testing and of formulary medications add to treatment disparities. Altogether there is a lack of coherence and shared understanding likely to undermine collaborative health, trust and self-management in bronchiectasis. The British Thoracic Society Guidelines for Bronchiectasis 2010 (1) on page 27 note the lack of, and need for education:

> *'Education*
> *What are the key facts that a patient should know about their condition? There are no trials of the use of self-management plans for the treatment of bronchiectasis. As early treatment of exacerbations is recommended, it is important to ensure that patients with bronchiectasis understand the basic principles of disease management and recognition of an exacerbation.'*

The need for bronchiectasis self-management support.

Opportunities:

A search for, and lack of, a unified approach to bronchiectasis self-management is summarised in the literature search. National and international guidelines relating to bronchiectasis care have set standards to guide health professionals in delivering treatment (1, 20, 124). Providing people who have bronchiectasis with information, education and support in maintaining their quality of life offers an opportunity to engage and collaborate with them and promote their ability to take an active role in their health. This supportive approach is advocated internationally by the World Health Organisation. The need for self-management support is reflected throughout this investigation by people with bronchiectasis illustrated from the outset by the following comments within Appendix 16

JS (page 3 of 9) feels that self-management support is *"Long overdue"*

EC (page 4 of 9) comments that *"I hope it reduces time to treatment"*.

The telephone education within BET was very positively received and further research is required to investigate the support opportunities represented by a help line or mobile service to reach people with bronchiectasis nearer home as identified in the focus groups.

Barriers:

Health funding disparities within the UK are likely to cause disparities in health provision despite national guidelines. Participant focus groups highlighted the importance of medical expertise or specialist nurse knowledge in bronchiectasis self-management support. There were clear disparities in health delivery that mirror those reported in the National BTS audit 2012 (8). Individuals treated in a standard and stable fashion may feel encouraged to trust and collaborate with healthcare professionals delivering consistent healthcare messages and treatments.

Building on BET methodologically

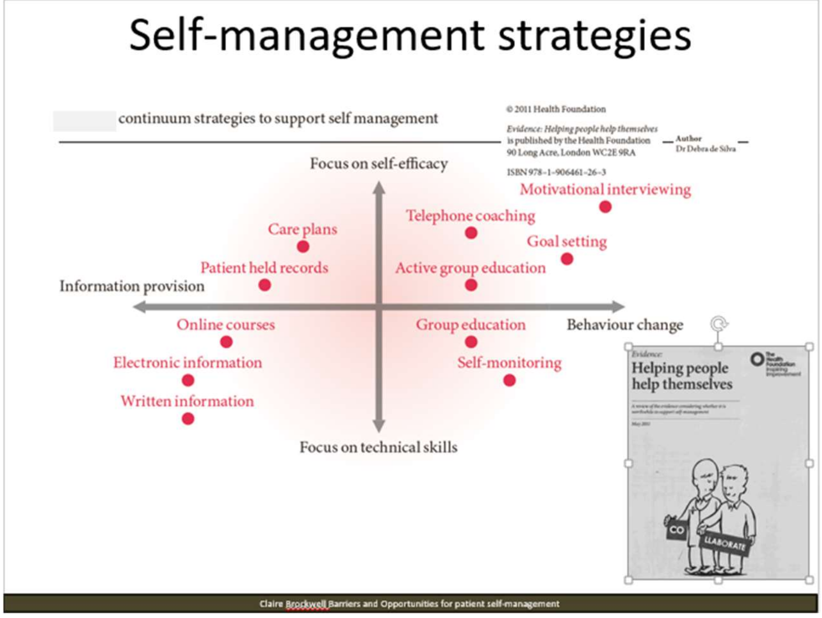
In BET patient and public advice was followed and inconvenience of research visits were kept to a minimum by using postal questionnaires. This may have increased the need for self-motivation in completion. Questionnaires could not be checked for completeness (to avoid missing data) until they were returned by mail. Participants who returned the outcomes completed them alone at home without assistance regarding meanings, concepts or other queries that might relate to literacy. Although some participants struggled with dexterity issues of writing when initialling their consent to research no alternative methods for questionnaire completion were considered. Finally there was no inter-personal encouragement.

In order to keep inconvenience low, mutually agreed appointments for home visits from a practitioner might avoid the issues listed above. Home visits would increase the cost of the research conducted.

Self-management strategies

The Health Foundation (78) in their book *Helping People help themselves* provided a diagram shown below summarising self-management strategies.

Figure 11 Health Foundation strategies to support self-management


Self-management strategies

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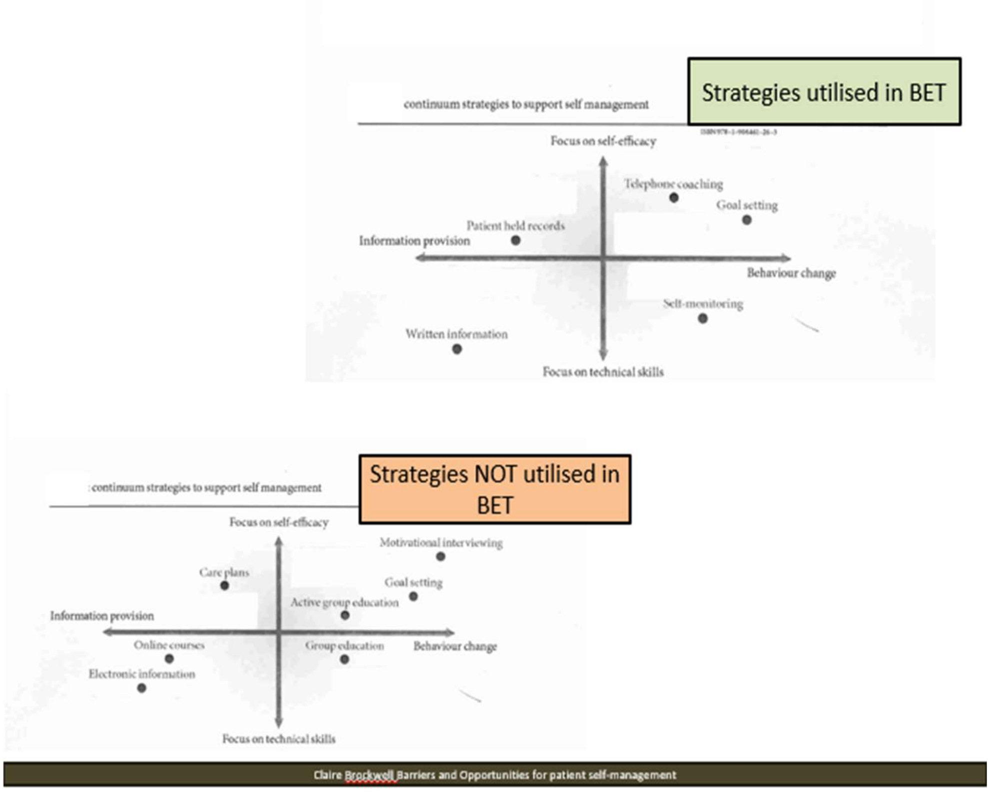
Claire Brockwell Barriers and Opportunities for patient self-management

By adapting their diagram the strategies utilised and omitted in BET are displayed below. This visual depiction offers possibilities for consideration in future bronchiectasis self-management development.

Figure 12 BET strategies Health Foundation Self-management Continuum



Burden of outcome measures

When BET was designed there were no bronchiectasis specific quality of life questionnaires validated in the UK and completion of outcomes is likely to have been frustrating. There are bronchiectasis specific measures available now that might improve the participant experience and hence reduce loss to follow-up (422).

Number of Questionnaires

In future research of this type careful consideration of whether it is possible to either reduce the number of questionnaires or the frequency of measurement should be made. Or more innovatively to use methods (perhaps audio, visual, web, or face-to-face that require less literacy and present less burden to participants when they are exacerbating.

Homogenisation or rationalisation of questionnaire formats

Where multiple questionnaires are necessary, consideration of how congruent and understandable the various scales are in aggregate should be evaluated to facilitate ease of completion and understanding for participants.

Co-morbidity

Finding novel ways to evaluate the cumulative effects of multiple-morbidities are required. Quality of life measures usually reflect the sum total of physical and psychological impairment, therefore it is hard to extract change specific to one disease only and attribute change to a specific education intervention.

Existing technologies

BET revealed the acceptability of existing telephone technology in reaching people with bronchiectasis, structured telephone support is also used in heart failure (423). Telehealth (424-427) is also increasingly used throughout the world and may be a further avenue of self-management collaboration that was not evaluated within this thesis.

New technologies

New technologies such as the use of smart mobile telephones (428-434) may represent less of a burden of literacy and a way of reaching geographically distant people with bronchiectasis. The possibilities of big-data (435, 436) may also enhance our understanding of behaviour change and self-management.

Service Standards

The bronchiectasis quality standards (284) and BTS guidelines provide (1, 20) represent clearly stated service standards for individual aspects of the care pathway to guide health professionals in the management of bronchiectasis with the people affected. Similar clarity in documents available to people affected by bronchiectasis such as when to expect microbiology results, recommended point of contact when worstening occurs and/or helpline would help support self-management. Knowing what to expect is likely to increase patient empowerment and satisfaction (437) the updated BTS bronchiectasis guidelines public summary may help in this (20).

Roles and expectations

To engage in collaborative health commonality is important. The chronic care model provides an aspirational goal fully integrated in a societal environment. To achieve patient-centred care and shared decisions there needs to be confidence in the dialogue, the roles and expectations. Frameworks such as ‘AskShareNow’ (438) could guide and embed shared-decision making. Necessary and defined assistance with building confidence and maintaining motivation with approaches such as motivational interviewing (439-441), cognitive behaviour therapy and individualised psychological support are being used in other chronic disease management (442). Harnessing these techniques to make the most of opportunities to change behaviours and to overcome the barriers presented by long-held health beliefs may assist people with bronchiectasis in adjusting to a more active self-management and collaboration with health advisors.

Patient self-management materials in common diseases such as diabetes have evolved to the point where there are standards for self-management education (443). It is reassuring to see that Katy Hester and the team at Newcastle University are developing novel information resources for bronchiectasis (444, 445).

Decison support tools

Both health professionals and patients making decisions with regard to bronchiectasis might benefit from decision support tools offering a guided pathway which might promote confidence and reduce disparities of care (281, 446, 447).

Frameworks and curricula for education

Providing highly accessible and organised learning and resources for health professionals and patients is likely to promote understanding. To promote access to a population with a diversity of health literacy, cognitive ability and burden of disease a choice of modalities (face-to-face education, web-based, podcasts, audible, written and group) are required from which to provide the best fit for the individual.

Context and concepts of self-management

Opportunities:

Self-management provides an opportunity to engage people with bronchiectasis in the 'day-to-day care and management in chronic disease'. It highlights the requirements of the Chronic Care Model. This includes development and support of personal self-management skills, information systems, decision support, the reorientation of health services (such as the use of telephone triage or an advice line) within supportive environments and evolving public health policy.

The Chronic Care Model emphasises the importance of collaboration between the patient, community, practice teams and community partners to arrive at shared decision making, improved health communication empowerment, self-efficacy and choice.

Improvements in communication, technologies and frameworks of research excellence now allow a more global sharing of knowledge relating to promoting health and self-management. Concepts of health belief and psychology, empowerment and self-efficacy relevant to behaviour change, motivation and self-determination help inform self-management. The World Health Organisation promotion of the self-management concept in response to non-communicable disease unites and promotes development.

Useful templates of positive integration of self-management exist in other diseases such as in diabetes where there are clear standards for self-management education (448).

Barriers:

Issues of trust and the relatively recent shift from paternalistic healthcare towards aspirations of a more collaborative interaction. Generational differences in attitudes to health interactions discussed in the introduction may represent challenges to the adoption of self-management. For the aged who grew up with paternalistic care the behaviour and attitude change to self-management is a leap requiring changes in health belief, illness and sick roles. In addition the burden of ill-health, depression or multi-morbidities are likely to influence psychological perspectives relevant to self-management, motivation and locus of control.

Participant KH in chapter 5 illustrates this *'I can't process information when I am too tired or too ill.'*

Appendix 24 a letter from participant ACB underlines the impact of the disease:

> *"I am so depressed at present…I am not exaggerating when I say I have over 20 things wrong – some major some minor. If I was able to dispense with one it would be the bronchiectasis. It rules my life completely and exhausts me. Where does all this sputum come from? I keep myself up as late as I can at night. If I fall asleep in the chair (my nights are so bad) my chest fills up. Put my book down 11.30ish 2 hour sleep and up again getting rid of the sputum and so the night goes on. I mix very little apart from Sundays …careful to avoid personal contact. Thus I keep clear of infections…Sorry about this grumble but sometimes life is very difficult indeed."* ACB 1105

Fundamentals of research

Opportunities:

Quantitative research provides the opportunity to provide empirical evidence of the safety and efficacy of an intervention providing information from which health professionals and patients weigh treatment decisions. The allocation of funds (from the public purse) to translate research to practice are also based on expected benefits. Qualitative research is highly contextual and subjective and it provides insight from individuals on how they are affected. BET used mixed methods to explore the experience of navigating healthcare and living with bronchiectasis, as well as seeking evidence of whether the BET intervention helped improve self-efficacy. This approach provided a richer understanding of the pitfalls and benefits of current healthcare and how an intervention and research affects people physically and emotionally.

Barriers:

Quantitative research seeks to answer one question, to prove or disprove a hypothesis i.e.: In BET did a novel bronchiectasis self-management intervention help improve the confidence with which a person can manage the symptoms of their chronic disease (self-efficacy)?

The narrower and better defined the population the greater likelihood of measuring a difference. For the result to be generalisable the population tested should match the general population as nearly as possible. Population diversity accounts for the growing popularity of pragmatic trials.

Qualitative research due to its contextual nature may be transferable but it is difficult to evaluate to what extent and hence to extrapolate findings to a larger population.

Cost

Opportunity:

Without the funding provided by the National Institute for Health Research and the support provided by the NHS and the Clinical Research Network this research would not have been possible.

Barrier:

The cost of clinical research and the difficulty of obtaining competitive research funding creates a bias toward research in more common diseases evident in the literature search. In addition, the financial pressures on health services make low-cost interventions more attractive from a capacity and capability perspective. This influenced decisions in the design and evaluation of BET. A written intervention was the cheapest presentation of information. Posting and receiving self-reported outcomes was cheaper than sending a researcher to each person’s home at each outcome measure time-point (3 monthly – five times within a year for 220 people). The BET education was brief (approximately 24 mins each) and was delivered by telephone and not in person within the participant’s home. There was no further telephone follow-up. There were not sufficient staff (funding) available to provide a physiotherapy education aspect to the BET study.

Patient and public involvement

Opportunities:

The engagement of our multiple patient and public advisors kept the evaluation patient-centred. The guidance and information shared by our advisors helped shape all aspects of the trial from recruitment and visit strategy to focus group design and evaluation of the outcome methods.

Barrier:

Although patient and public advice was integral to this trial there was still a divide apparent within steering meetings where researchers did not seem habituated to this collaborative approach which echoes the collaboration required in self-management. Despite patient and public advice there were still some surprises with regard to participant reactions to the name of the intervention with reference to the word ‘tool’ feared as some kind scary device and the cover photo with which they did not identify.

The evaluation of BET

Opportunities:

The bronchiectasis population within the East of England were keen to take part and hence we were able to recruit the number of participants required.

Future research design should seek to consider issues of literacy and motivation. The loss to follow-up seen in BET is not unusual in postal questionnaire studies (449).

Barriers:

For reasons more fully explained in the previously as part of the bias and confounders, only 127 of the 220 participants completed the self-efficacy questionnaire at 12 months. This loss to follow-up (including 25 who gave reasons for withdrawal) provides insight into the acceptability of the trial methodology to the target population.

Although multiple patient reported outcomes were used none showed a measurable benefit from the self-management intervention. The lack of coherence in our multiple questionnaire outcomes was identified by our patient and public advisors as a source of confusion and an added burden of literacy that may have accounted for people who dropped out of the study.

Participants' insights regarding self-management

Opportunity:

The qualitative information collected within BET led to a much better understanding of the opportunities and pitfalls of navigating healthcare and bronchiectasis self-management of value in considering and designing future support for people with bronchiectasis.

Barrier:

We only sought qualitative feedback from the intervention arm of BET, a more holistic approach may have been more balanced but would not have been 'treatment as usual' and may therefore have confounded any findings made.

Recording and transcribing the telephone calls rather than taking jottings have provided added detail to consider that may have had greater value though more time consuming.

Focus groups evaluating the use of BET

Barrier: It was evident from the focus groups that although some were very positive about the intervention that the presentation of the BET booklet and the brief education did not meet the participants' needs closely enough for them to abandon their own methods of monitoring and keeping track of bronchiectasis.

Opportunity: Although there was a reluctance to attend groups due to a fear of sharing infections the isolation experienced by participants with bronchiectasis was mitigated by meeting others - an unexpected positive finding.

Health Professional Interviews

The qualitative evaluation of health professional interviews highlights areas of confusion that could be addressed through decision support materials (based on bronchiectasis guidelines and standards) for health professionals and for participants.

Diversity of formularies in healthcare trusts provide obstacles to coherent care, currently what the secondary care consultant has prescribed may not be available from primary care.

Lack of multidisciplinary staff such as physiotherapists for airway clearance training and regular airway clearance updates are a missed opportunity in preventative care and in follow-up of people too ill to leave home. Dietetics, occupational health and psychological support are all highly relevant to bronchiectasis care and currently scarce in availability in the region studied in BET.

There are not sufficient community matrons or other specialist self-management support staff for individuals who are housebound. These individuals require specialist advice and follow-up to manage severe symptoms and complex co-morbidities and for the collection of sputum samples and the prescribing of antibiotics and other medications.

Lack of consensus among healthcare professionals about what constitutes an exacerbation led to confusion amongst patients during the study this may now be alleviated by the recently published definition of exacerbation.

Different attitudes, targets and public health messages with regard to antibiotic use confuse both patients and health professionals. Lack of consensus between specialist secondary care and primary care tasked with reduction of antibiotic use and whether an individual is appropriate for home or reserve antibiotics causes confusion to the patient and can lead to unnecessary delay in treatment.

Discussion

Although BET was a first step and common foundation in providing structured education to people with bronchiectasis it unfortunately did not increase the self-efficacy of those using it or meet their preferences for keeping track of their disease. Designed as a fully-powered study withdrawal meant that the study was under-powered. Qualitative aspects of the study have provided important insights into feasibility and acceptability and a better understanding of the opportunities for and barriers to bronchiectasis self-management in the region studied. The impact of health literacy on the trial and burden of questionnaire evaluation are likely to have affected withdrawal

In the United Kingdom health services are not standard, so there is a need for frameworks, models of care, and pathways within which patients are guided to feel more secure in building their self-management skills and knowledge. This thesis demonstrates the need for harmonisation of expectations and delivery in bronchiectasis management and self-management through better adherence to published guidelines and standards. Patient feedback in this research has provided an informative ‘voice’ speaking of a need for education and support in self-management.

The lack of objective measures of disease progression in bronchiectasis when BET was devised and the lack of coherence in quality of life outcome measures make it more difficult to evaluate whether the intervention or the trial methodology accounted for the high drop-out rate in BET or whether it was a combination of both.

Conclusion

There is a need for coherence in bronchiectasis care. A necessity for a common foundation of self-management knowledge for people with bronchiectasis and their care teams. BET was designed to provide a patient-held, patient-centred foundation of information and basis of communication around which to coordinate a multi-disciplinary approach to bronchiectasis. It sought to guide access to healthcare, to know what to expect and to support self-management. The concept was embraced by potential participants and by health professionals. However, the written format and burden of questionnaire evaluation meant that only a small proportion of people with bronchiectasis completed the study. In addition, qualitative feedback revealed that participants were unable to access healthcare as suggested, variability in standards of care were also reported in the National BTS bronchiectasis audit of 2012 (8). The need for self-management support in bronchiectasis has not been satisfied. Recent developments in bronchiectasis research may help harmonise the characterisation of the condition. Information and guidance must be highly available to both health professionals and patients smoothing the transition between hospital and home. This may also reduce the disparity caused by the current need for individual motivation in seeking information that disadvantages the very busy and the very ill.

Without agreed goals and innovative ways of meeting patients’ and health professionals’ knowledge needs progress is likely to be limited. Consideration of how exacerbations are likely to affect the participants’ ability to respond to research outcomes is necessary to reduce the dual burden of ill-health and research participation. Research outcome measures that are less dependent on literacy are needed to clinically test interventions without deterring the population likely to require them the most.

Future Directions for Bronchiectasis Self-Management

The British Thoracic Guidelines for non-CF bronchiectasis bronchiectasis (1) and the BTS Quality standards for clinically significant bronchiectasis (284) advocate patient education and individualised self-management plans as part of bronchiectasis management. The Australia and New Zealand Guideline for bronchiectasis also suggests self-management where possible. This advice aligns with the international importance of the self-management concept. Disappointingly, the Sept 2017 European Respiratory Society guidelines for the management of adult bronchiectasis (124) do not consider self-management and only mention education with regard to airway clearance.

In order to build on the findings within this thesis it is necessary to consider how we use this knowledge in future research and look forward to what might be considered next.

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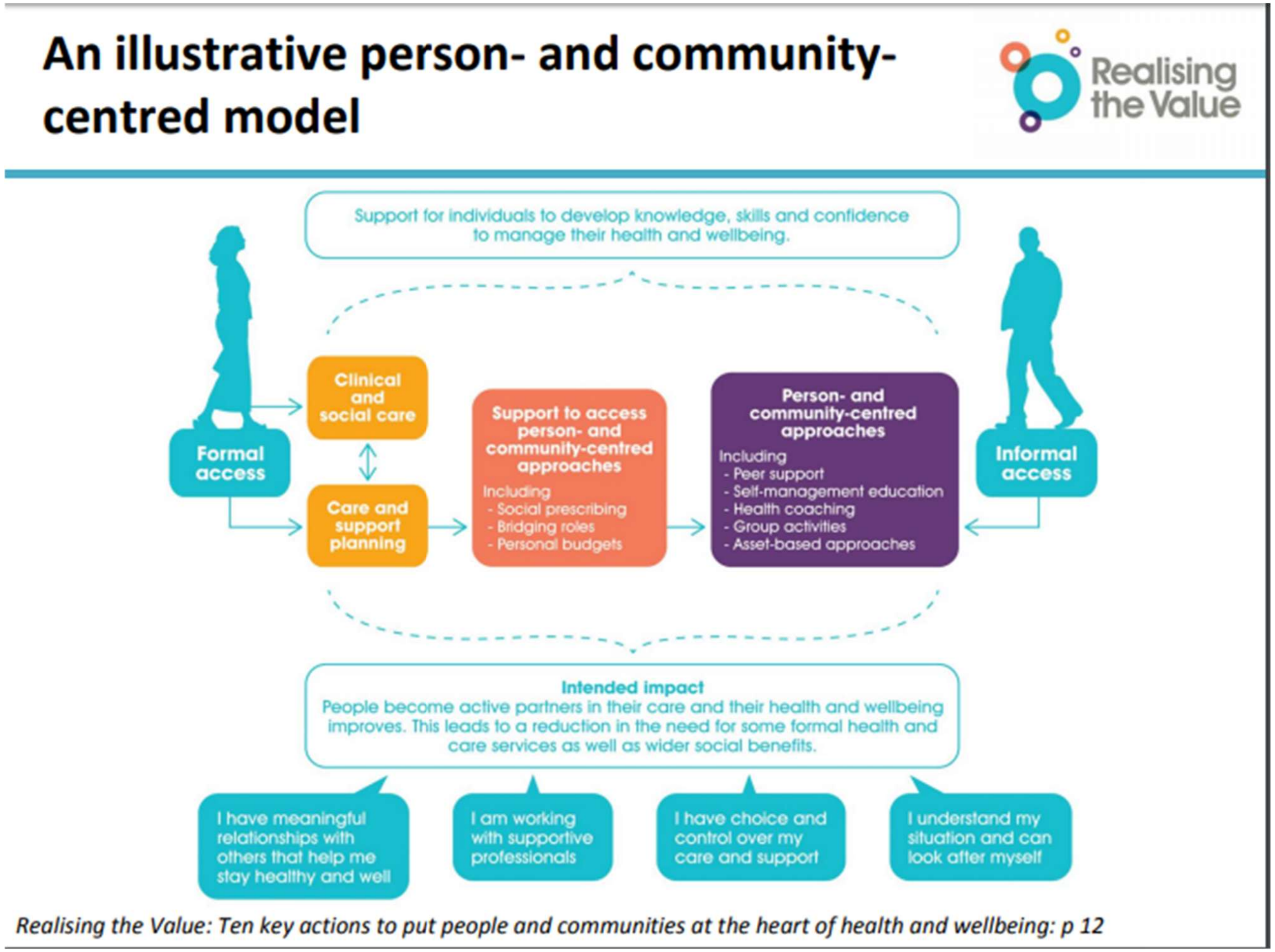
Appendices

Appendix 1 Realising the Value Page 1 of 2



An illustrative person- and community-centred model

Realising the Value

Support for individuals to develop knowledge, skills and confidence to manage their health and wellbeing.

Support to access person- and community-centred approaches

Including
- Social prescribing
- Bridging roles
- Personal budgets

Person- and community-centred approaches

Including
- Peer support
- Self-management education
- Health coaching
- Group activities
- Asset-based approaches

Intended impact

People become active partners in their care and their health and wellbeing improves. This leads to a reduction in the need for some formal health and care services as well as wider social benefits.

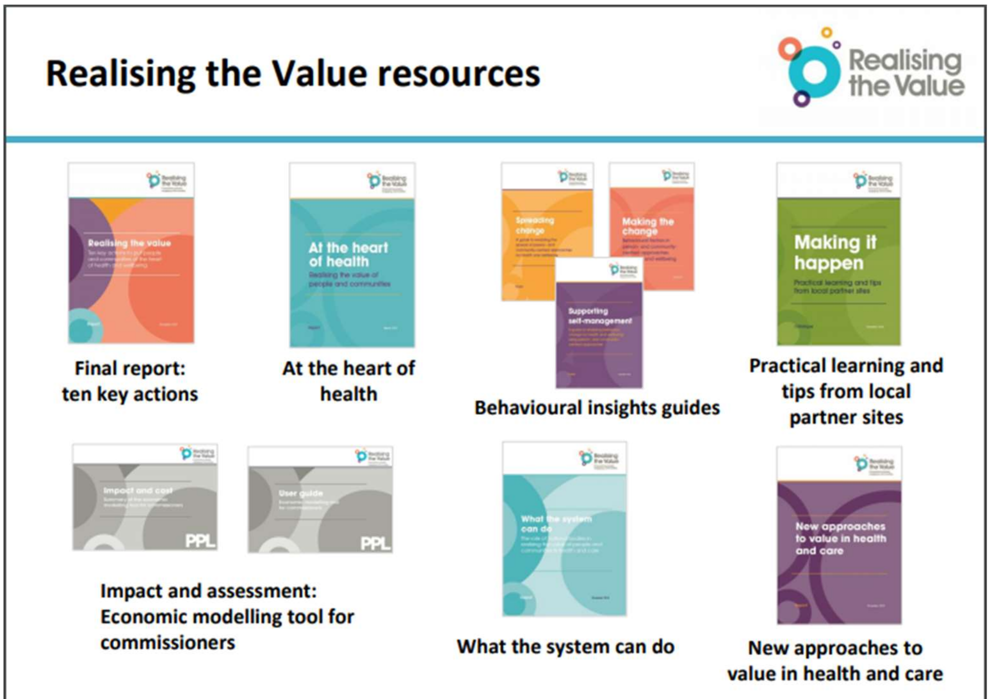
I have meaningful relationships with others that help me stay healthy and well

I am working with supportive professionals

I have choice and control over my care and support

I understand my situation and can look after myself

Realising the Value: Ten key actions to put people and communities at the heart of health and wellbeing: p 12



Realising the Value resources

Realising the Value

Final report: ten key actions

At the heart of health

Behavioural insights guides

Practical learning and tips from local partner sites

Impact and assessment: Economic modelling tool for commissioners

What the system can do

New approaches to value in health and care

Realising the Value: Ten key actions to put people and communities at the heart of health and wellbeing: Back cover

Realising the Value

Led by:

The Health Foundation

Nesta

Funded by:

NHS England

In partnership with:

The Behavioural Insights Team

National Voices

navca local focus national voice

PPL

regional voices

Volunteering Matters

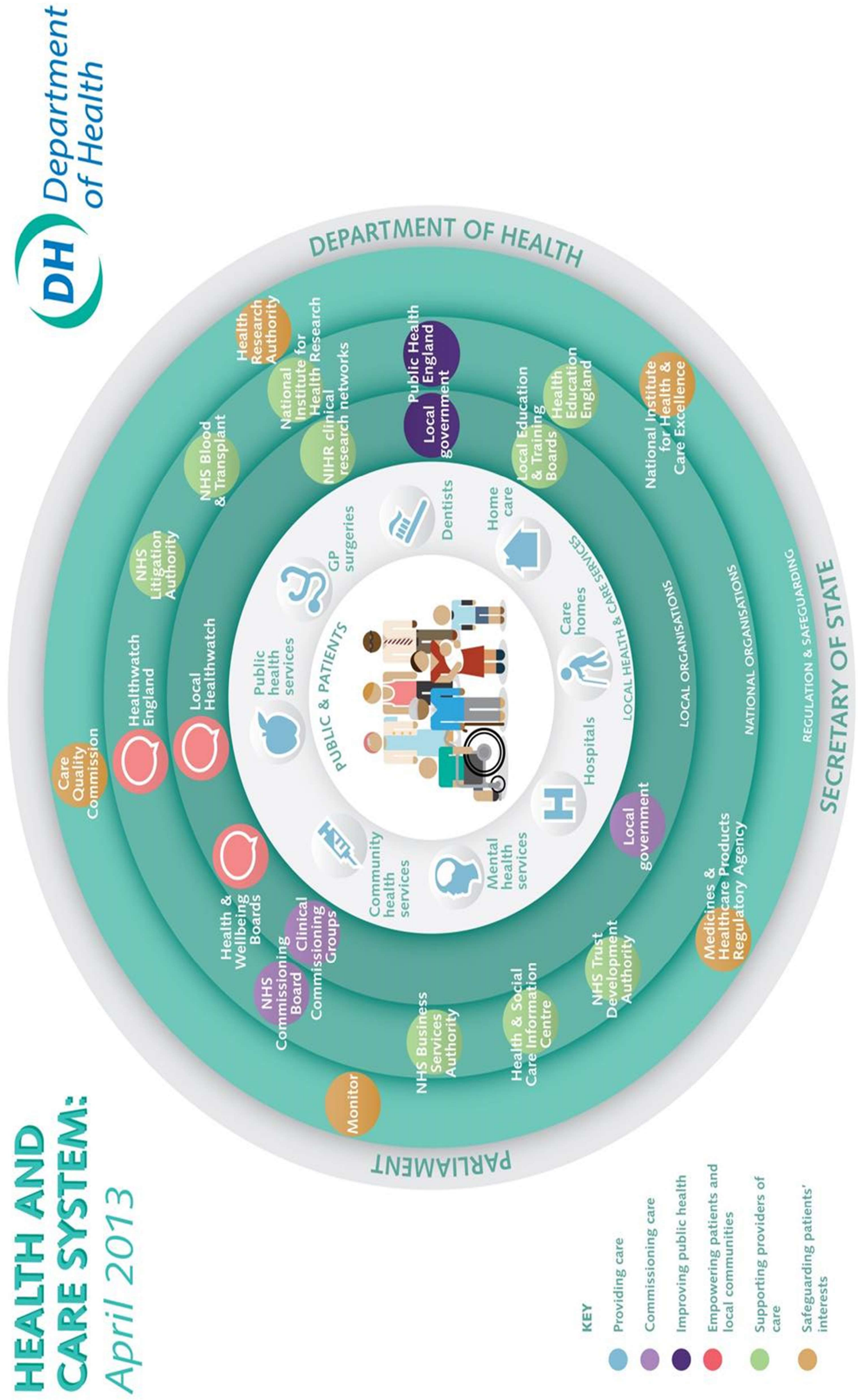
Newcastle University

Appendix 2 Guidelines for the reporting of research

Order referred to in thesis	Study Type	Guideline 1	Guideline 1 Summary	Guideline 2	Guideline 2 Summary
Chapter 1 Lit review	Systematic reviews	PRISMA	**P**referred **R**eporting **I**tems for **S**ystematic **R**eviews and **M**eta-**A**nalyses		
2	Randomised trials	CONSORT	**Co**nsolidated **S**tandards **o**f **R**eporting **T**rials		
3	Qualitative research	SRQR	**S**tandards for **R**eporting **Q**ualitative **R**esearch	COREQ	**CO**nsolidated criteria for **RE**porting **Q**ualitative research
4	Study protocols	SPIRIT	**S**tandard **P**rotocol **I**tems: **R**ecommendations for **I**nterventional **T**rials	PRISMA-P	**P**referred **R**eporting **I**tems for **S**ystematic Review and **M**eta-**A**nalysis **P**rotocols (PRISMA-P) 2015 statement
5	Case reports	CARE	**CA**se **RE**ports: Consensus-based Clinical Case Reporting Guideline Development		
6	Observational studies	STROBE	**S**trengthening **t**he **R**eporting of **Ob**servational Studies in **E**pidemiology		
7	Economic evaluations	CHEERS	**C**onsolidated **H**ealth **E**conomic **E**valuation **R**eporting **S**tandards		
8	Quality improvement studies	SQUIRE	**S**tandards **F**or **QU**ality **I**mprovement **R**eporting **E**xcellence		
9	Diagnostic / prognostic studies	STARD	**STA**ndards for the **R**eporting of **D**iagnostic Accuracy	TRIPOD	**T**ransparent **r**eporting of a multivariable prediction model for

Table derived from data on the 'Equator network' website
http://www.equator-network.org/reporting-guidelines/ accessed 26/Jan/2015

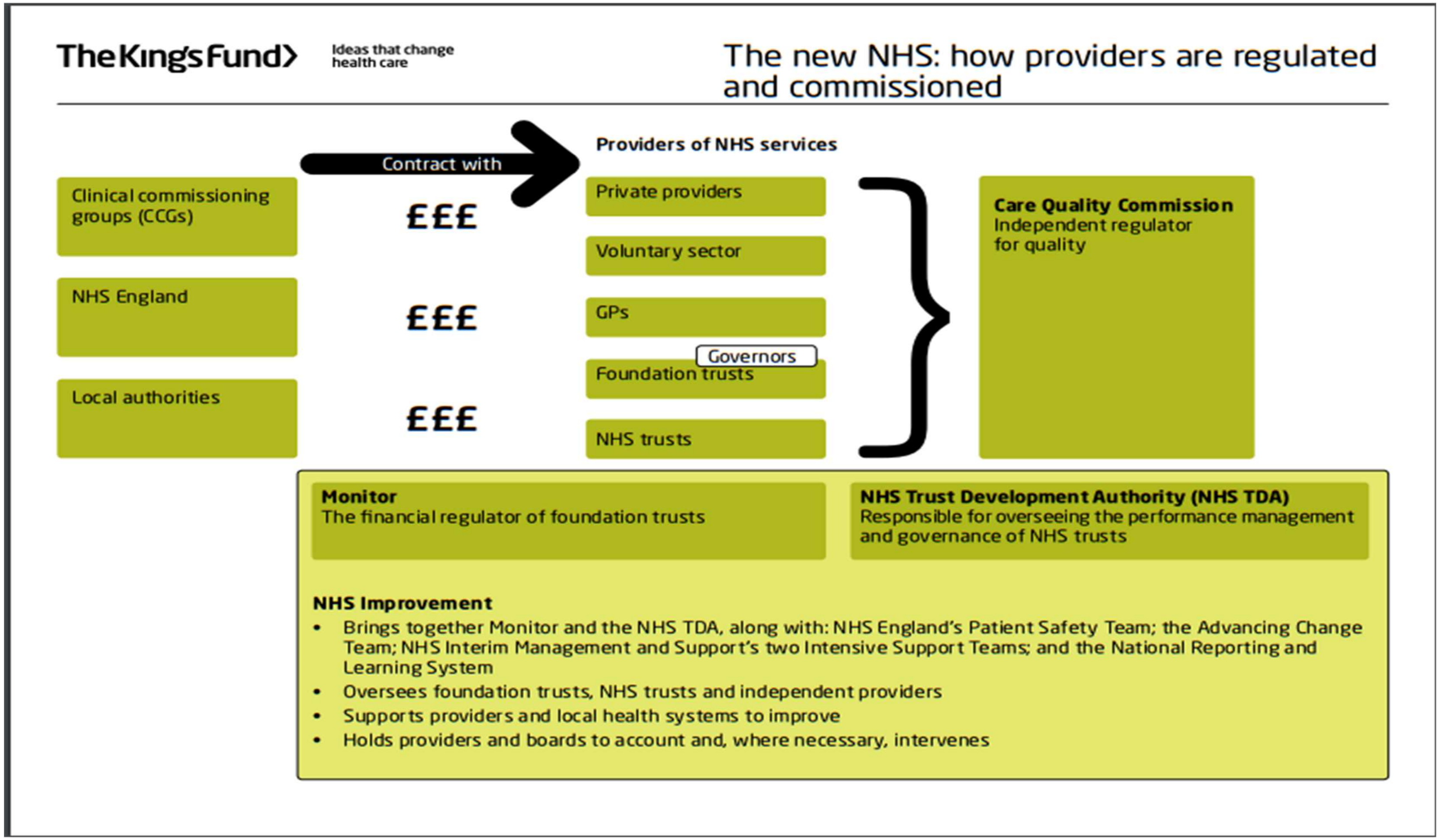
Appendix 3 DoH Health & Care System 2013



Appendix 4 King's Fund The New NHS

retrieved 09/Aug/2017 (4 pages)

https://www.kingsfund.org.uk/sites/default/files/media/NHS%20Structure_2016.pdf



The King's Fund Ideas that change health care

The new NHS: how providers are regulated and commissioned

Clinical commissioning groups (CCGs)

NHS England

Local authorities

Contract with

£££

£££

£££

Providers of NHS services

Private providers

Voluntary sector

GPs

Governors

Foundation trusts

NHS trusts

Care Quality Commission
Independent regulator for quality

Monitor
The financial regulator of foundation trusts

NHS Trust Development Authority (NHS TDA)
Responsible for overseeing the performance management and governance of NHS trusts

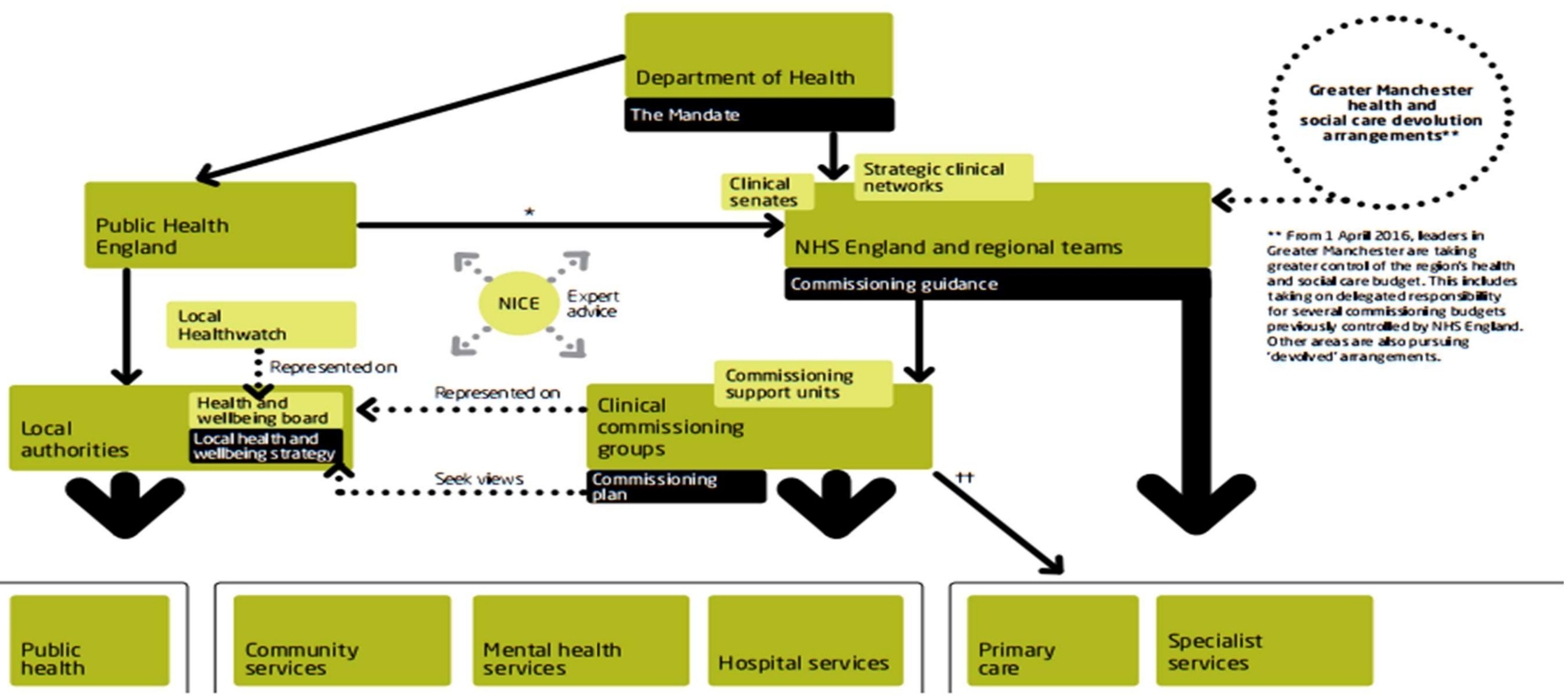
NHS Improvement

- Brings together Monitor and the NHS TDA, along with: NHS England's Patient Safety Team; the Advancing Change Team; NHS Interim Management and Support's two Intensive Support Teams; and the National Reporting and Learning System
- Oversees foundation trusts, NHS trusts and independent providers
- Supports providers and local health systems to improve
- Holds providers and boards to account and, where necessary, intervenes

Page 1 of 4 from The King's Fund

The King's Fund› Ideas that change health care

The new NHS: who can influence commissioning of services

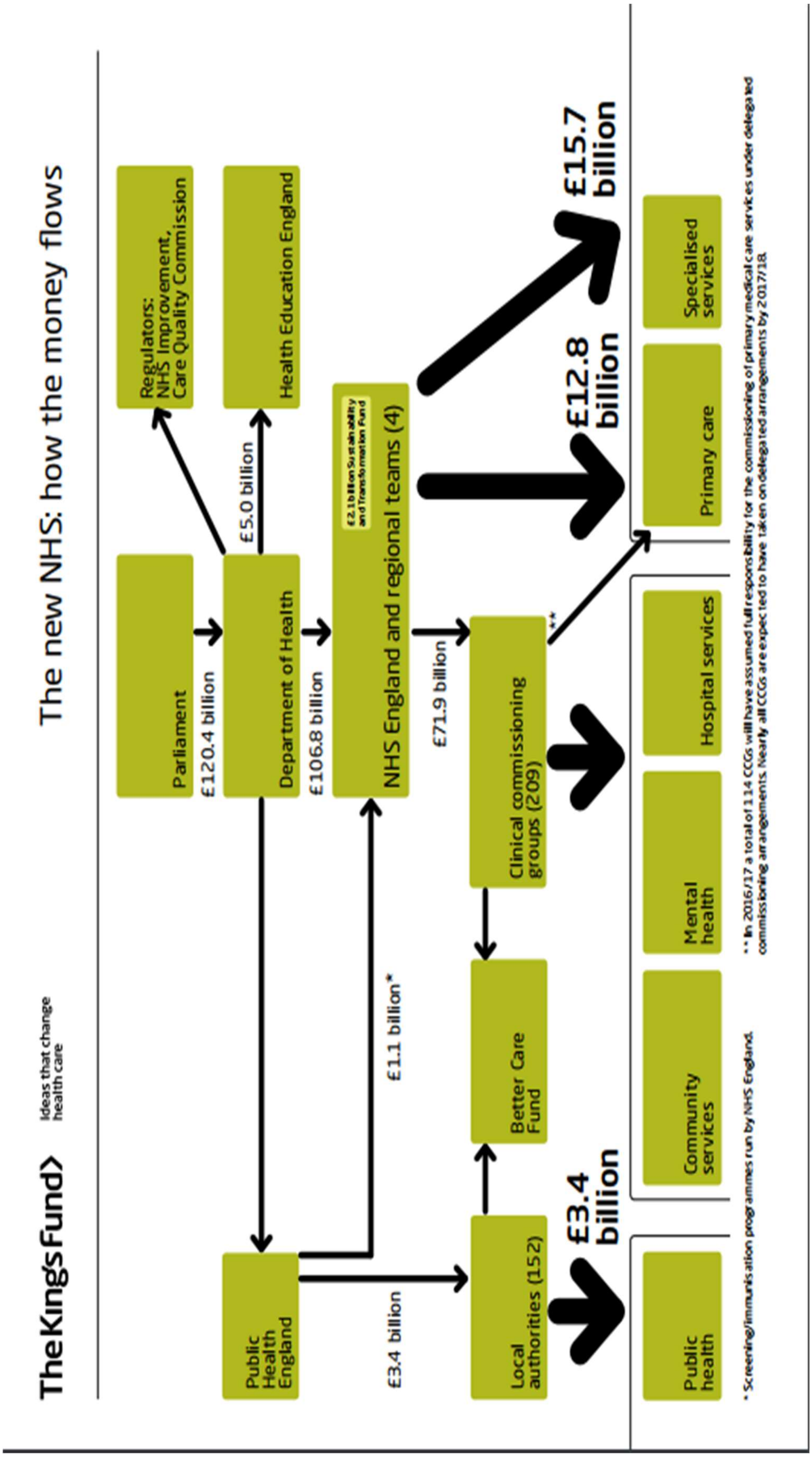


** From 1 April 2016, leaders in Greater Manchester are taking greater control of the region's health and social care budget. This includes taking on delegated responsibility for several commissioning budgets previously controlled by NHS England. Other areas are also pursuing 'devolved' arrangements.

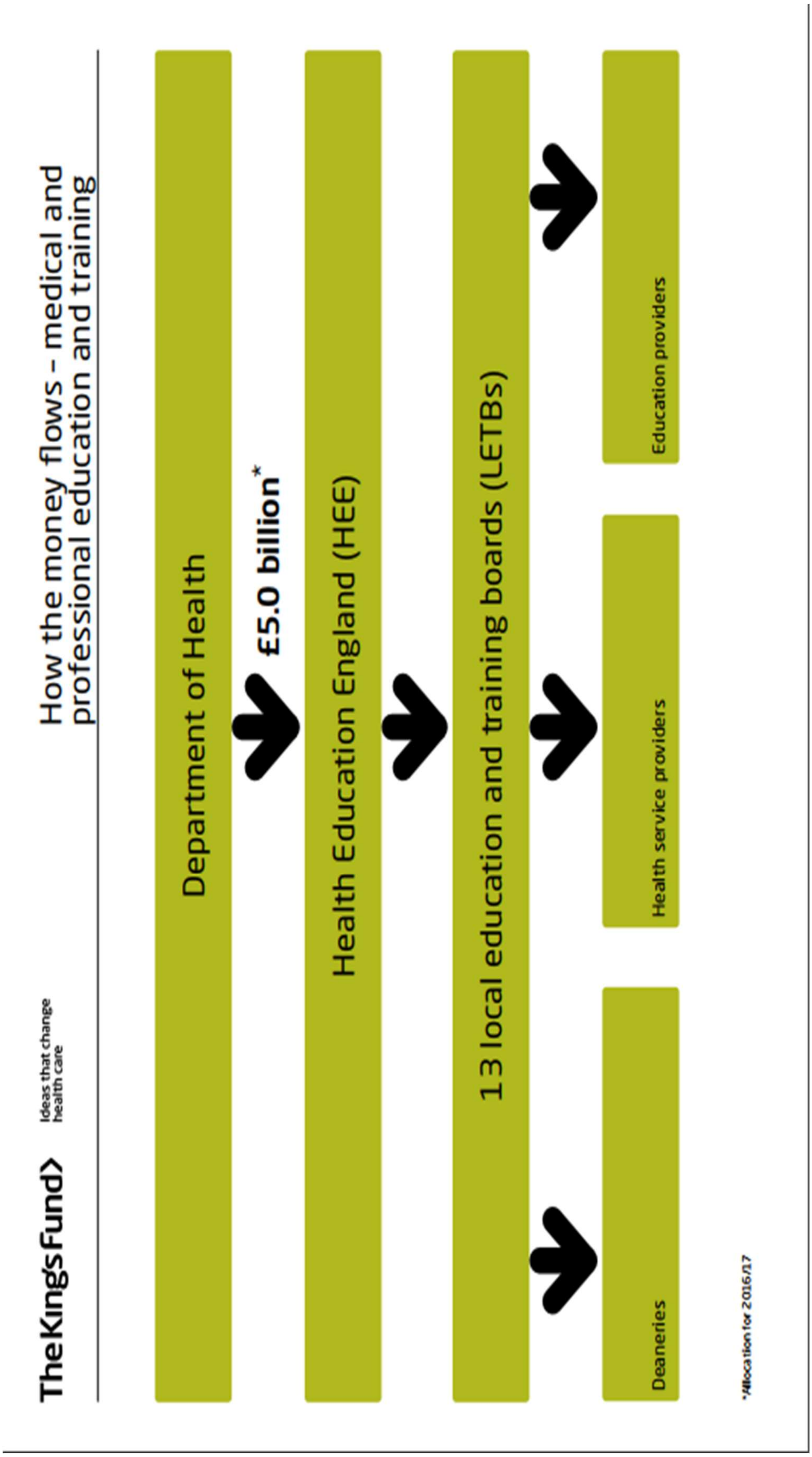
* Screening/immunisation programmes run by NHS England.

†† In 2016/17 a total of 114 CCGs will have assumed full responsibility for the commissioning of primary medical care services under delegated commissioning arrangements. Nearly all CCGs are expected to have taken on delegated arrangements by 2017/18.

Page 2 of 4 from The King's Fund

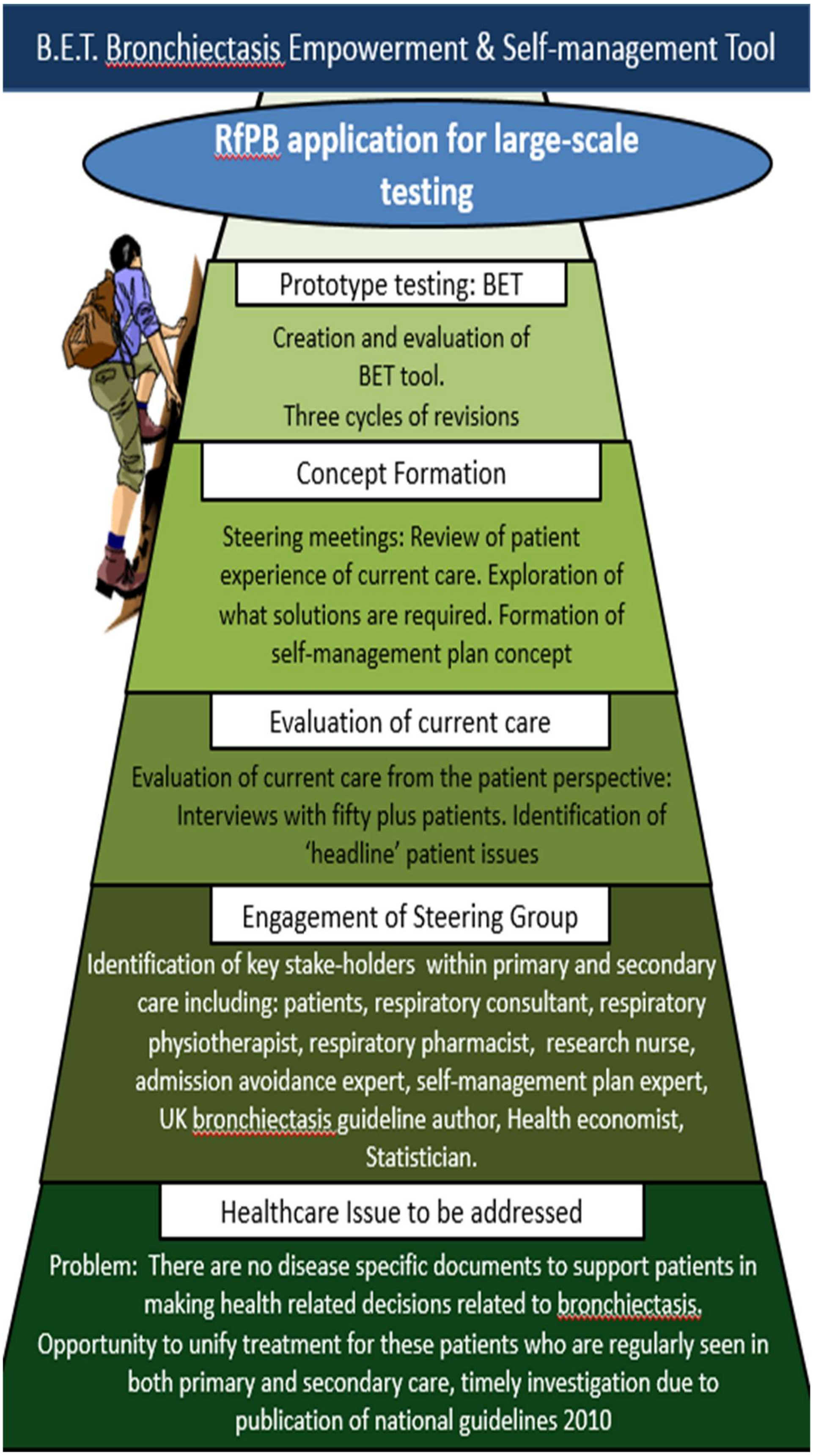


Page 3 of 4 from The King's Fund


The King's Fund
Ideas that change health care
How the money flows – medical and professional education and training
Department of Health
£5.0 billion*
Health Education England (HEE)
13 local education and training boards (LETBs)
Deaneries
Health service providers
Education providers
*Allocation for 2016/17

Page 4 of 4

Appendix 5 BET Project Development



B.E.T. Bronchiectasis Empowerment & Self-management Tool

RfPB application for large-scale testing

Prototype testing: BET

Creation and evaluation of BET tool.
Three cycles of revisions

Concept Formation

Steering meetings: Review of patient experience of current care. Exploration of what solutions are required. Formation of self-management plan concept

Evaluation of current care

Evaluation of current care from the patient perspective: Interviews with fifty plus patients. Identification of 'headline' patient issues

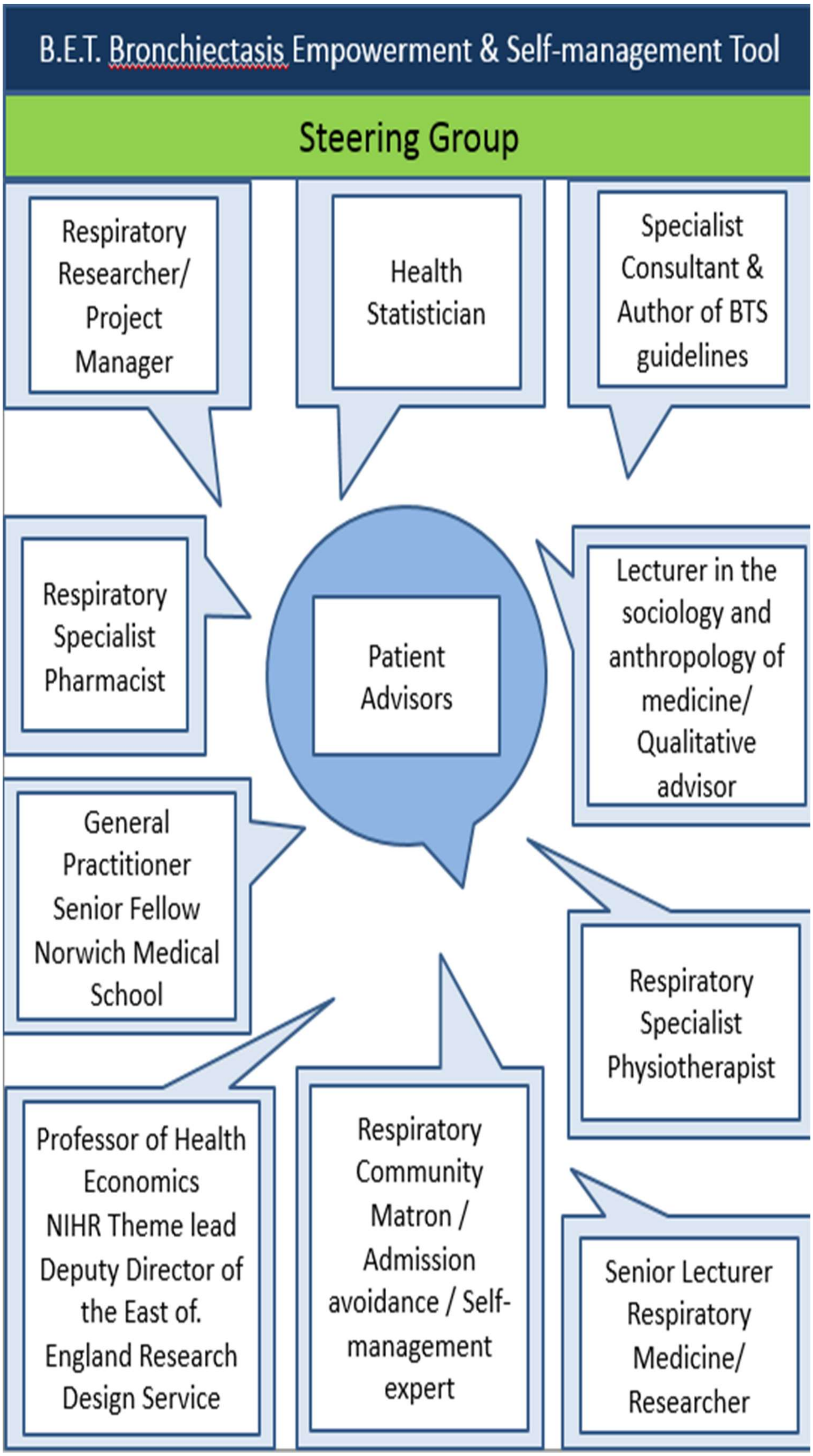
Engagement of Steering Group

Identification of key stake-holders within primary and secondary care including: patients, respiratory consultant, respiratory physiotherapist, respiratory pharmacist, research nurse, admission avoidance expert, self-management plan expert, UK bronchiectasis guideline author, Health economist, Statistician.

Healthcare Issue to be addressed

Problem: There are no disease specific documents to support patients in making health related decisions related to bronchiectasis.
Opportunity to unify treatment for these patients who are regularly seen in both primary and secondary care, timely investigation due to publication of national guidelines 2010

Page 1 of 4 BET Project Development



B.E.T. Bronchiectasis Empowerment & Self-management Tool

Steering Group

Respiratory Researcher/ Project Manager

Health Statistician

Specialist Consultant & Author of BTS guidelines

Respiratory Specialist Pharmacist

Patient Advisors

Lecturer in the sociology and anthropology of medicine/ Qualitative advisor

General Practitioner Senior Fellow Norwich Medical School

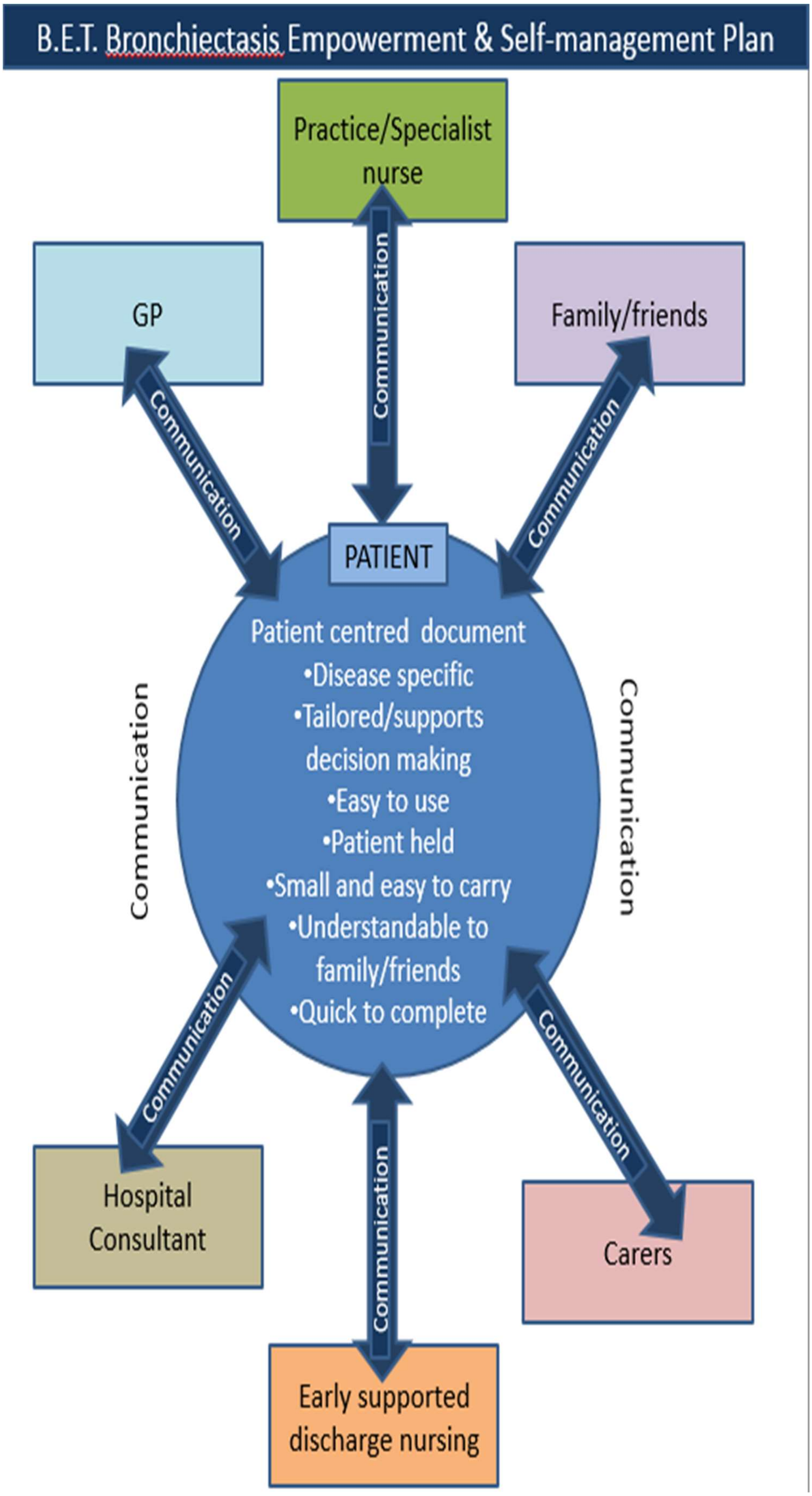
Respiratory Specialist Physiotherapist

Professor of Health Economics NIHR Theme lead Deputy Director of the East of. England Research Design Service

Respiratory Community Matron / Admission avoidance / Self-management expert

Senior Lecturer Respiratory Medicine/ Researcher

Page 2 of 4 BET Project Development

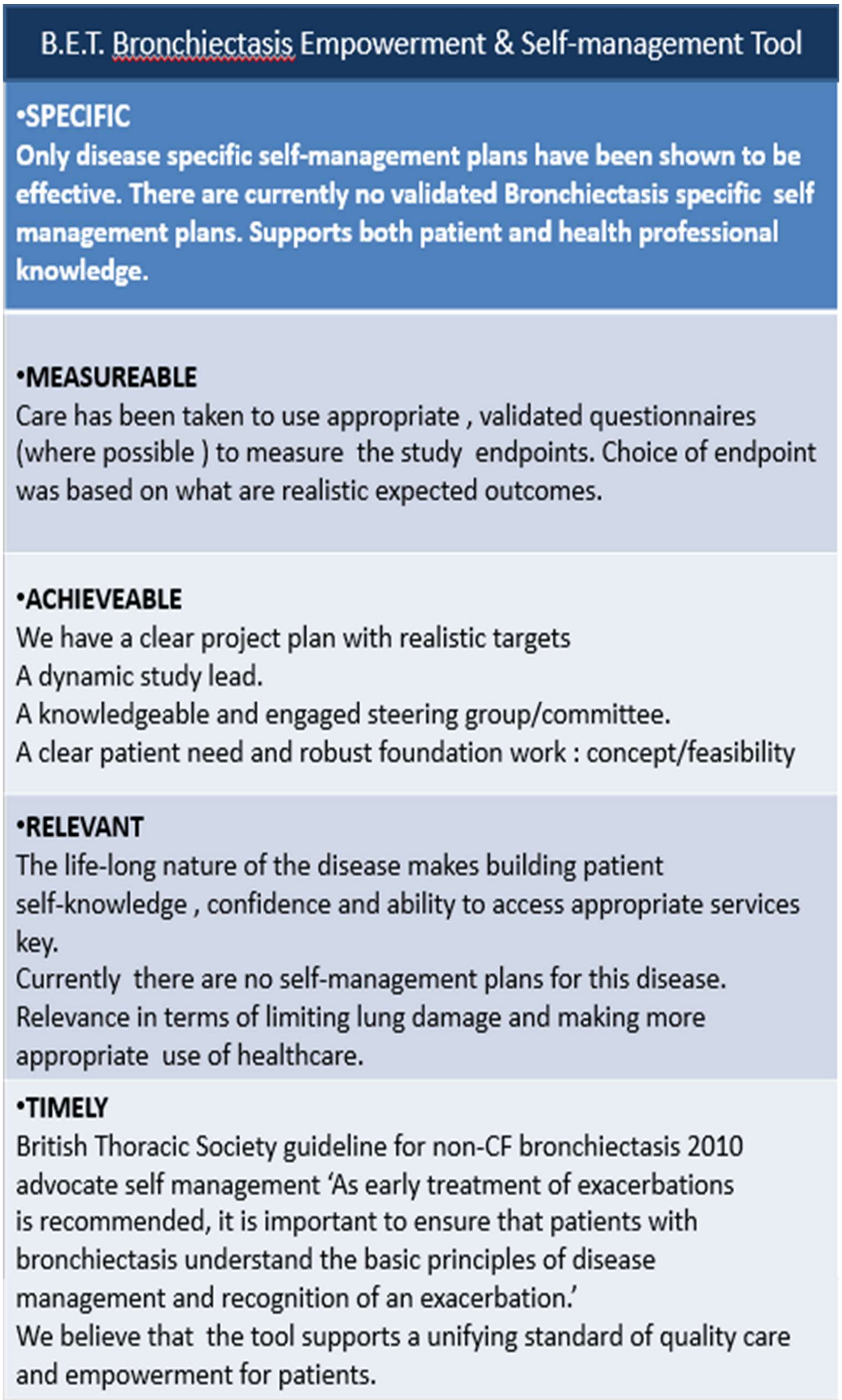


B.E.T. Bronchiectasis Empowerment & Self-management Plan

PATIENT

Patient centred document
- Disease specific
- Tailored/supports decision making
- Easy to use
- Patient held
- Small and easy to carry
- Understandable to family/friends
- Quick to complete

Page 3 of 4 BET Project Development



B.E.T. Bronchiectasis Empowerment & Self-management Tool

•SPECIFIC

Only disease specific self-management plans have been shown to be effective. There are currently no validated Bronchiectasis specific self management plans. Supports both patient and health professional knowledge.

•MEASUREABLE

Care has been taken to use appropriate , validated questionnaires (where possible) to measure the study endpoints. Choice of endpoint was based on what are realistic expected outcomes.

•ACHIEVEABLE

We have a clear project plan with realistic targets
A dynamic study lead.
A knowledgeable and engaged steering group/committee.
A clear patient need and robust foundation work : concept/feasibility

•RELEVANT

The life-long nature of the disease makes building patient self-knowledge , confidence and ability to access appropriate services key.
Currently there are no self-management plans for this disease.
Relevance in terms of limiting lung damage and making more appropriate use of healthcare.

•TIMELY

British Thoracic Society guideline for non-CF bronchiectasis 2010 advocate self management 'As early treatment of exacerbations is recommended, it is important to ensure that patients with bronchiectasis understand the basic principles of disease management and recognition of an exacerbation.'
We believe that the tool supports a unifying standard of quality care and empowerment for patients.

Page 4 of 4 BET Project Development

Appendix 6: Qualitative coding of jottings

EMERGING THEMES

AD	Acceptance/habituation to health impairment
BH	Barriers to healthcare/ process unlikely to support best practice/Bad practice
ECHP	Empowered self-care health promotion
EK	Experience/Knowledge
ER	Expectation v Reality
FA	Fears and anxieties
IH	Interaction with healthcare
OH	Opportunities in Healthcare/process likely to support better practice/Good practice
SI	Social impact of bronchiectasis
TBOSE	Trust based on shared experience

MASLOW CODES - HIGHER ORDER CODING

PN	Physiological Needs/psychological needs
SEN	Security Needs
SON	Social Needs
EN	Esteem Needs
SAN	Self-actualisation Needs

Appendix 7: Qualitative Reporting Standards (SRQR)

Standards for Reporting Qualitative Research

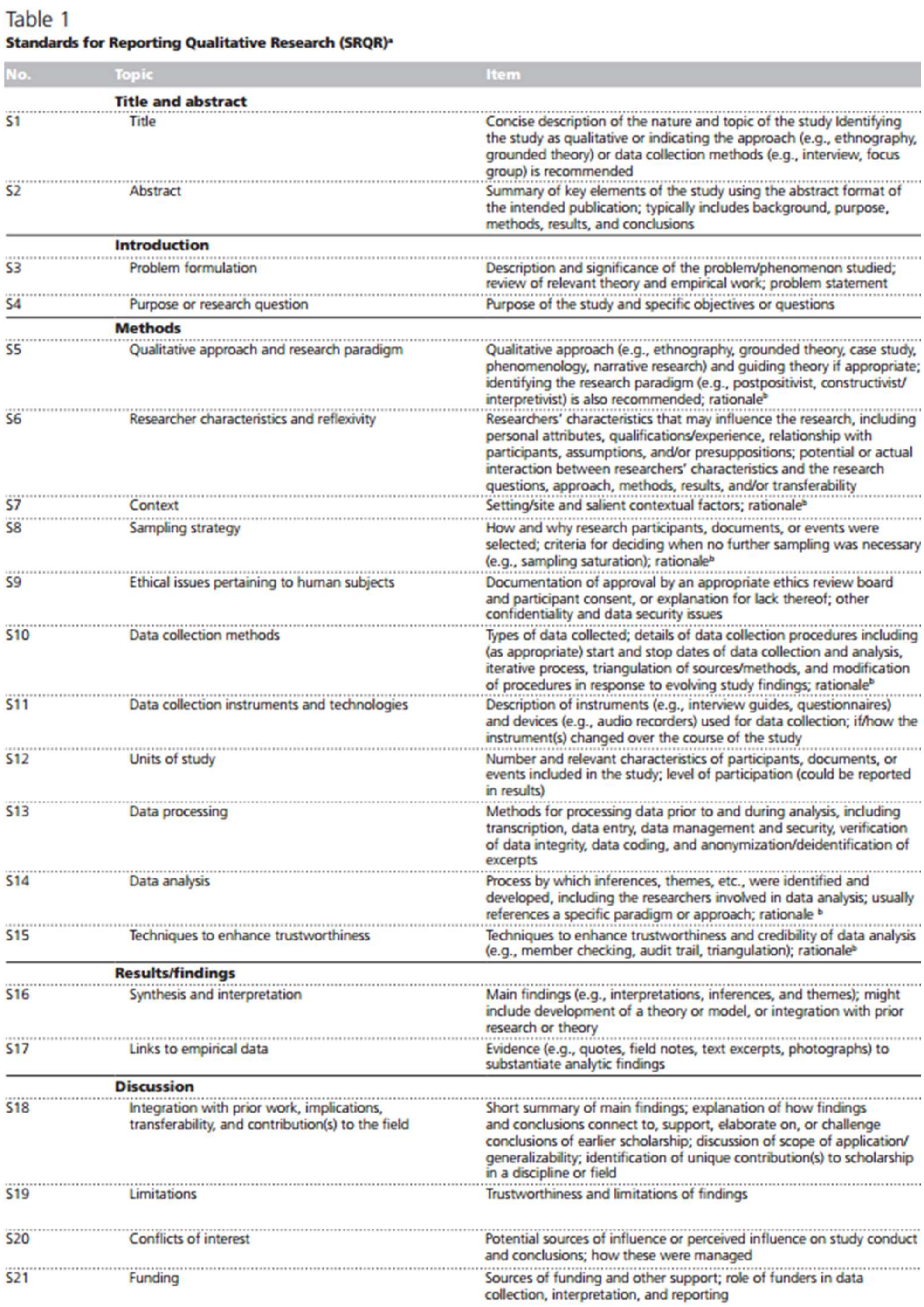
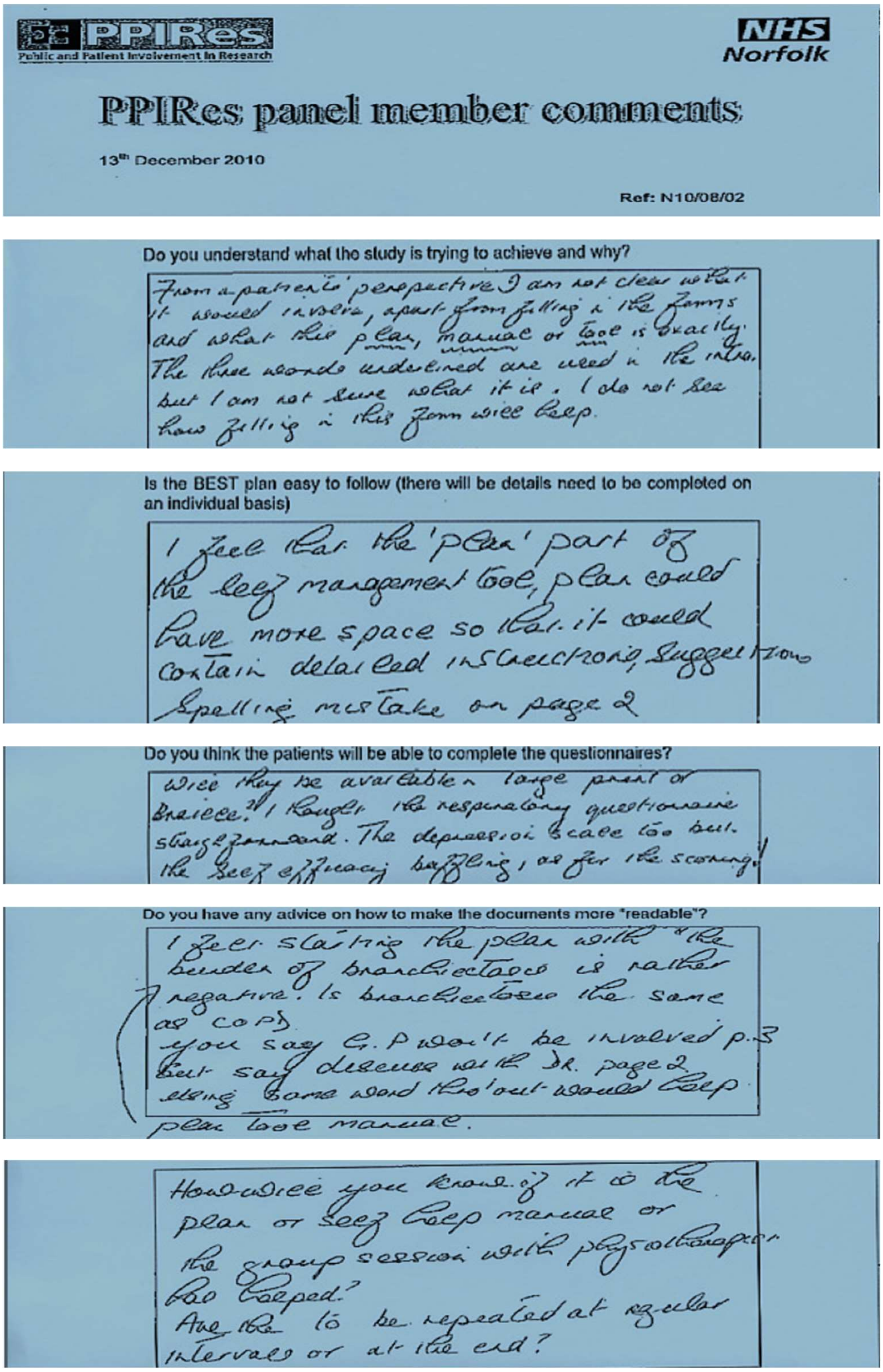


Table 1
Standards for Reporting Qualitative Research (SRQR)[a]

No.	Topic	Item
	Title and abstract	
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions
	Introduction	
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement
S4	Purpose or research question	Purpose of the study and specific objectives or questions
	Methods	
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale[b]
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability
S7	Context	Setting/site and salient contextual factors; rationale[b]
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale [b]
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]
	Results/findings	
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings
	Discussion	
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field
S19	Limitations	Trustworthiness and limitations of findings
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting

Appendix 8 PPIRes response to RfPB first round application



PPIRes
Public and Patient Involvement in Research

NHS
Norfolk

PPIRes panel member comments

13th December 2010

Ref: N10/08/02

Do you understand what the study is trying to achieve and why?

From a patients' perspective I am not clear what it would involve, apart from filling in the forms and what the plan, manual or tool is exactly. The three words underlined are used in the intro. but I am not sure what it is. I do not see how filling in this form will help.

Is the BEST plan easy to follow (there will be details need to be completed on an individual basis)

I feel that the 'plan' part of the self management tool, plan could have more space so that it could contain detailed instructions, suggestions
Spelling mistake on page 2

Do you think the patients will be able to complete the questionnaires?

Will they be available in large print or Braille?? I thought the respiratory questionnaire straightforward. The depression scale too but the self efficacy baffling, as for the scoring!

Do you have any advice on how to make the documents more "readable"?

I feel starting the plan with "the burden of bronchiectasis is rather negative. Is bronchiectasis the same as COPD
you say G.P won't be involved p.3 but say discuss with Dr. page 2
using same word thro'out would help
plan tool manual.

How will you know if it is the plan or self help manual or the group session with physiotherapist has helped?
Are they to be repeated at regular intervals or at the end?

Page 1 of 2 PPIRes and actions taken

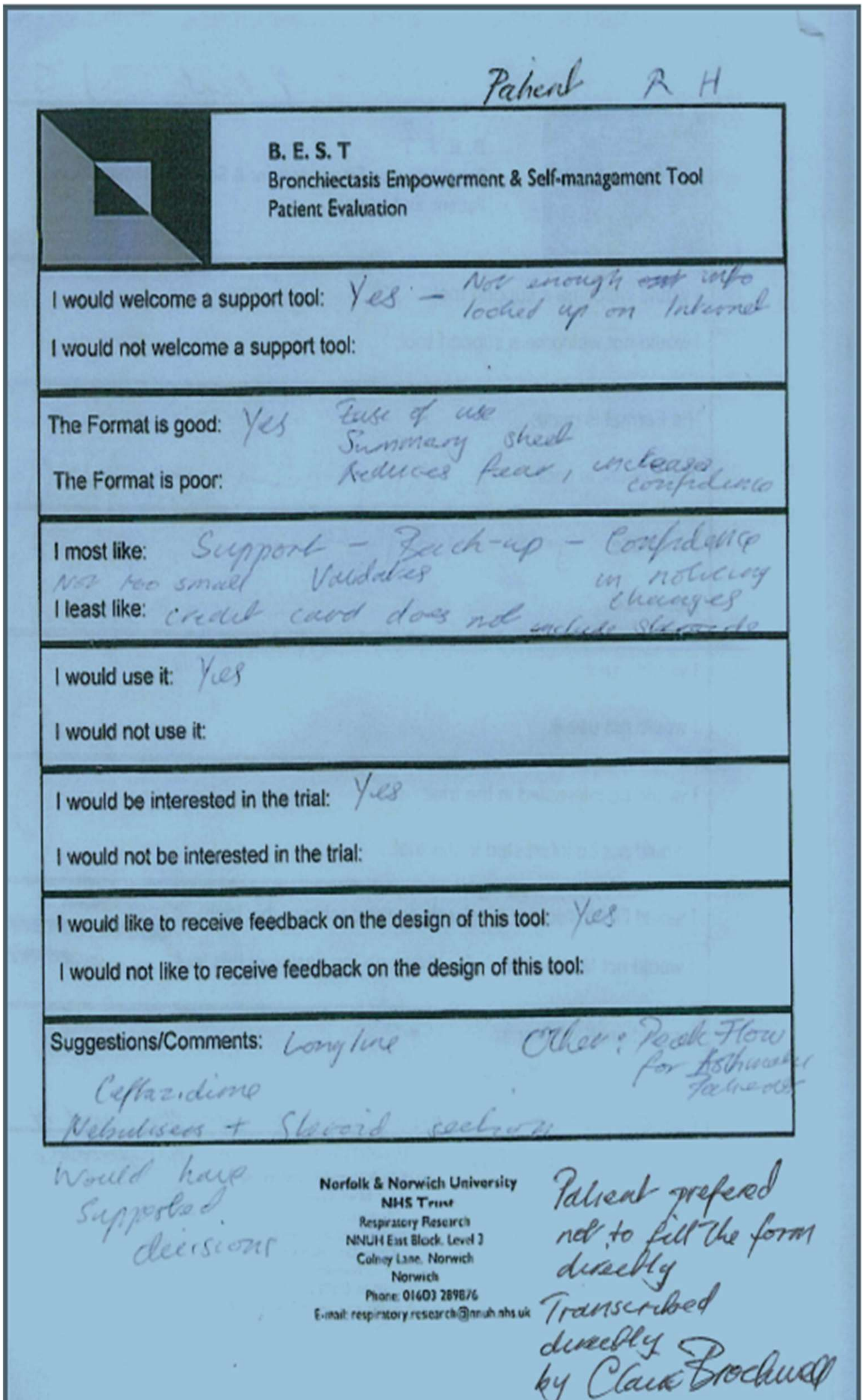
Actions resulting from PPIRes feedback

1. Attach sample of the tool for clarity of evaluation in next submission.
   N.B. It is envisaged that if the intervention were to prove successful the 'tool' would be introduced through education delivered by a nurse (during the study a single nurse/researcher will deliver this to prevent cross-contamination (shared knowledge) in the treatment as usual comparison group.
   Patient information lay summary has been made more explicit, protocol similarly amended.
2. Plan part of the tool expanded per advisor suggestion and now contains instructions and suggestions in four key areas important to bronchiectasis.
3. Large print will be made available as suggested. The increase of size will be from A5 to A4 (doubled) size. A5 size was preferred in the pilot for portability to appointments. Braille documents will be provided on request and after consent to the trial (a 4 week delay to study start will apply to these participants to allow transcription and printing).
4. Rewording and increased clarity in the lay summary. An added explanation relating to multi-disciplinary involvement for the duration of the study has not been envisaged to reduce the likelihood of accidental cross-contamination of information to the treatment as usual participants, variability of interdisciplinary support and associated costs and time requirements. GPs are advised that their patient is taking part in a self-management study as a professional courtesy and to keep them in the loop regarding patient involvement in research (good practice). Tool now used throughout for consistency as advised.
5. Rewording of how trial questionnaire responses at specific repetitive intervals provide data about trial outcomes which are then evaluated to see whether there has been a change. Explanation of minimum clinically significant change in (our primary outcome) which is self-efficacy. Physiotherapy group session was removed due to lack of specialist staff availability and reluctance from bronchiectasis to attend added appointments particularly with others who may have infection (due to susceptibility to infection)

Page 2 of 2 PPIRes and actions taken.

Appendix 9 PPI evolution of BET

(previously named BEST in first round application for RfPB funding)



Patient R H

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: Yes – Not enough ~~ext~~ info looked up on Internet
I would not welcome a support tool:

The Format is good: Yes Ease of use Summary sheet Reduces fear, increase confidence
The Format is poor:

I most like: Support – Back-up – Confidence in noticing changes Validates
Not too small
I least like: credit card does not include Steroids

I would use it: Yes
I would not use it:

I would be interested in the trial: Yes
I would not be interested in the trial:

I would like to receive feedback on the design of this tool: Yes
I would not like to receive feedback on the design of this tool:

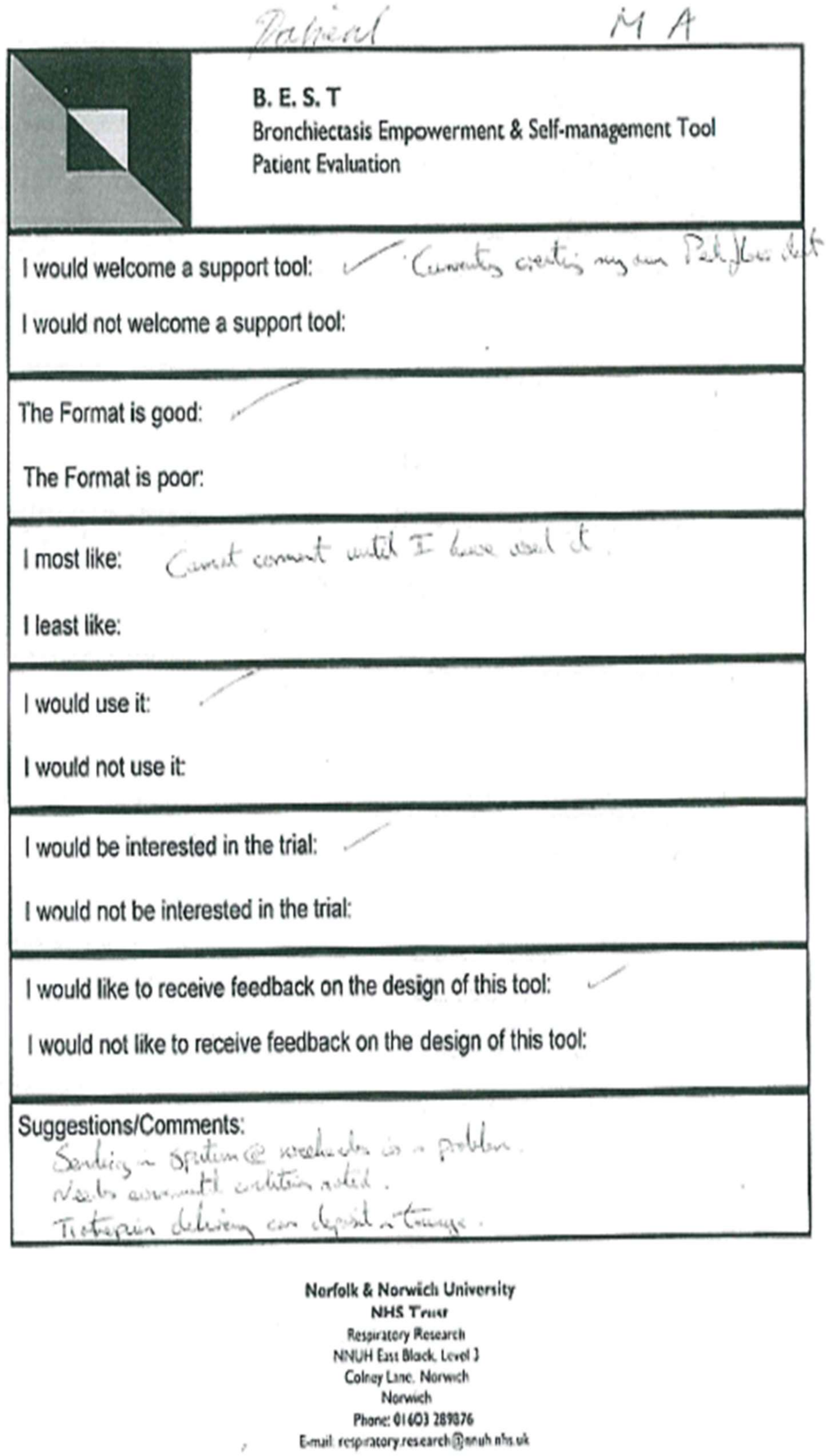
Suggestions/Comments: Long line
Ceftazidime
Nebulisers + Steroid section
Other: Peak Flow for Asthmatic Patients

Would have supported decisions

Norfolk & Norwich University
NHS Trust
Respiratory Research
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Patient prefered not to fill the form directly
Transcribed directly by Claire Brockwell

Page 1 of 9 PPI evolution of BET



Patient M A

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: ✓ Currently creating my own Peak flow chart.
I would not welcome a support tool:

The Format is good: ✓
The Format is poor:

I most like: Cannot comment until I have used it.
I least like:

I would use it: ✓
I would not use it:

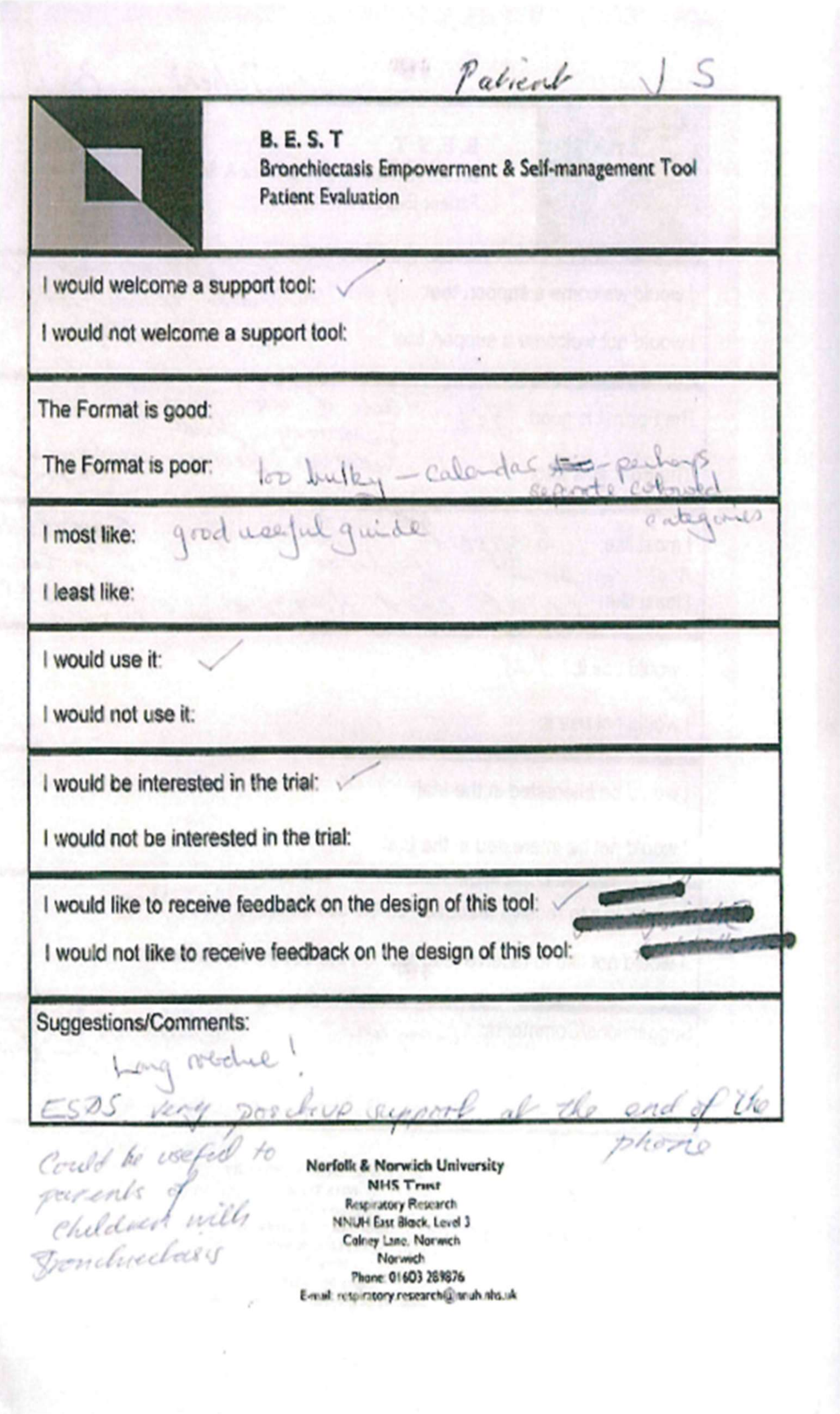
I would be interested in the trial: ✓
I would not be interested in the trial:

I would like to receive feedback on the design of this tool: ✓
I would not like to receive feedback on the design of this tool:

Suggestions/Comments:
Sending in sputum @ weekends is a problem.
Needs assessment criteria noted.
[illegible] delivering can deposit in Garage.

Norfolk & Norwich University
NHS Trust
Respiratory Research
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Page 2 of 9 PPI evolution of BET



Patient J S

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: ✓

I would not welcome a support tool:

The Format is good:

The Format is poor: too bulky – calendar ~~is~~ – perhaps separate coloured categories

I most like: good useful guide

I least like:

I would use it: ✓

I would not use it:

I would be interested in the trial: ✓

I would not be interested in the trial:

I would like to receive feedback on the design of this tool: ✓ [redacted]

I would not like to receive feedback on the design of this tool:

Suggestions/Comments:
Long overdue!
ESDS very positive support at the end of the phone

Could be useful to parents of children with Bronchiectasis

Norfolk & Norwich University NHS Trust
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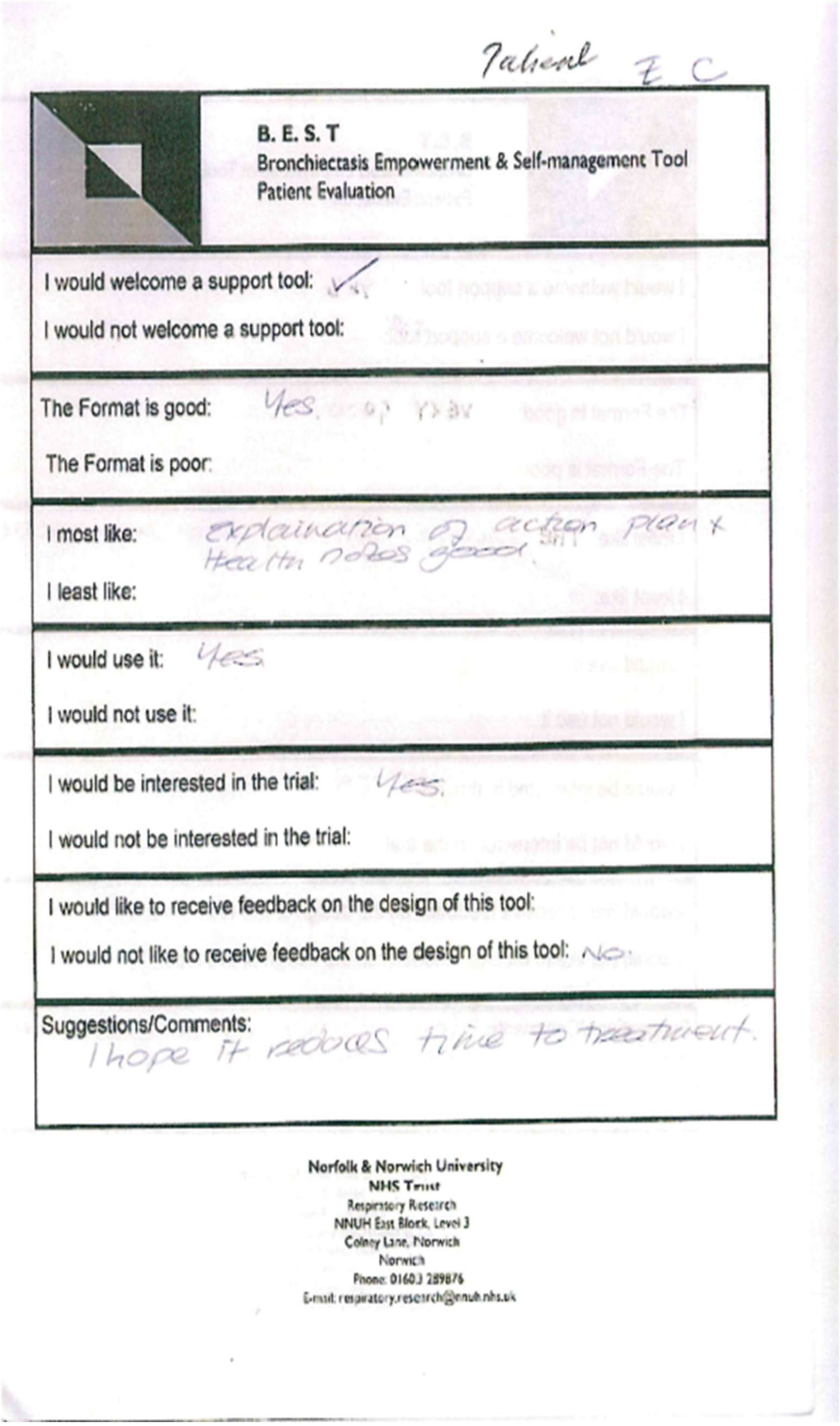
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Page 3 of 9 PPI evolution of BET



Patient E C

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: ✓

I would not welcome a support tool:

The Format is good: Yes.

The Format is poor:

I most like: explaination of action plan + Health notes good.

I least like:

I would use it: Yes

I would not use it:

I would be interested in the trial: Yes.

I would not be interested in the trial:

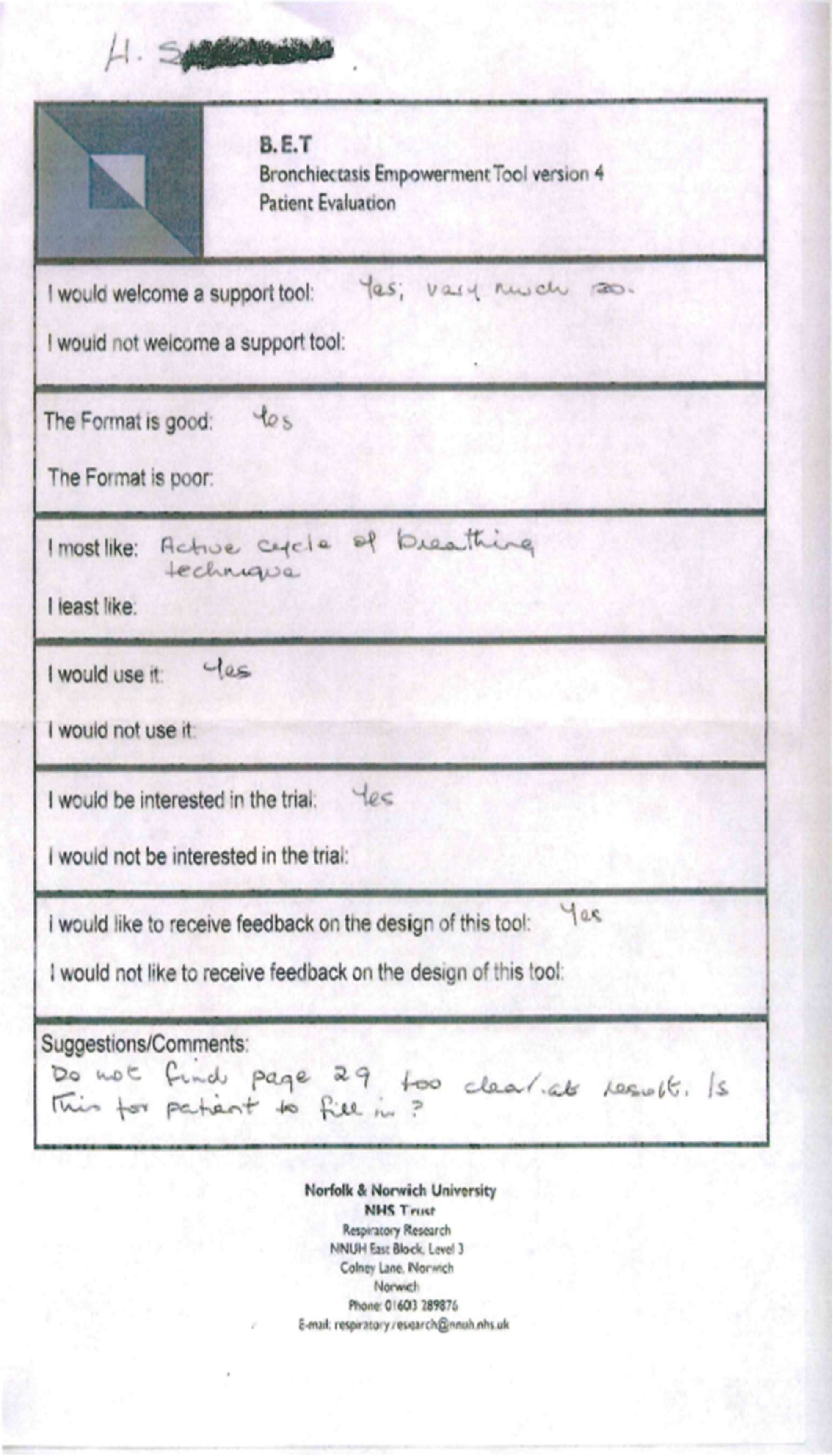
I would like to receive feedback on the design of this tool:

I would not like to receive feedback on the design of this tool: No.

Suggestions/Comments:
I hope it reduces time to treatment.

Norfolk & Norwich University
NHS Trust
Respiratory Research
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Page 4 of 9 PPI evolution of BET



H. [redacted].

B.E.T
Bronchiectasis Empowerment Tool version 4
Patient Evaluation

I would welcome a support tool: Yes; very much so.

I would not welcome a support tool:

The Format is good: Yes

The Format is poor:

I most like: Active cycle of breathing technique

I least like:

I would use it: Yes

I would not use it:

I would be interested in the trial: Yes

I would not be interested in the trial:

I would like to receive feedback on the design of this tool: Yes

I would not like to receive feedback on the design of this tool:

Suggestions/Comments:
Do not find page 29 too clear/at result. Is This for patient to fill in?

Norfolk & Norwich University
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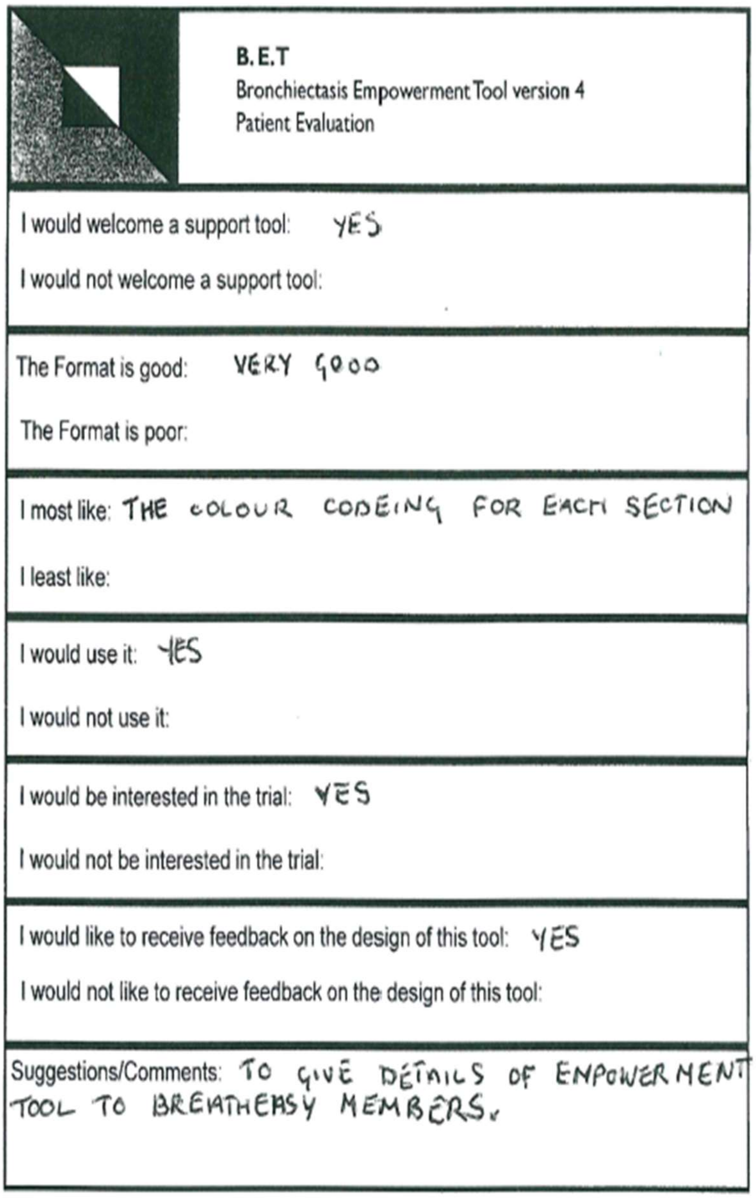
E-mail: respiratoryresearch@nnuh.nhs.uk

Page 5 of 9 PPI evolution of BET



B.E.T
Bronchiectasis Empowerment Tool version 4
Patient Evaluation

I would welcome a support tool: YES
I would not welcome a support tool:

The Format is good: VERY GOOD
The Format is poor:

I most like: THE COLOUR CODEING FOR EACH SECTION
I least like:

I would use it: YES
I would not use it:

I would be interested in the trial: YES
I would not be interested in the trial:

I would like to receive feedback on the design of this tool: YES
I would not like to receive feedback on the design of this tool:

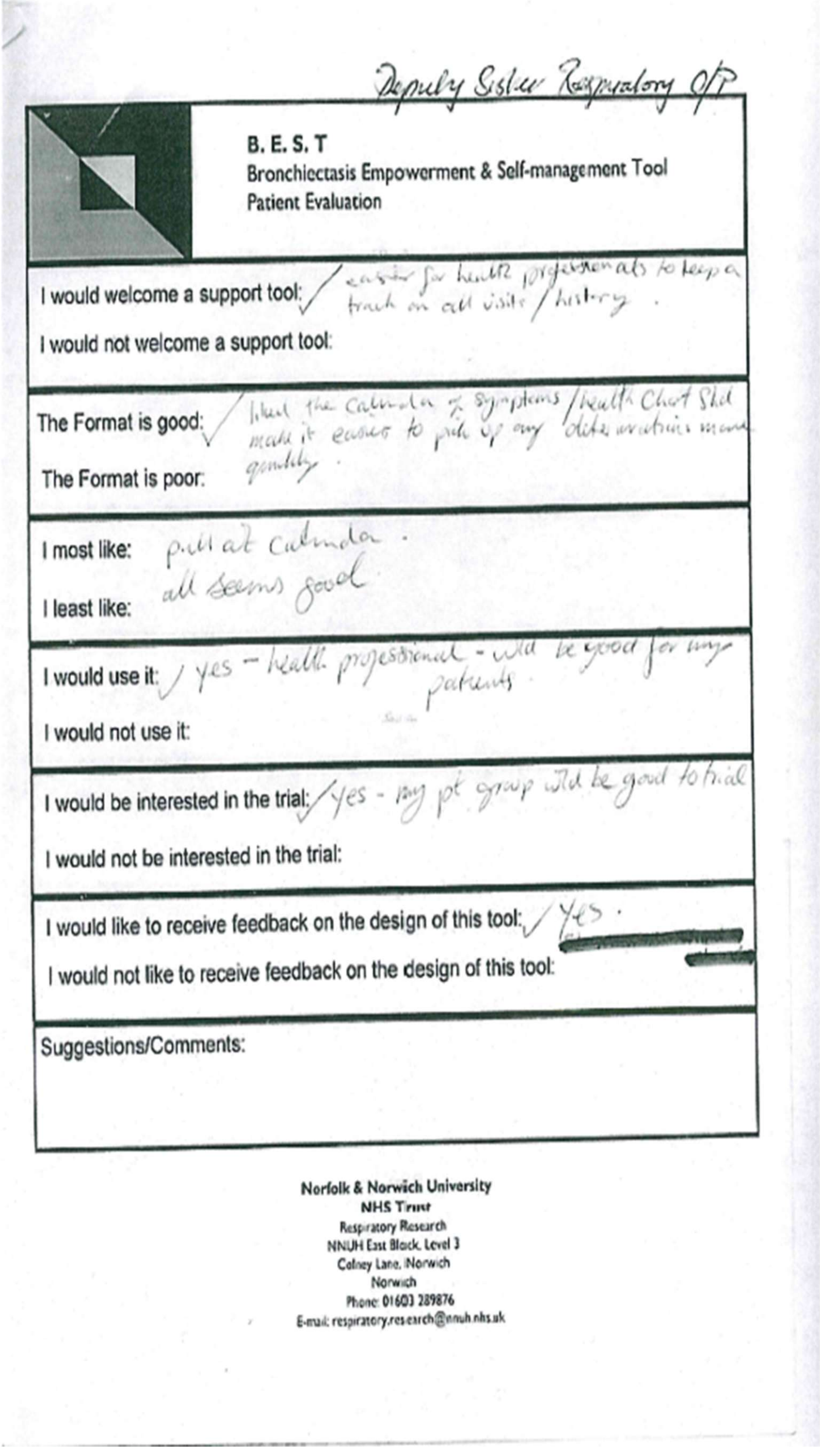
Suggestions/Comments: TO GIVE DETAILS OF ENPOWERMENT TOOL TO BREATHEASY MEMBERS.

Responses faded
and difficult
to read so re-enforced

Norfolk & Norwich University
NHS Trust
Respiratory Research
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Patient details
not documented

Page 6 of 9 PPI evolution of BET



Deputy Sister Respiratory O/P

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: ✓ easier for health professionals to keep a track on all visits / history.

I would not welcome a support tool:

The Format is good: ✓ liked the calendar of symptoms / health chart shd make it easier to pick up any deteriorations more quickly.

The Format is poor:

I most like: pull out calendar.

I least like: all seems good

I would use it: ✓ yes – health professional – wld be good for my patients.

I would not use it:

I would be interested in the trial: ✓ yes – my pt group wld be good to trial

I would not be interested in the trial:

I would like to receive feedback on the design of this tool: ✓ Yes. [redacted]

I would not like to receive feedback on the design of this tool:

Suggestions/Comments:

Norfolk & Norwich University
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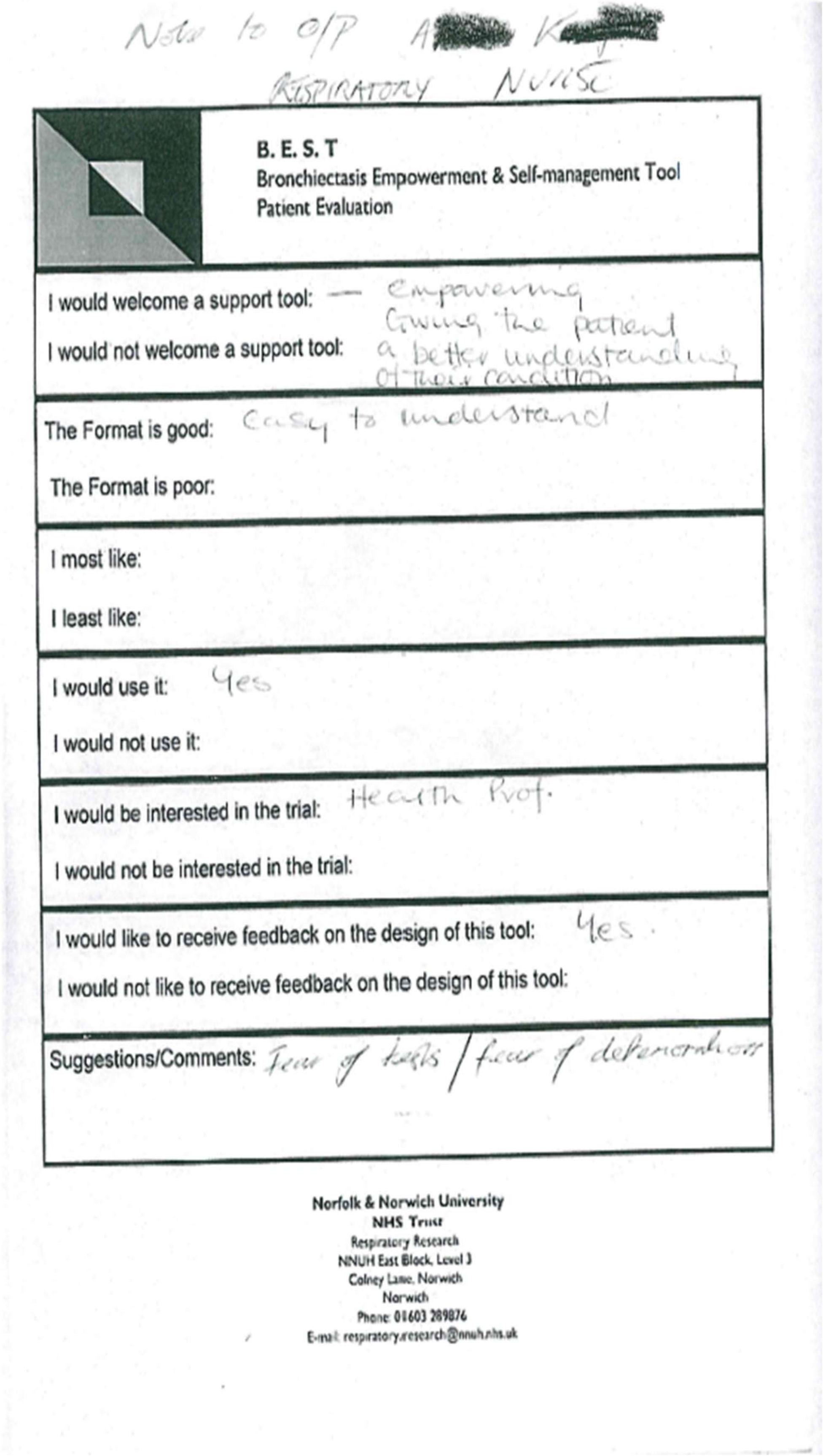
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Page 7 of 9 PPI evolution of BET



Note to O/P A[redacted] K[redacted]
RESPIRATORY NURSE

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: — Empowering
I would not welcome a support tool: Giving the patient a better understanding of their condition

The Format is good: easy to understand
The Format is poor:

I most like:
I least like:

I would use it: Yes
I would not use it:

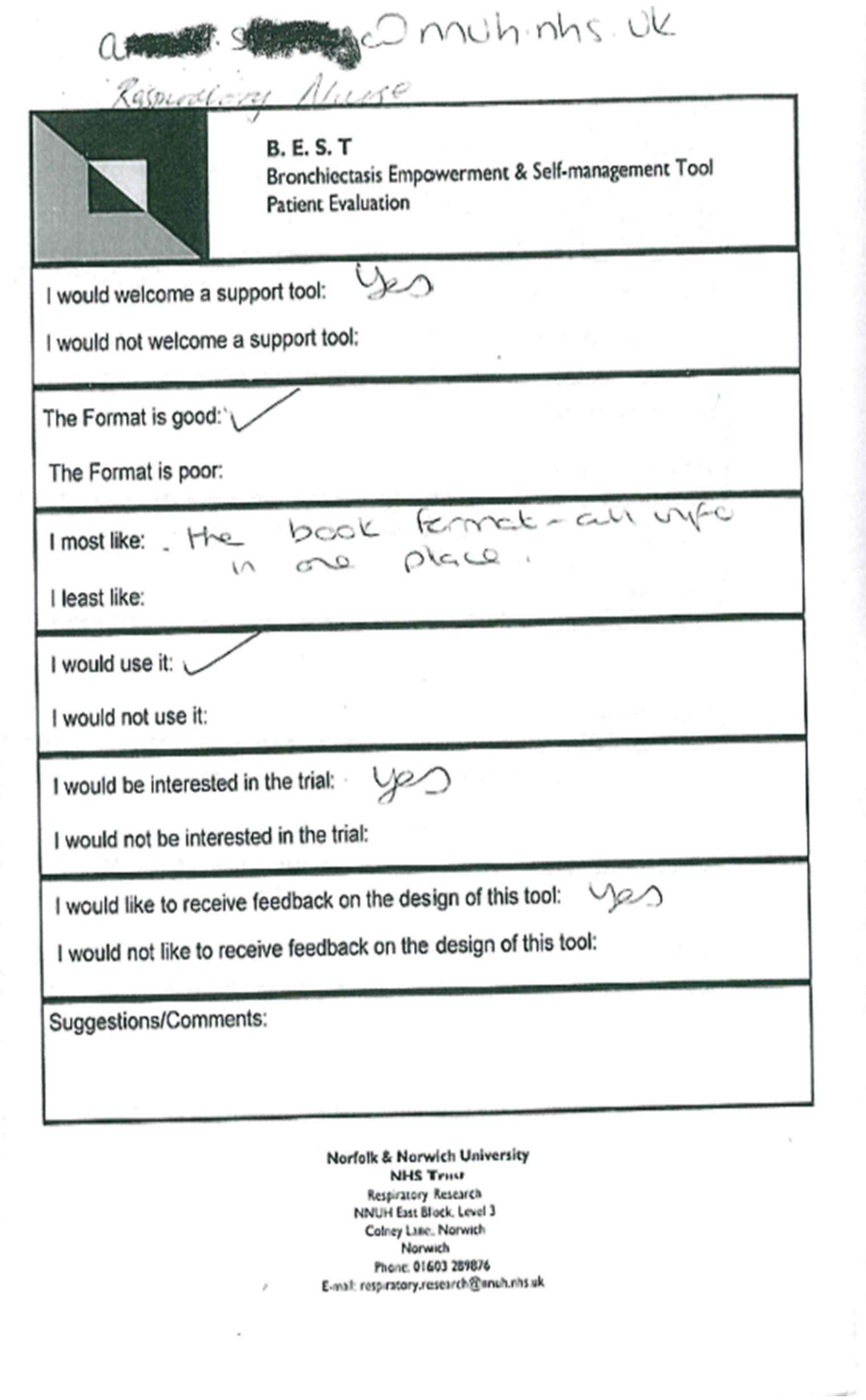
I would be interested in the trial: Health Prof.
I would not be interested in the trial:

I would like to receive feedback on the design of this tool: Yes.
I would not like to receive feedback on the design of this tool:

Suggestions/Comments: Fear of tests / fear of deterioration

Norfolk & Norwich University
NHS Trust
Respiratory Research
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Page 8 of 9 PPI evolution of BET



a[redacted] s[redacted]@nnuh.nhs.uk

Respiratory Nurse

B. E. S. T
Bronchiectasis Empowerment & Self-management Tool
Patient Evaluation

I would welcome a support tool: Yes

I would not welcome a support tool:

The Format is good: ✓

The Format is poor:

I most like: - the book format - all info in one place.

I least like:

I would use it: ✓

I would not use it:

I would be interested in the trial: Yes

I would not be interested in the trial:

I would like to receive feedback on the design of this tool: Yes

I would not like to receive feedback on the design of this tool:

Suggestions/Comments:

Norfolk & Norwich University
NHS Trust
Respiratory Research
NNUH East Block, Level 3
Colney Lane, Norwich
Norwich
Phone: 01603 289876
E-mail: respiratory.research@nnuh.nhs.uk

Page 9 of 9 PPI evolution of BET

Appendix 10: Patient & Public Involvement

Morag Butcher (steering group advisor):

"I knew from my experience of bronchiectasis and from nursing respiratory patients before I retired what a lonely and isolating effect illness can have and I wanted others to feel less alone and supported with understanding."

"I enjoyed the steering groups because I found them really interesting I was fascinated."

Cathy Spinks (steering advisor)

"I joined this project to help health professionals and researchers understand what it is to live and work with bronchiectasis and in order to help others with the condition. It was a shock to be diagnosed with respiratory disease having never smoked. Bronchiectasis has social impacts throughout my life including at work where I have to find a quiet place to cough to save embarrassment."

Noreen Neal first advised as a volunteer on the development of the BET document with specialist knowledge of self-management in diabetes and subsequently as a patient ambassador evaluating outcome measurement burden and qualitative focus group evaluation provides her insights in her own words below:

"When I was first presented with this study and the effects of Bronchiectasis on people, I felt the Investigator had attained a major achievement in successfully obtaining funding for a relatively unknown condition with a small amount of diagnosed patients. I applauded her for not going for an easier option such as Asthma, which is a more widely recognised disease with a potentially larger percentage of volunteers for any study. After discussing the disease/ condition with the Investigator and reading both the Bronchiectasis tool (BET) and studying the focus group notes, I am now left wondering what the true number of sufferers would be if those currently incorrectly diagnosed as Asthmatics, or those with no diagnosis at all were to be added to the numbers.

The study highlights the need for health professionals to have greater knowledge and understanding of this potentially debilitating condition to ensure that patients receive the correct treatment as soon as possible."

Page 1 of 3 PPI

I feel that the focus group discussions have shown a high percentage of patients have benefitted from using the BET tool. By writing down when they have exacerbations and infections it helps them track what is happening to them, and at a glance being able to have an overview of their health from the previous months. Some participants expressed a dislike of filling in forms, this hopefully could be addressed with alterations to the format to make cataloguing of events easier to note down. I am sure that both clinicians and other health professionals would value the BET tool as if completed and kept up to date it will also give them an overview of what infections and exacerbations their patient had suffered and what if any treatment worked more effectively.

Furthermore I believe this study has highlighted the need for a dedicated nurse practitioner, who could be available to patients on the end of the phone, especially when they suffer from infections which require immediate treatment as this doesn't always seem to be available via the GP's. Also a dedicated nurse could potentially set up a monthly clinic at GP surgeries where Bronchiectasis sufferers could attend and discuss any concerns. This time could also be used to enhance the medical professional's knowledge of the condition in the various practices.

Finally the other strong message that I felt came from the study and using the BET tool, was the need for the patients to be kept fully informed of their condition and medication in general and to themselves specifically. The BET tool could be further utilised by including updates about any advances concerning the condition or medication as and when it became available.

Page 2 of 3 PPI

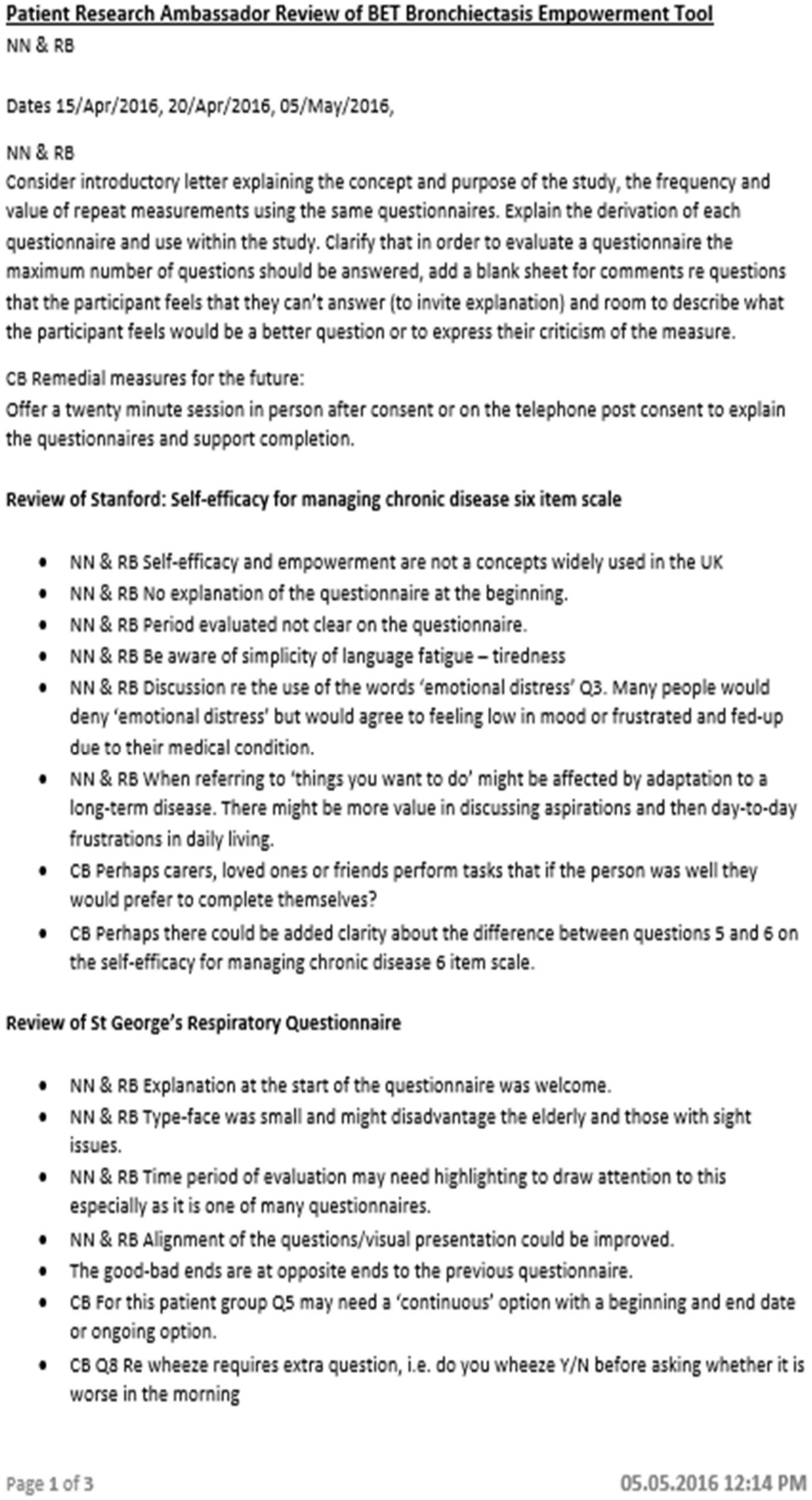
Rosalinde Bailey's evaluation of the anonymised focus group transcripts.

RB REVIEW

Written on the transcript during analysis and explained in person.

1. The tone, environment and refreshments seemed to put the participants at their ease.
2. The initial facilitation comments from CB encouraged an open discussion.
3. RB was interested in the ways that participants had evolved their own methods of recording bronchiectasis events.
4. RB discussed the personality and power differences within the group and the fact that the facilitator assisted the quieter members in finding opportunities to express themselves and reined in the more robust opinions without apparent effort.
5. RB commented that the participants described late diagnosis.
6. Different participant health beliefs relating to how infections are acquired were of interest.
7. Noted anger and frustration expressed freely by one participant relating to diagnosis and the extensive delay caused by family and NHS communication.
8. Noted Interpersonal support/solidarity from focus group members despite not previously having met the individual who was angry/frustrated
9. RB noted that the focus group members were given latitude to explore topics between themselves and were gently reminded of the main questions by the facilitator.
10. RB noted the discussion theme relating to being reluctant to take antibiotics
11. RB noted that the participants were concerned about their health professional's knowledge and experience relating to bronchiectasis.
12. RB noted that group discussions and interactions were *'brilliant'.*

Appendix 11 PRA Evaluation of outcome questionnaire burden



Patient Research Ambassador Review of BET Bronchiectasis Empowerment Tool

NN & RB

Dates 15/Apr/2016, 20/Apr/2016, 05/May/2016,

NN & RB
Consider introductory letter explaining the concept and purpose of the study, the frequency and value of repeat measurements using the same questionnaires. Explain the derivation of each questionnaire and use within the study. Clarify that in order to evaluate a questionnaire the maximum number of questions should be answered, add a blank sheet for comments re questions that the participant feels that they can't answer (to invite explanation) and room to describe what the participant feels would be a better question or to express their criticism of the measure.

CB Remedial measures for the future:
Offer a twenty minute session in person after consent or on the telephone post consent to explain the questionnaires and support completion.

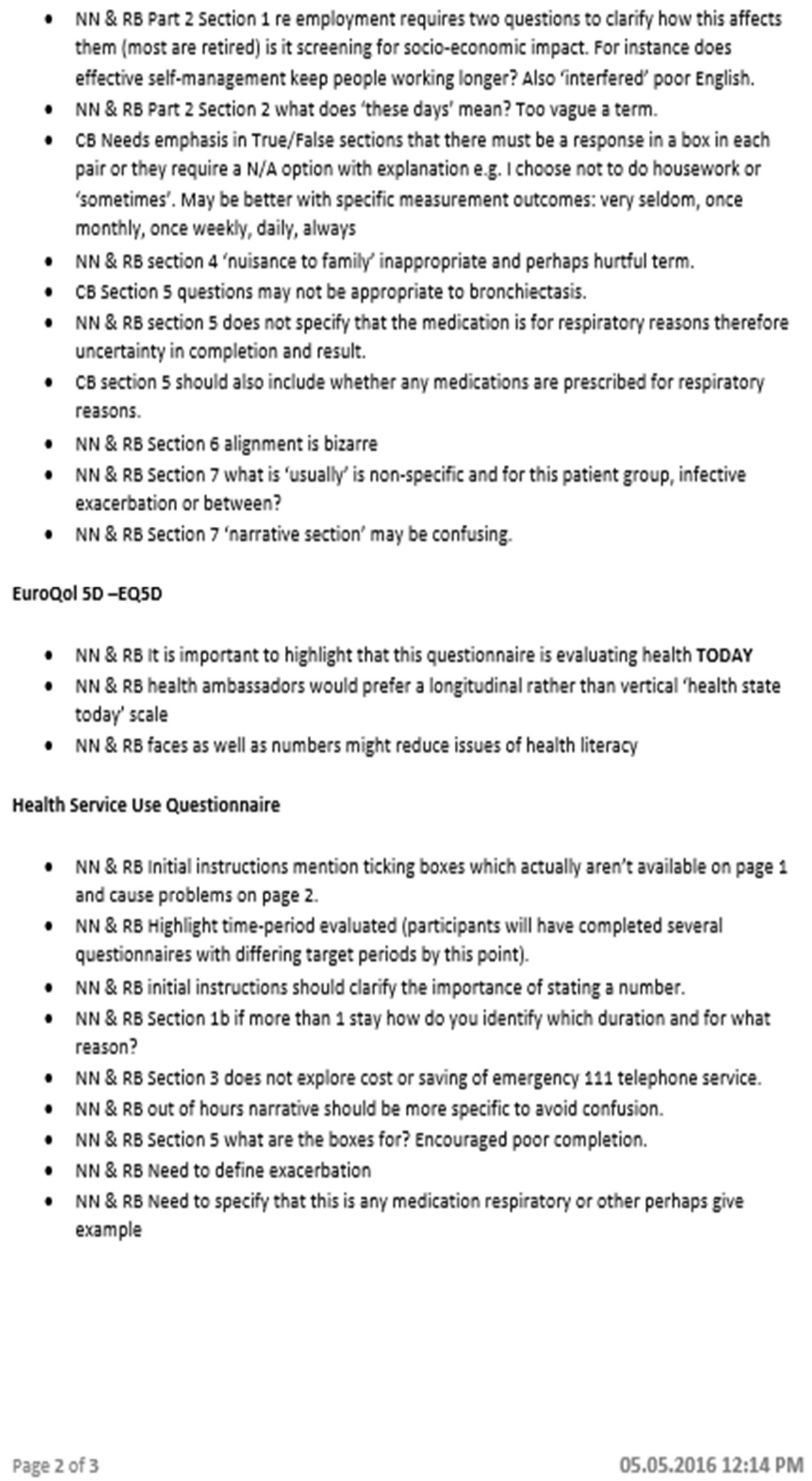
Review of Stanford: Self-efficacy for managing chronic disease six item scale

- NN & RB Self-efficacy and empowerment are not a concepts widely used in the UK
- NN & RB No explanation of the questionnaire at the beginning.
- NN & RB Period evaluated not clear on the questionnaire.
- NN & RB Be aware of simplicity of language fatigue – tiredness
- NN & RB Discussion re the use of the words 'emotional distress' Q3. Many people would deny 'emotional distress' but would agree to feeling low in mood or frustrated and fed-up due to their medical condition.
- NN & RB When referring to 'things you want to do' might be affected by adaptation to a long-term disease. There might be more value in discussing aspirations and then day-to-day frustrations in daily living.
- CB Perhaps carers, loved ones or friends perform tasks that if the person was well they would prefer to complete themselves?
- CB Perhaps there could be added clarity about the difference between questions 5 and 6 on the self-efficacy for managing chronic disease 6 item scale.

Review of St George's Respiratory Questionnaire

- NN & RB Explanation at the start of the questionnaire was welcome.
- NN & RB Type-face was small and might disadvantage the elderly and those with sight issues.
- NN & RB Time period of evaluation may need highlighting to draw attention to this especially as it is one of many questionnaires.
- NN & RB Alignment of the questions/visual presentation could be improved.
- The good-bad ends are at opposite ends to the previous questionnaire.
- CB For this patient group Q5 may need a 'continuous' option with a beginning and end date or ongoing option.
- CB Q8 Re wheeze requires extra question, i.e. do you wheeze Y/N before asking whether it is worse in the morning

Page 1 of 3 05.05.2016 12:14 PM



- NN & RB Part 2 Section 1 re employment requires two questions to clarify how this affects them (most are retired) is it screening for socio-economic impact. For instance does effective self-management keep people working longer? Also 'interfered' poor English.
- NN & RB Part 2 Section 2 what does 'these days' mean? Too vague a term.
- CB Needs emphasis in True/False sections that there must be a response in a box in each pair or they require a N/A option with explanation e.g. I choose not to do housework or 'sometimes'. May be better with specific measurement outcomes: very seldom, once monthly, once weekly, daily, always
- NN & RB section 4 'nuisance to family' inappropriate and perhaps hurtful term.
- CB Section 5 questions may not be appropriate to bronchiectasis.
- NN & RB section 5 does not specify that the medication is for respiratory reasons therefore uncertainty in completion and result.
- CB section 5 should also include whether any medications are prescribed for respiratory reasons.
- NN & RB Section 6 alignment is bizarre
- NN & RB Section 7 what is 'usually' is non-specific and for this patient group, infective exacerbation or between?
- NN & RB Section 7 'narrative section' may be confusing.

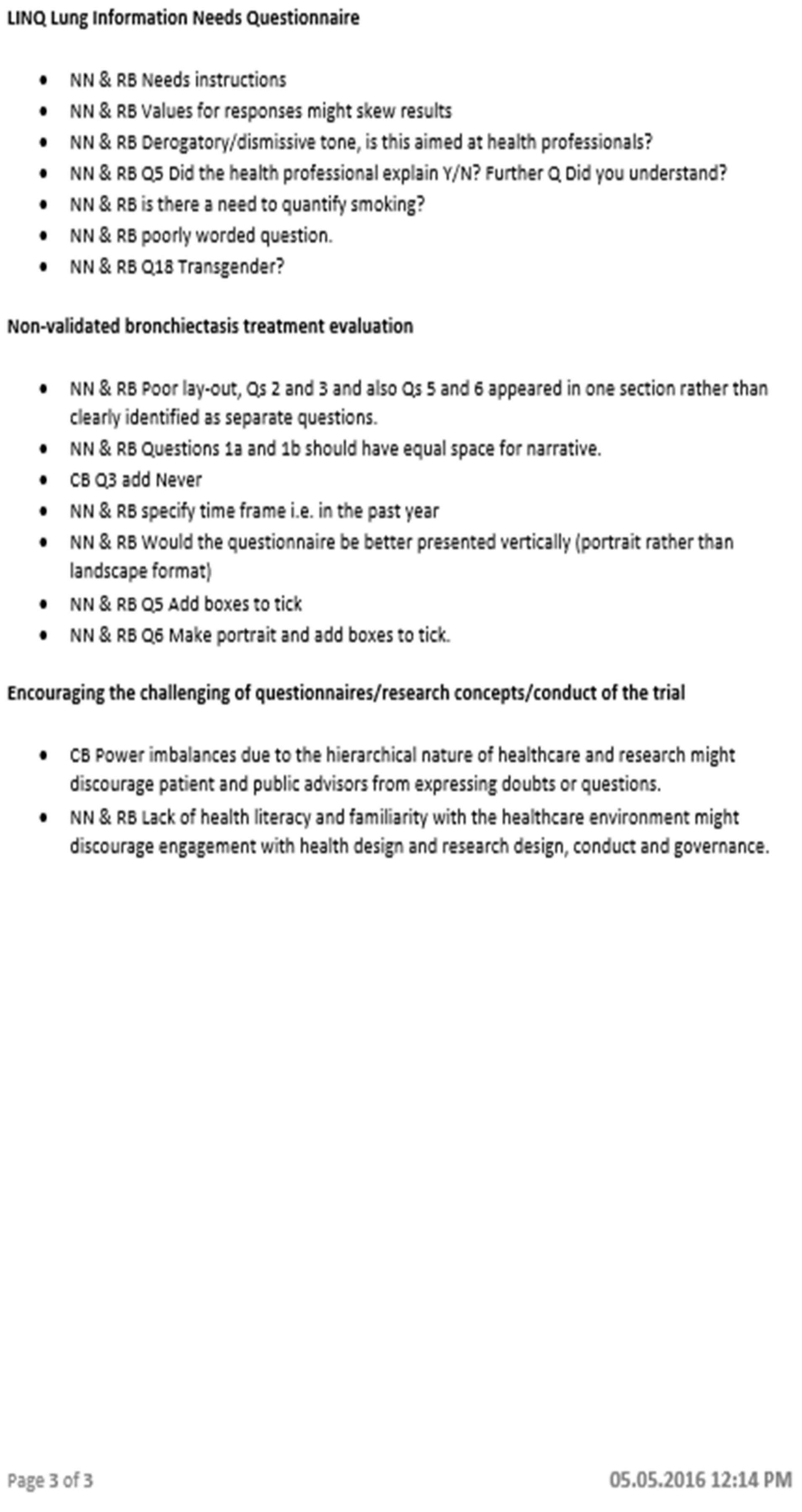
EuroQol 5D –EQ5D

- NN & RB It is important to highlight that this questionnaire is evaluating health **TODAY**
- NN & RB health ambassadors would prefer a longitudinal rather than vertical 'health state today' scale
- NN & RB faces as well as numbers might reduce issues of health literacy

Health Service Use Questionnaire

- NN & RB Initial instructions mention ticking boxes which actually aren't available on page 1 and cause problems on page 2.
- NN & RB Highlight time-period evaluated (participants will have completed several questionnaires with differing target periods by this point).
- NN & RB initial instructions should clarify the importance of stating a number.
- NN & RB Section 1b if more than 1 stay how do you identify which duration and for what reason?
- NN & RB Section 3 does not explore cost or saving of emergency 111 telephone service.
- NN & RB out of hours narrative should be more specific to avoid confusion.
- NN & RB Section 5 what are the boxes for? Encouraged poor completion.
- NN & RB Need to define exacerbation
- NN & RB Need to specify that this is any medication respiratory or other perhaps give example

Page 2 of 3 05.05.2016 12:14 PM



LINQ Lung Information Needs Questionnaire

- NN & RB Needs instructions
- NN & RB Values for responses might skew results
- NN & RB Derogatory/dismissive tone, is this aimed at health professionals?
- NN & RB Q5 Did the health professional explain Y/N? Further Q Did you understand?
- NN & RB is there a need to quantify smoking?
- NN & RB poorly worded question.
- NN & RB Q18 Transgender?

Non-validated bronchiectasis treatment evaluation

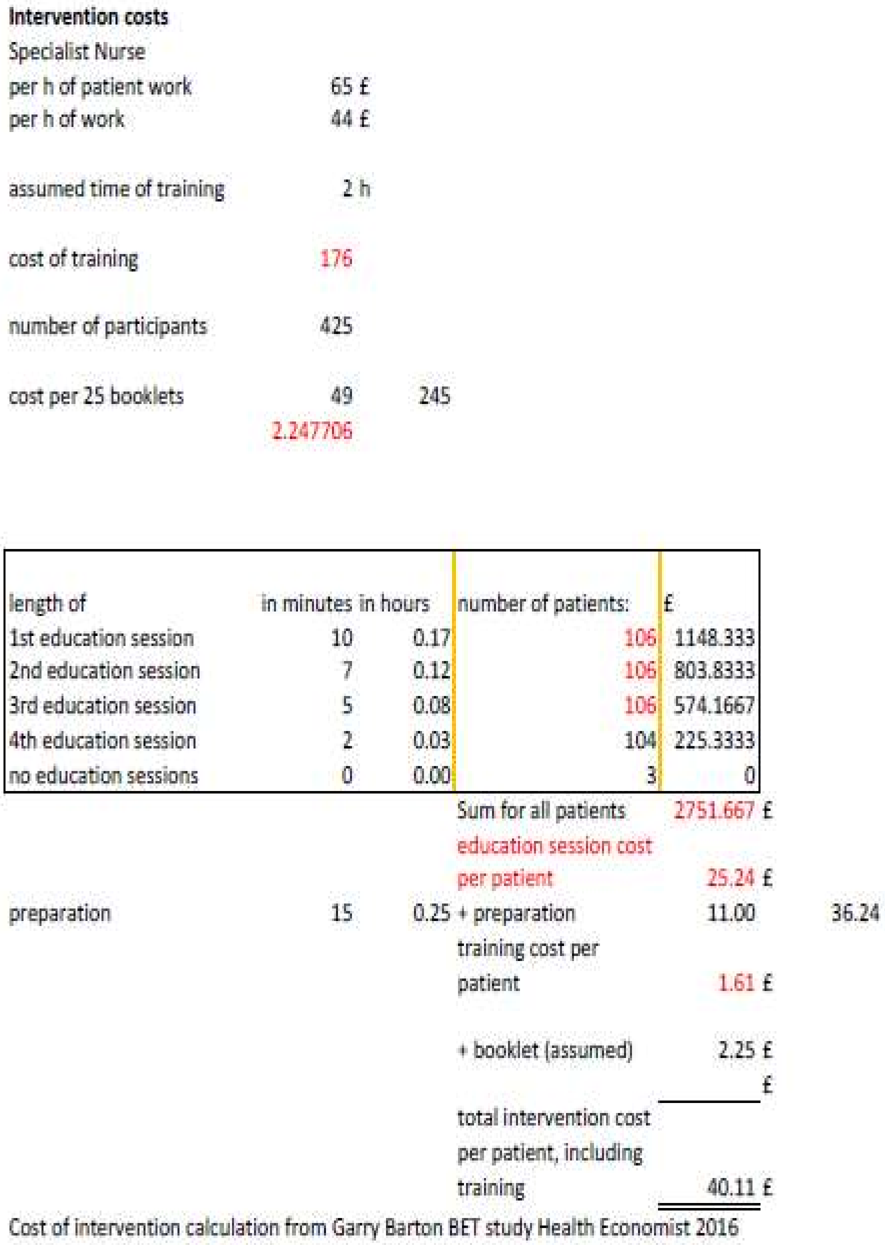
- NN & RB Poor lay-out, Qs 2 and 3 and also Qs 5 and 6 appeared in one section rather than clearly identified as separate questions.
- NN & RB Questions 1a and 1b should have equal space for narrative.
- CB Q3 add Never
- NN & RB specify time frame i.e. in the past year
- NN & RB Would the questionnaire be better presented vertically (portrait rather than landscape format)
- NN & RB Q5 Add boxes to tick
- NN & RB Q6 Make portrait and add boxes to tick.

Encouraging the challenging of questionnaires/research concepts/conduct of the trial

- CB Power imbalances due to the hierarchical nature of healthcare and research might discourage patient and public advisors from expressing doubts or questions.
- NN & RB Lack of health literacy and familiarity with the healthcare environment might discourage engagement with health design and research design, conduct and governance.

Page 3 of 3 05.05.2016 12:14 PM

Appendix 12: Intervention Cost Calculation for BET



Intervention costs

Specialist Nurse		
per h of patient work	65 £	
per h of work	44 £	
assumed time of training	2 h	
cost of training	176	
number of participants	425	
cost per 25 booklets	49	245
	2.247706	

length of	in minutes	in hours	number of patients:	£	
1st education session	10	0.17	106	1148.333	
2nd education session	7	0.12	106	803.8333	
3rd education session	5	0.08	106	574.1667	
4th education session	2	0.03	104	225.3333	
no education sessions	0	0.00	3	0	
			Sum for all patients	2751.667 £	
			education session cost per patient	25.24 £	
preparation	15	0.25	+ preparation	11.00	36.24
			training cost per patient	1.61 £	
			+ booklet (assumed)	2.25 £	
				£	
			total intervention cost per patient, including training	40.11 £	

Cost of intervention calculation from Garry Barton BET study Health Economist 2016

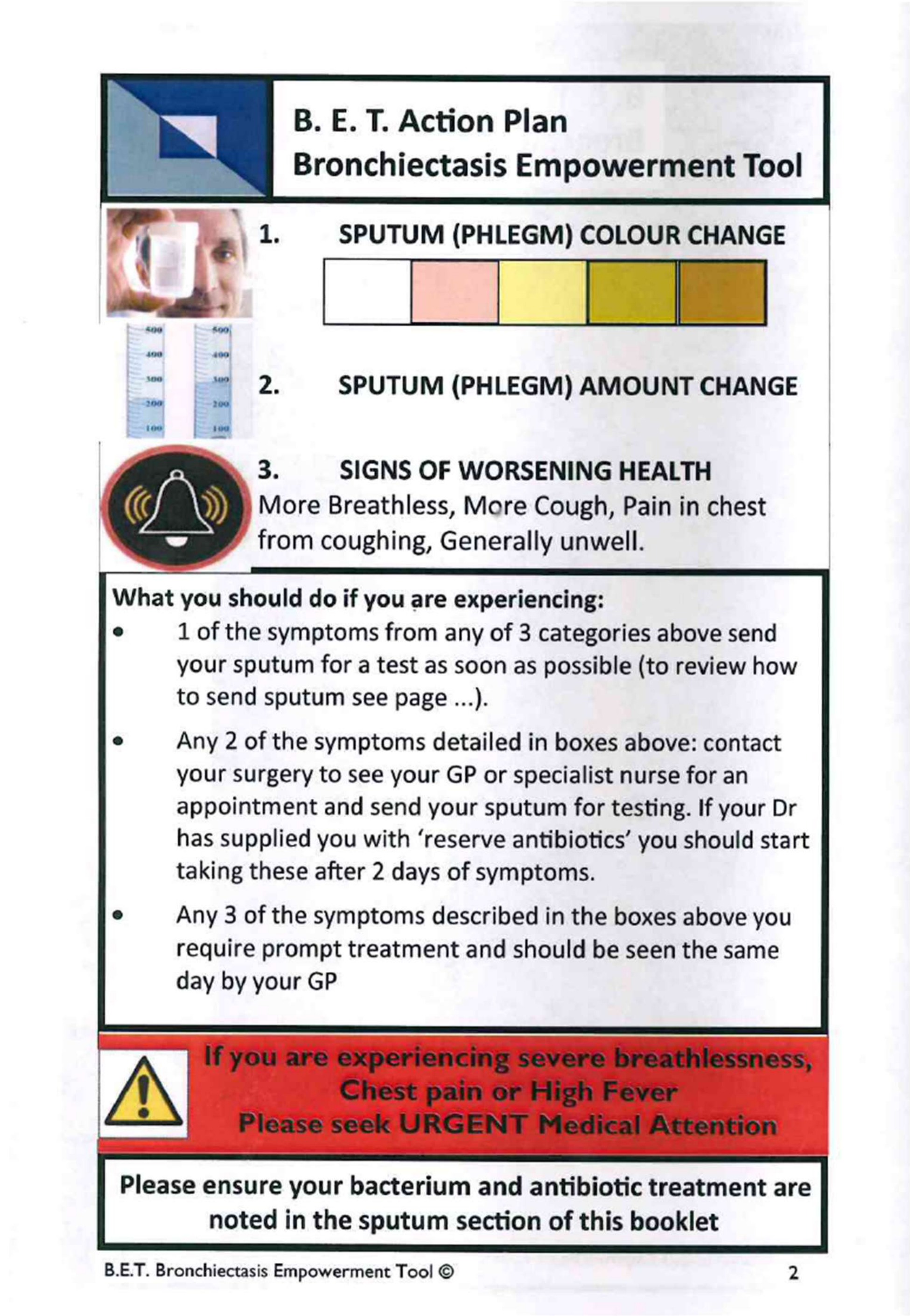
Appendix 13: Bronchiectasis Empowerment Tool

B. E. T.
Bronchiectasis Empowerment Tool

Participant pack number:

B.E.T. Bronchiectasis Empowerment Tool ©

1



B. E. T. Action Plan
Bronchiectasis Empowerment Tool

1. SPUTUM (PHLEGM) COLOUR CHANGE

2. SPUTUM (PHLEGM) AMOUNT CHANGE

3. SIGNS OF WORSENING HEALTH

More Breathless, More Cough, Pain in chest from coughing, Generally unwell.

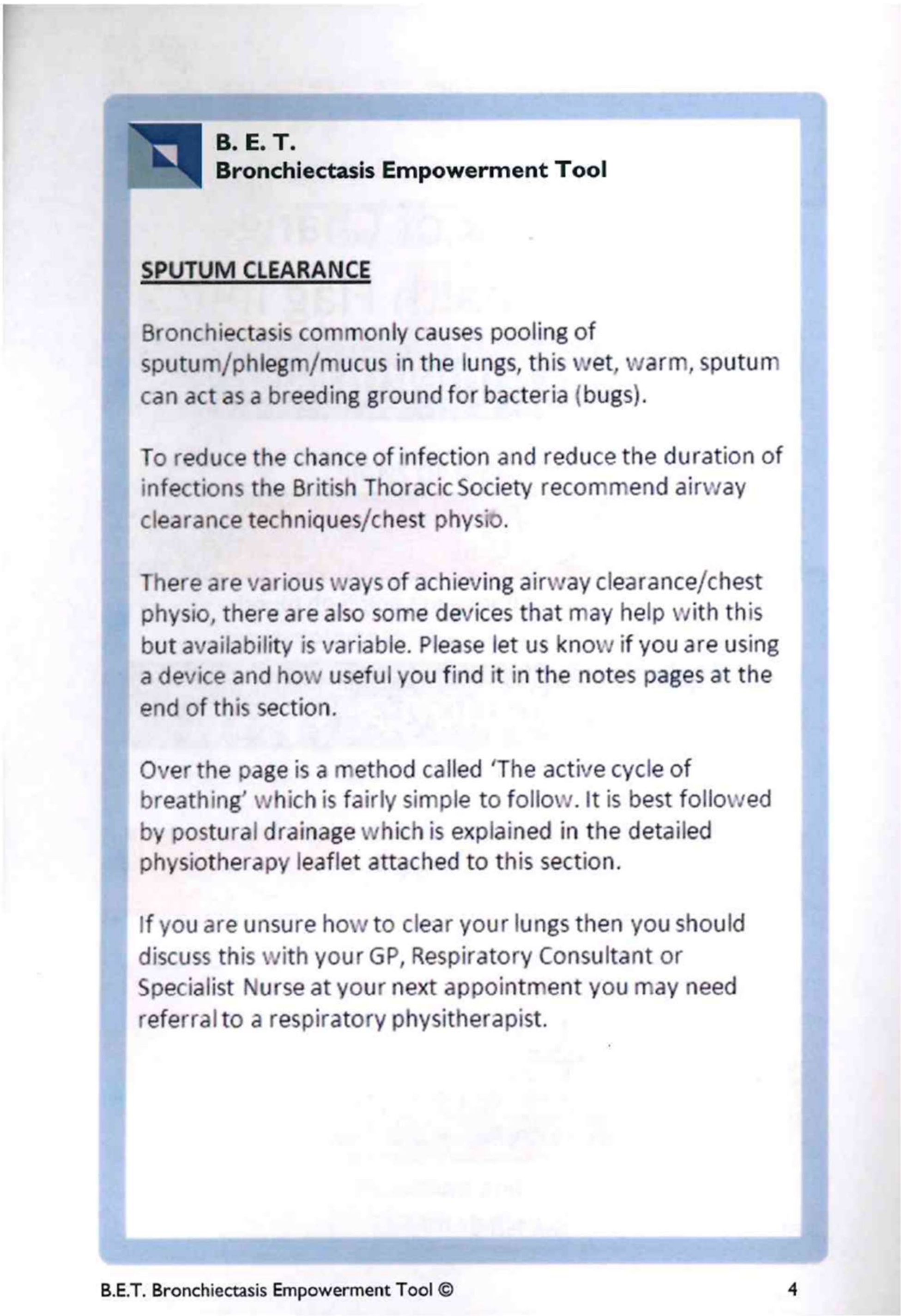
What you should do if you are experiencing:

- 1 of the symptoms from any of 3 categories above send your sputum for a test as soon as possible (to review how to send sputum see page ...).
- Any 2 of the symptoms detailed in boxes above: contact your surgery to see your GP or specialist nurse for an appointment and send your sputum for testing. If your Dr has supplied you with 'reserve antibiotics' you should start taking these after 2 days of symptoms.
- Any 3 of the symptoms described in the boxes above you require prompt treatment and should be seen the same day by your GP

**If you are experiencing severe breathlessness,
Chest pain or High Fever
Please seek URGENT Medical Attention**

Please ensure your bacterium and antibiotic treatment are noted in the sputum section of this booklet

B.E.T. Bronchiectasis Empowerment Tool © 2



B. E. T.
Bronchiectasis Empowerment Tool

SPUTUM CLEARANCE

Bronchiectasis commonly causes pooling of sputum/phlegm/mucus in the lungs, this wet, warm, sputum can act as a breeding ground for bacteria (bugs).

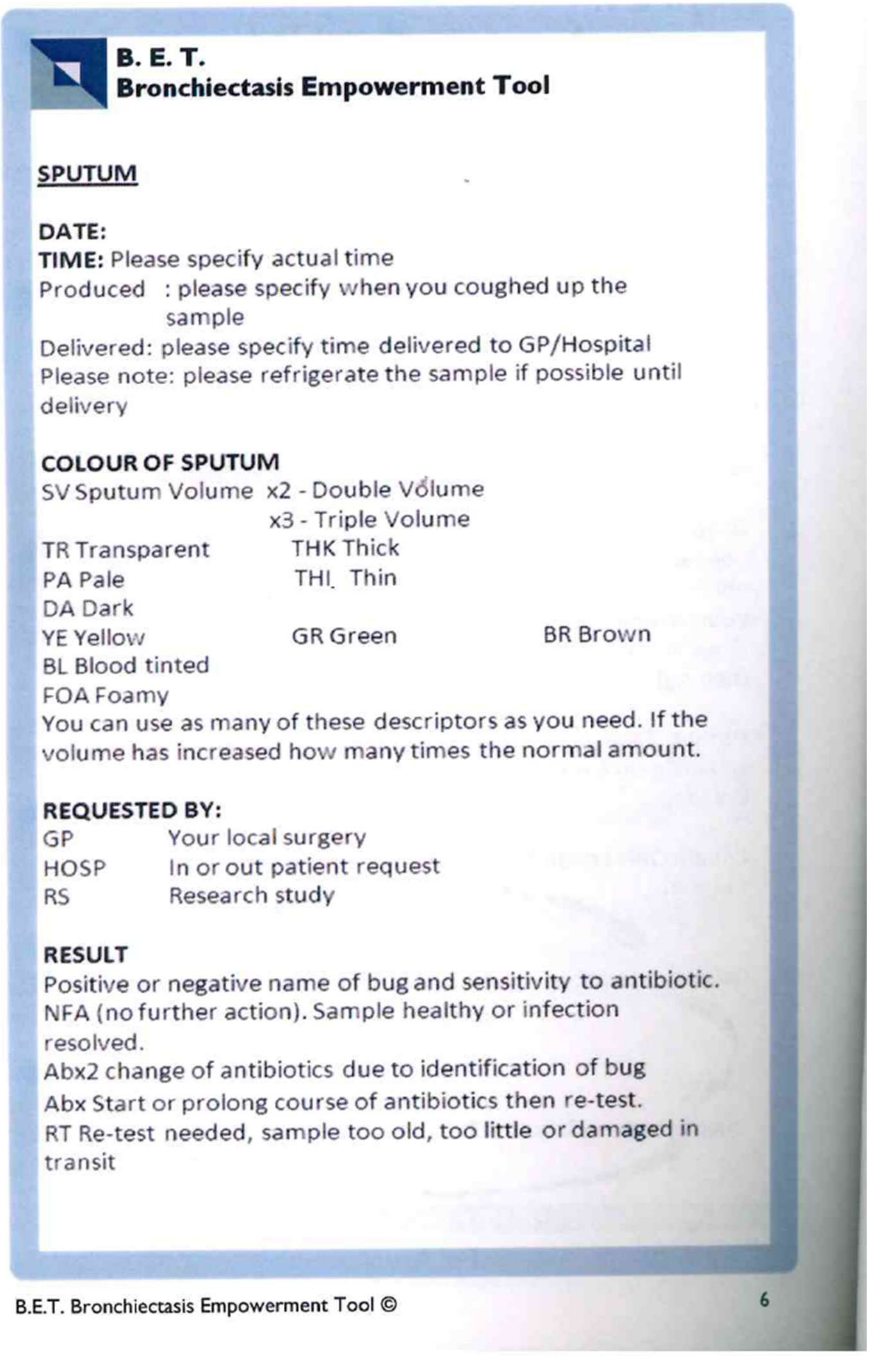
To reduce the chance of infection and reduce the duration of infections the British Thoracic Society recommend airway clearance techniques/chest physio.

There are various ways of achieving airway clearance/chest physio, there are also some devices that may help with this but availability is variable. Please let us know if you are using a device and how useful you find it in the notes pages at the end of this section.

Over the page is a method called 'The active cycle of breathing' which is fairly simple to follow. It is best followed by postural drainage which is explained in the detailed physiotherapy leaflet attached to this section.

If you are unsure how to clear your lungs then you should discuss this with your GP, Respiratory Consultant or Specialist Nurse at your next appointment you may need referral to a respiratory physitherapist.

B.E.T. Bronchiectasis Empowerment Tool © 4



B. E. T.
Bronchiectasis Empowerment Tool

SPUTUM

DATE:
TIME: Please specify actual time
Produced : please specify when you coughed up the sample
Delivered: please specify time delivered to GP/Hospital
Please note: please refrigerate the sample if possible until delivery

COLOUR OF SPUTUM
SV Sputum Volume x2 - Double Volume
x3 - Triple Volume
TR Transparent THK Thick
PA Pale THI Thin
DA Dark
YE Yellow GR Green BR Brown
BL Blood tinted
FOA Foamy
You can use as many of these descriptors as you need. If the volume has increased how many times the normal amount.

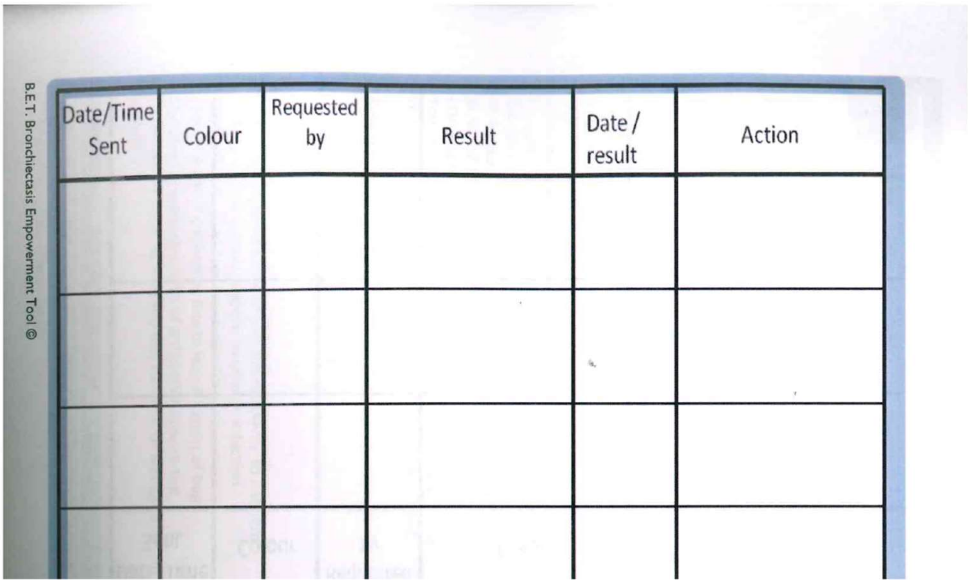
REQUESTED BY:

GP	Your local surgery
HOSP	In or out patient request
RS	Research study

RESULT
Positive or negative name of bug and sensitivity to antibiotic.
NFA (no further action). Sample healthy or infection resolved.
Abx2 change of antibiotics due to identification of bug
Abx Start or prolong course of antibiotics then re-test.
RT Re-test needed, sample too old, too little or damaged in transit

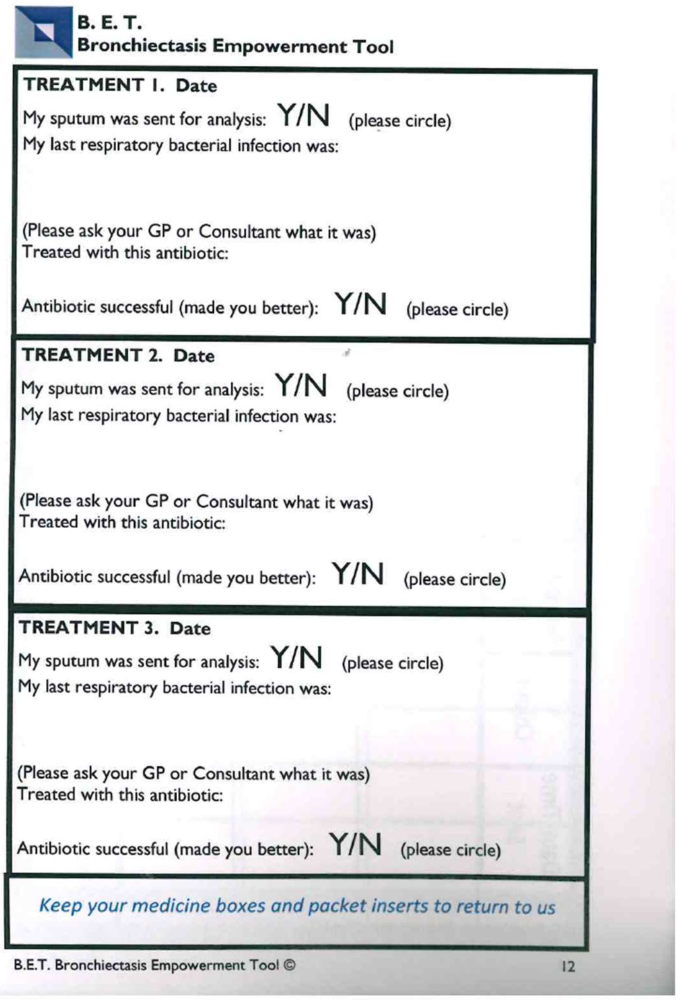
B.E.T. Bronchiectasis Empowerment Tool ©

6



B.E.T. Bronchiectasis Empowerment Tool ©

Date/Time Sent	Colour	Requested by	Result	Date / result	Action



B. E. T.
Bronchiectasis Empowerment Tool

TREATMENT 1. Date

My sputum was sent for analysis: Y/N (please circle)

My last respiratory bacterial infection was:

(Please ask your GP or Consultant what it was)

Treated with this antibiotic:

Antibiotic successful (made you better): Y/N (please circle)

TREATMENT 2. Date

My sputum was sent for analysis: Y/N (please circle)

My last respiratory bacterial infection was:

(Please ask your GP or Consultant what it was)

Treated with this antibiotic:

Antibiotic successful (made you better): Y/N (please circle)

TREATMENT 3. Date

My sputum was sent for analysis: Y/N (please circle)

My last respiratory bacterial infection was:

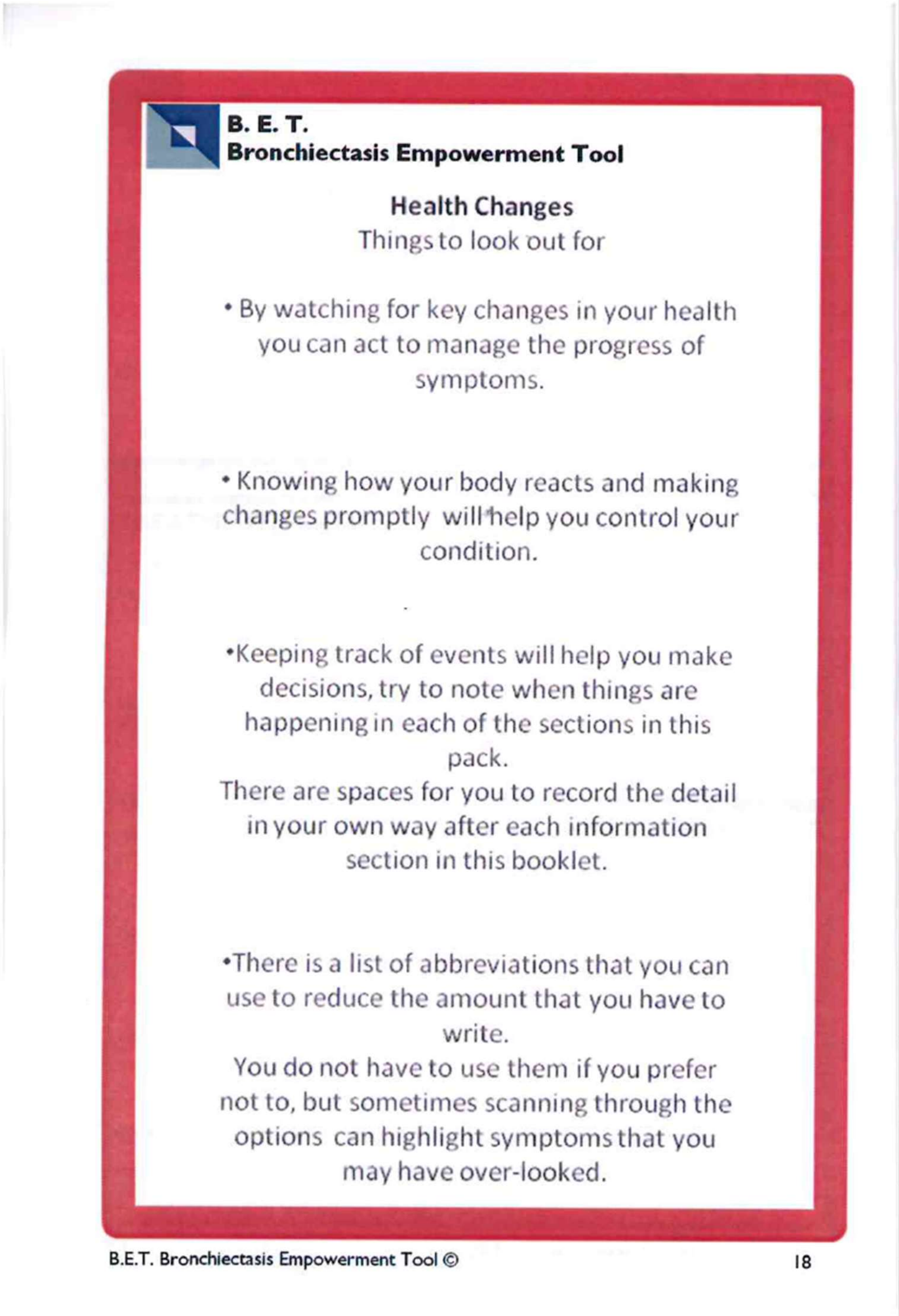
(Please ask your GP or Consultant what it was)

Treated with this antibiotic:

Antibiotic successful (made you better): Y/N (please circle)

Keep your medicine boxes and packet inserts to return to us

B.E.T. Bronchiectasis Empowerment Tool © 12



B. E. T.
Bronchiectasis Empowerment Tool

Health Changes

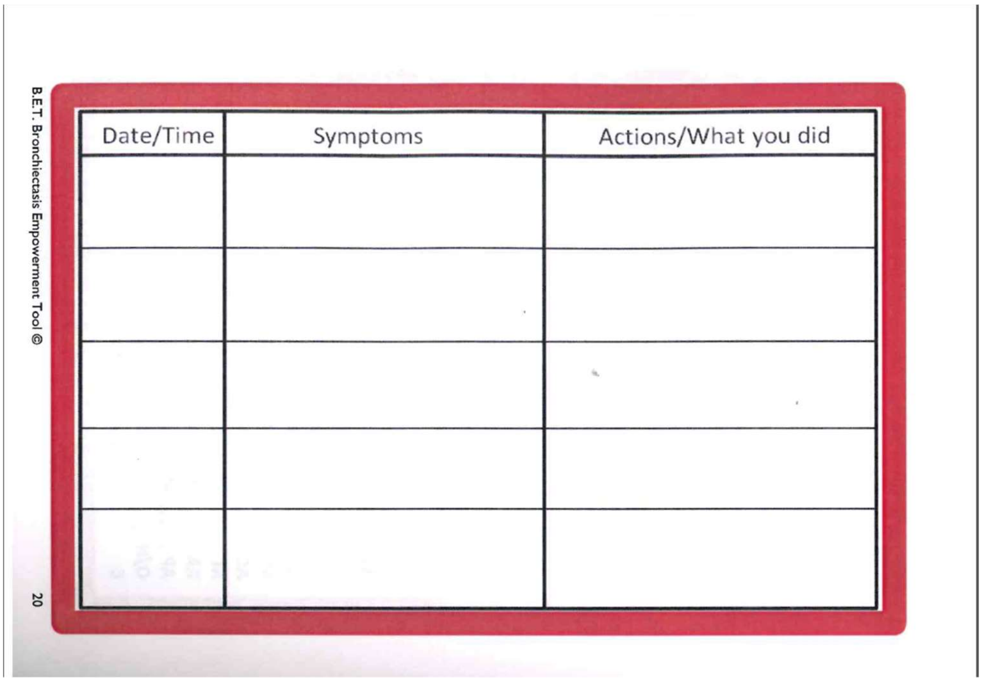
Things to look out for

- By watching for key changes in your health you can act to manage the progress of symptoms.

- Knowing how your body reacts and making changes promptly will help you control your condition.

- Keeping track of events will help you make decisions, try to note when things are happening in each of the sections in this pack.
  There are spaces for you to record the detail in your own way after each information section in this booklet.

- There is a list of abbreviations that you can use to reduce the amount that you have to write.
  You do not have to use them if you prefer not to, but sometimes scanning through the options can highlight symptoms that you may have over-looked.



Date/Time	Symptoms	Actions/What you did

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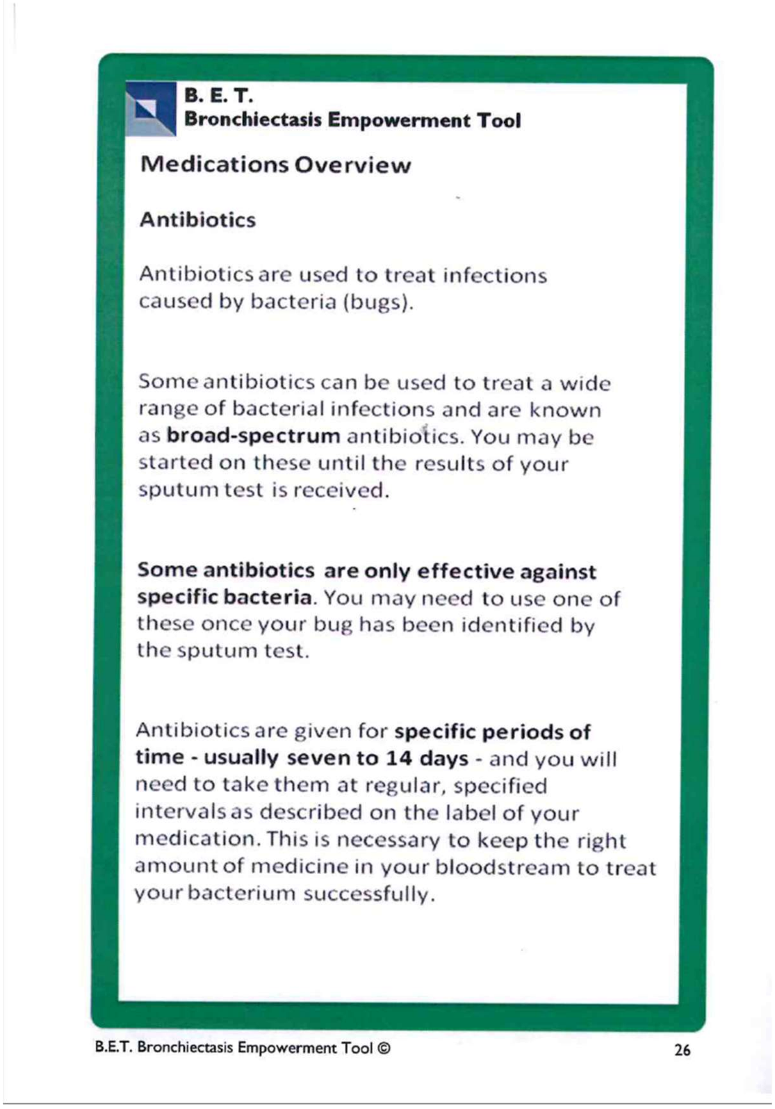


B. E. T.
Bronchiectasis Empowerment Tool

Medications Overview

Antibiotics

Antibiotics are used to treat infections caused by bacteria (bugs).

Some antibiotics can be used to treat a wide range of bacterial infections and are known as **broad-spectrum** antibiotics. You may be started on these until the results of your sputum test is received.

Some antibiotics are only effective against specific bacteria. You may need to use one of these once your bug has been identified by the sputum test.

Antibiotics are given for **specific periods of time - usually seven to 14 days** - and you will need to take them at regular, specified intervals as described on the label of your medication. This is necessary to keep the right amount of medicine in your bloodstream to treat your bacterium successfully.

B.E.T. Bronchiectasis Empowerment Tool © 26

B. E. T.
Bronchiectasis Empowerment Tool

Medications Overview

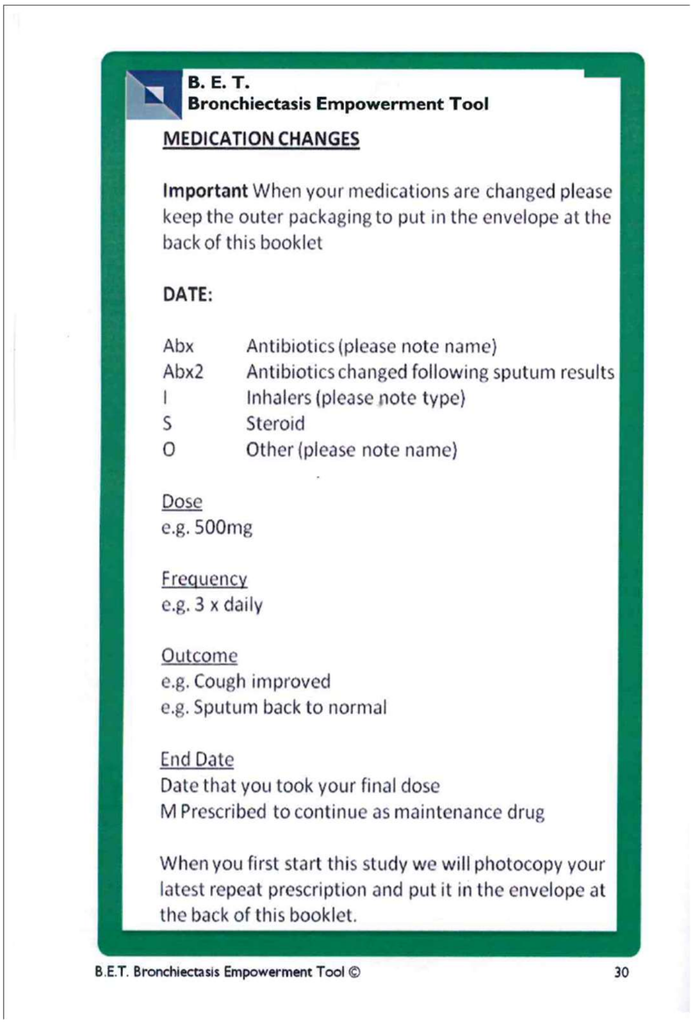
Antibiotics Continued…
Safety with other medications
Certain antibiotics (penicillins and others) can stop the contraceptive pill from working properly, check with your pharmacist or doctor. Diarrhoea or vomiting symptoms whilst taking an antibiotic, may prevent your contraceptive pill from being absorbed properly into your body you should use additional barrier contraception (such as condoms). Some antibiotics react with other medicines – check with your pharmacist.

Antibiotics are sometimes made breathable (nebulised) this is not yet a mainstream treatment but may be recommended by your doctor.

Other Respiratory Medications
Inhalers (puffers), nebulisers (mist machine).

A variety of medications are available to inhale (breathe in) these mostly work to open your airways so that it feels easier to get the air in. Those containing steroids bring down the swelling in your lungs and make it easier to breathe, you should rinse your mouth after taking these.

Sometimes a salt water solution called saline is nebulised (made into a breathable mist) to help moisten and loosen the sputum (phlegm) in your chest so that you can cough or huff it up and out.



B. E. T.
Bronchiectasis Empowerment Tool

MEDICATION CHANGES

Important When your medications are changed please keep the outer packaging to put in the envelope at the back of this booklet

DATE:

Abx	Antibiotics (please note name)
Abx2	Antibiotics changed following sputum results
I	Inhalers (please note type)
S	Steroid
O	Other (please note name)

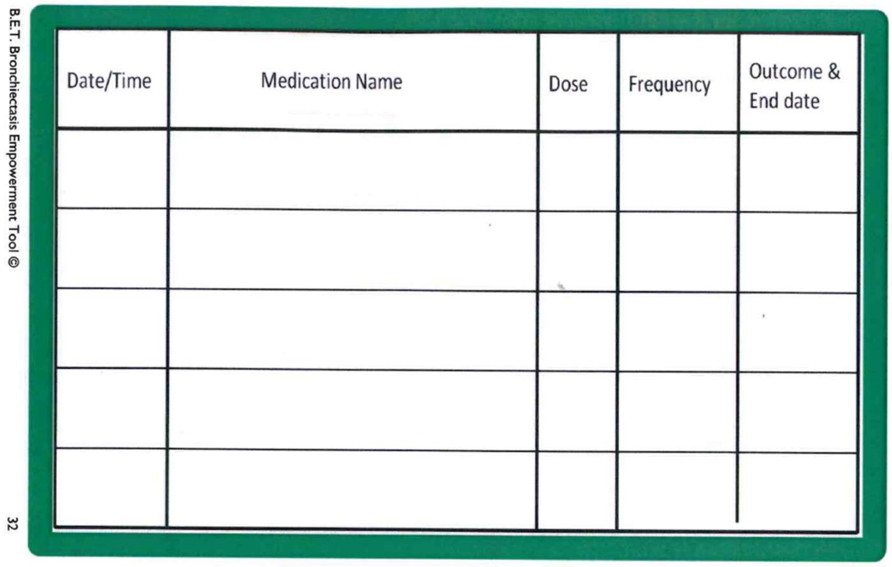
Dose
e.g. 500mg

Frequency
e.g. 3 x daily

Outcome
e.g. Cough improved
e.g. Sputum back to normal

End Date
Date that you took your final dose
M Prescribed to continue as maintenance drug

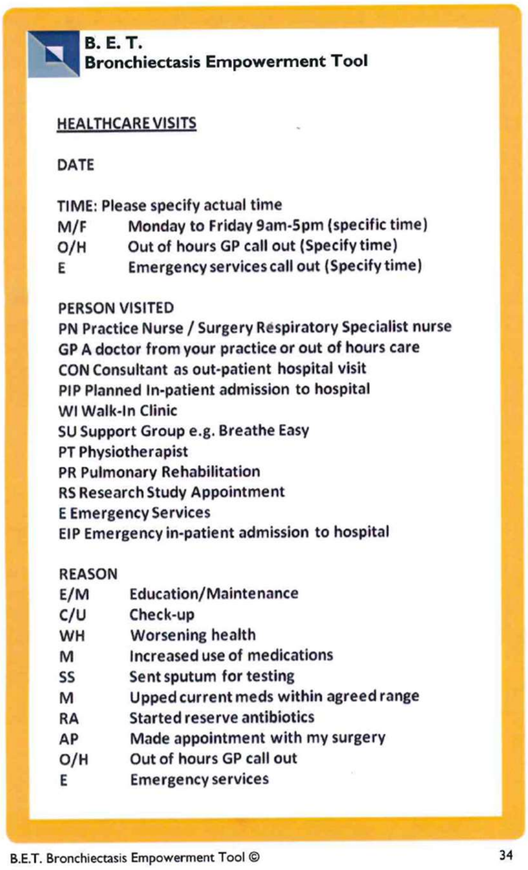
When you first start this study we will photocopy your latest repeat prescription and put it in the envelope at the back of this booklet.



B.E.T. Bronchiectasis Empowerment Tool ©

Date/Time	Medication Name	Dose	Frequency	Outcome & End date

32



B. E. T.
Bronchiectasis Empowerment Tool

HEALTHCARE VISITS

DATE

TIME: Please specify actual time

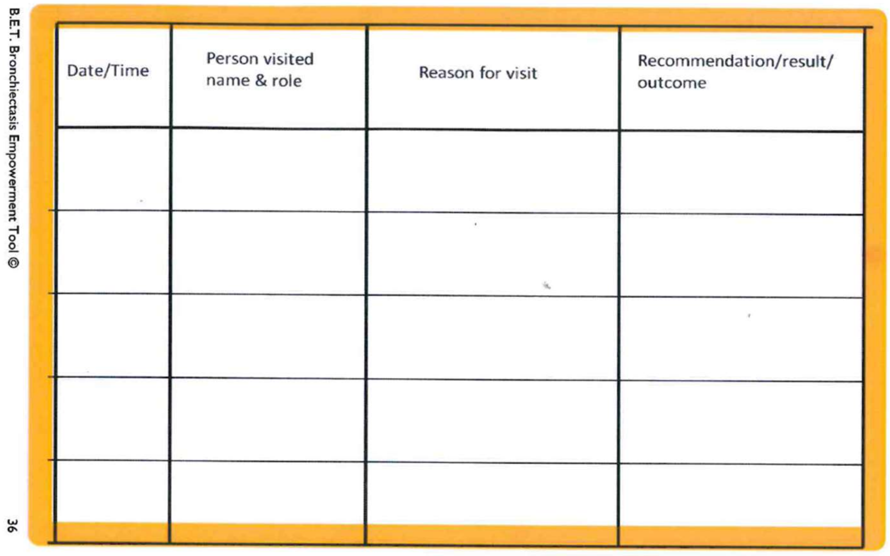
M/F	Monday to Friday 9am-5pm (specific time)
O/H	Out of hours GP call out (Specify time)
E	Emergency services call out (Specify time)

PERSON VISITED
PN Practice Nurse / Surgery Respiratory Specialist nurse
GP A doctor from your practice or out of hours care
CON Consultant as out-patient hospital visit
PIP Planned In-patient admission to hospital
WI Walk-In Clinic
SU Support Group e.g. Breathe Easy
PT Physiotherapist
PR Pulmonary Rehabilitation
RS Research Study Appointment
E Emergency Services
EIP Emergency in-patient admission to hospital

REASON

E/M	Education/Maintenance
C/U	Check-up
WH	Worsening health
M	Increased use of medications
SS	Sent sputum for testing
M	Upped current meds within agreed range
RA	Started reserve antibiotics
AP	Made appointment with my surgery
O/H	Out of hours GP call out
E	Emergency services

B.E.T. Bronchiectasis Empowerment Tool © 34

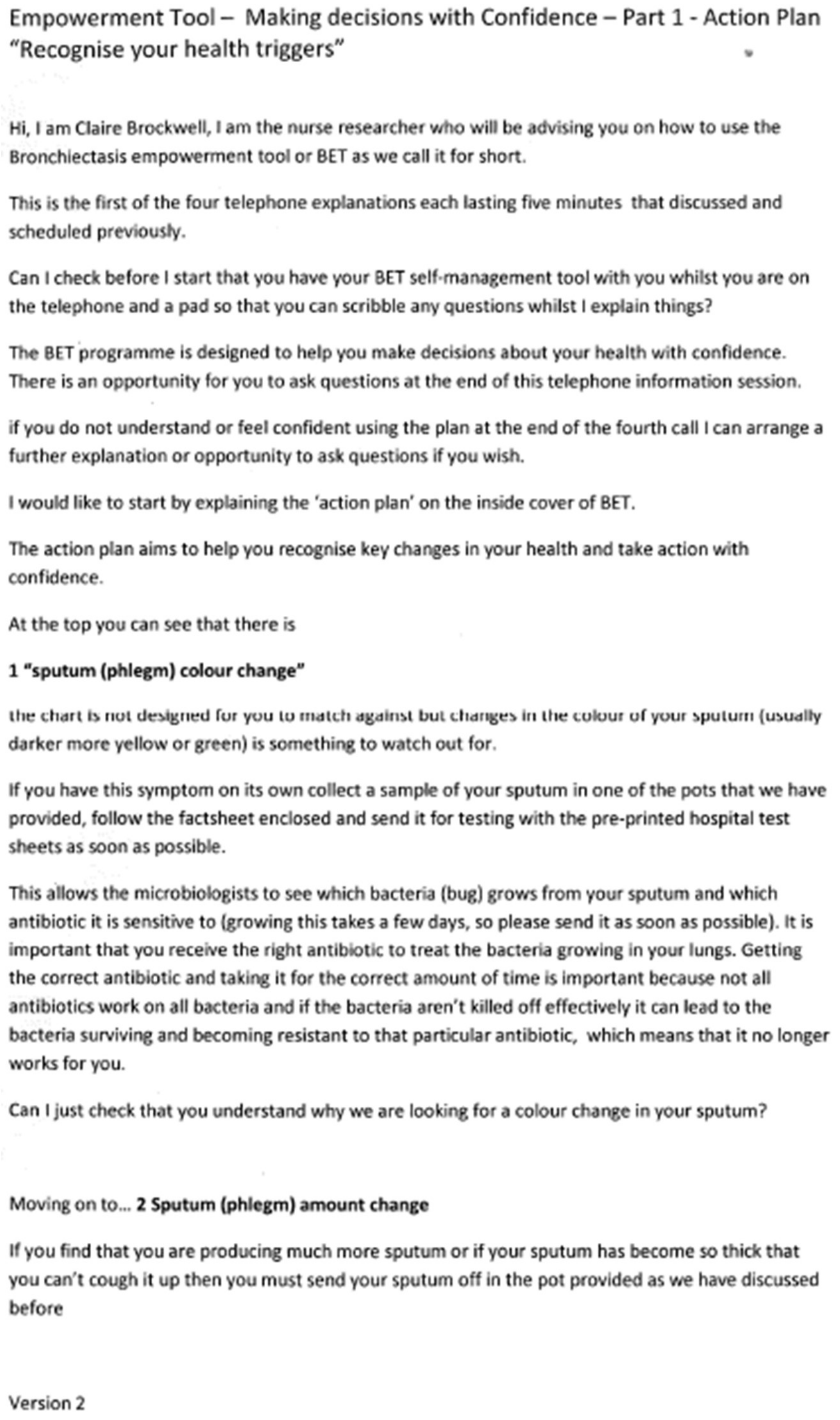


Date/Time	Person visited name & role	Reason for visit	Recommendation/result/ outcome

B.E.T. Bronchiectasis Empowerment Tool ©

36

Appendix 14: Topic guide for telephone education



Empowerment Tool – Making decisions with Confidence – Part 1 - Action Plan
"Recognise your health triggers"

Hi, I am Claire Brockwell, I am the nurse researcher who will be advising you on how to use the Bronchiectasis empowerment tool or BET as we call it for short.

This is the first of the four telephone explanations each lasting five minutes that discussed and scheduled previously.

Can I check before I start that you have your BET self-management tool with you whilst you are on the telephone and a pad so that you can scribble any questions whilst I explain things?

The BET programme is designed to help you make decisions about your health with confidence. There is an opportunity for you to ask questions at the end of this telephone information session.

if you do not understand or feel confident using the plan at the end of the fourth call I can arrange a further explanation or opportunity to ask questions if you wish.

I would like to start by explaining the 'action plan' on the inside cover of BET.

The action plan aims to help you recognise key changes in your health and take action with confidence.

At the top you can see that there is

1 "sputum (phlegm) colour change"

the chart is not designed for you to match against but changes in the colour of your sputum (usually darker more yellow or green) is something to watch out for.

If you have this symptom on its own collect a sample of your sputum in one of the pots that we have provided, follow the factsheet enclosed and send it for testing with the pre-printed hospital test sheets as soon as possible.

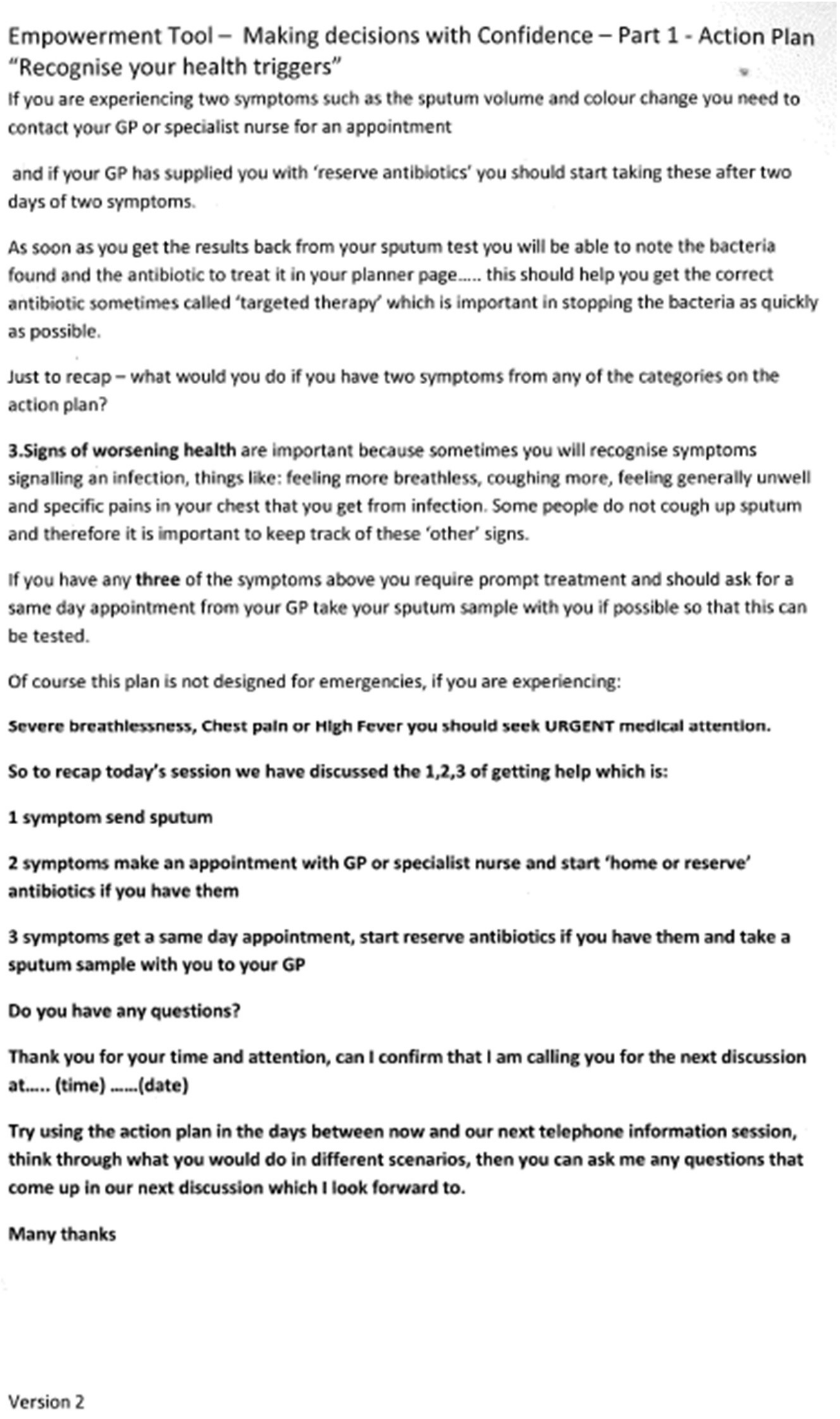
This allows the microbiologists to see which bacteria (bug) grows from your sputum and which antibiotic it is sensitive to (growing this takes a few days, so please send it as soon as possible). It is important that you receive the right antibiotic to treat the bacteria growing in your lungs. Getting the correct antibiotic and taking it for the correct amount of time is important because not all antibiotics work on all bacteria and if the bacteria aren't killed off effectively it can lead to the bacteria surviving and becoming resistant to that particular antibiotic, which means that it no longer works for you.

Can I just check that you understand why we are looking for a colour change in your sputum?

Moving on to... **2 Sputum (phlegm) amount change**

If you find that you are producing much more sputum or if your sputum has become so thick that you can't cough it up then you must send your sputum off in the pot provided as we have discussed before

Version 2



Empowerment Tool – Making decisions with Confidence – Part 1 - Action Plan “Recognise your health triggers”

If you are experiencing two symptoms such as the sputum volume and colour change you need to contact your GP or specialist nurse for an appointment

and if your GP has supplied you with ‘reserve antibiotics’ you should start taking these after two days of two symptoms.

As soon as you get the results back from your sputum test you will be able to note the bacteria found and the antibiotic to treat it in your planner page….. this should help you get the correct antibiotic sometimes called ‘targeted therapy’ which is important in stopping the bacteria as quickly as possible.

Just to recap – what would you do if you have two symptoms from any of the categories on the action plan?

3.Signs of worsening health are important because sometimes you will recognise symptoms signalling an infection, things like: feeling more breathless, coughing more, feeling generally unwell and specific pains in your chest that you get from infection. Some people do not cough up sputum and therefore it is important to keep track of these ‘other’ signs.

If you have any **three** of the symptoms above you require prompt treatment and should ask for a same day appointment from your GP take your sputum sample with you if possible so that this can be tested.

Of course this plan is not designed for emergencies, if you are experiencing:

Severe breathlessness, Chest pain or High Fever you should seek URGENT medical attention.

So to recap today’s session we have discussed the 1,2,3 of getting help which is:

1 symptom send sputum

2 symptoms make an appointment with GP or specialist nurse and start ‘home or reserve’ antibiotics if you have them

3 symptoms get a same day appointment, start reserve antibiotics if you have them and take a sputum sample with you to your GP

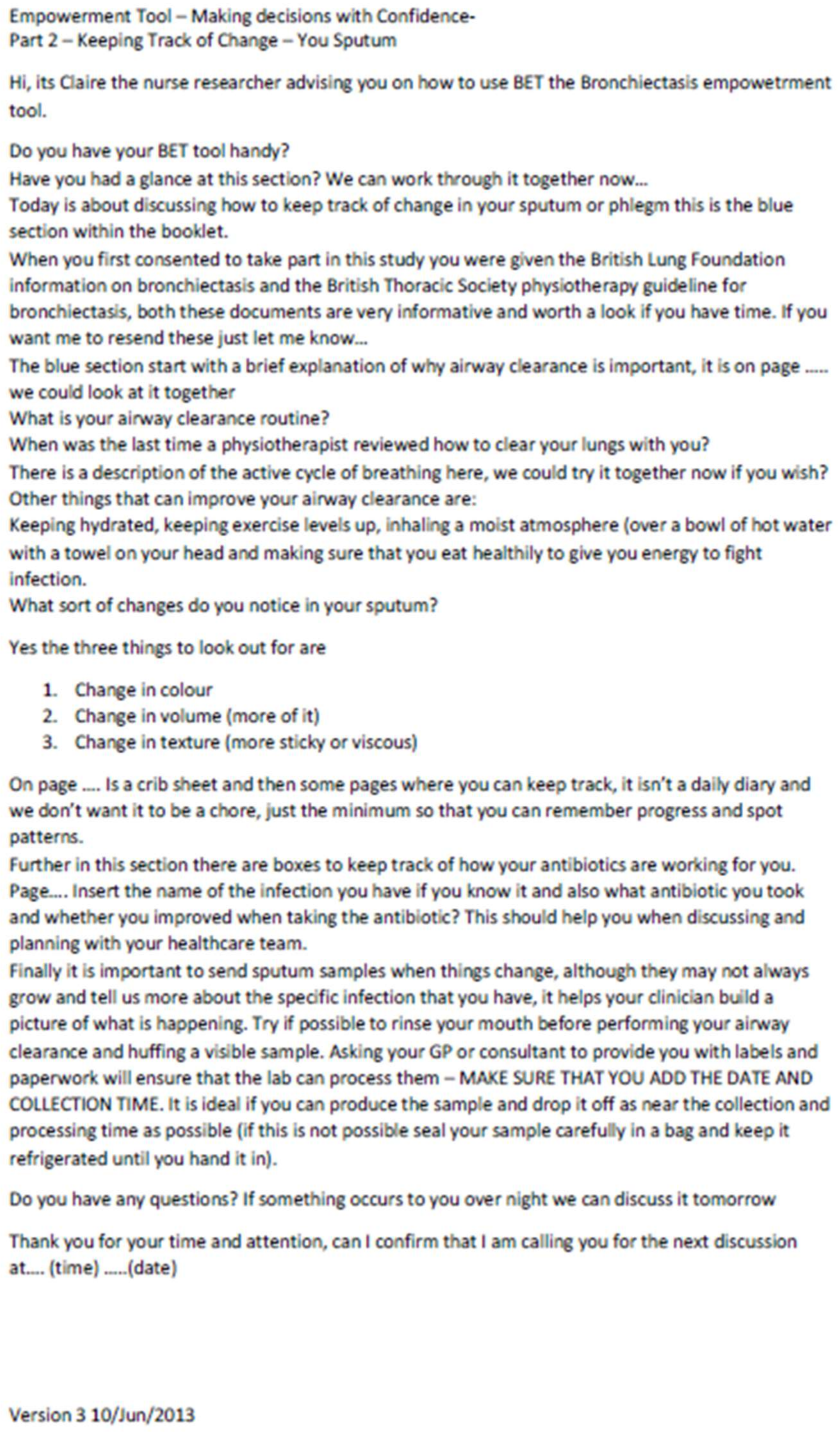
Do you have any questions?

Thank you for your time and attention, can I confirm that I am calling you for the next discussion at….. (time) ……(date)

Try using the action plan in the days between now and our next telephone information session, think through what you would do in different scenarios, then you can ask me any questions that come up in our next discussion which I look forward to.

Many thanks

Version 2



Empowerment Tool – Making decisions with Confidence-
Part 2 – Keeping Track of Change – You Sputum

Hi, its Claire the nurse researcher advising you on how to use BET the Bronchiectasis empowetrment tool.

Do you have your BET tool handy?
Have you had a glance at this section? We can work through it together now…
Today is about discussing how to keep track of change in your sputum or phlegm this is the blue section within the booklet.
When you first consented to take part in this study you were given the British Lung Foundation information on bronchiectasis and the British Thoracic Society physiotherapy guideline for bronchiectasis, both these documents are very informative and worth a look if you have time. If you want me to resend these just let me know…
The blue section start with a brief explanation of why airway clearance is important, it is on page ….. we could look at it together
What is your airway clearance routine?
When was the last time a physiotherapist reviewed how to clear your lungs with you?
There is a description of the active cycle of breathing here, we could try it together now if you wish?
Other things that can improve your airway clearance are:
Keeping hydrated, keeping exercise levels up, inhaling a moist atmosphere (over a bowl of hot water with a towel on your head and making sure that you eat healthily to give you energy to fight infection.
What sort of changes do you notice in your sputum?

Yes the three things to look out for are

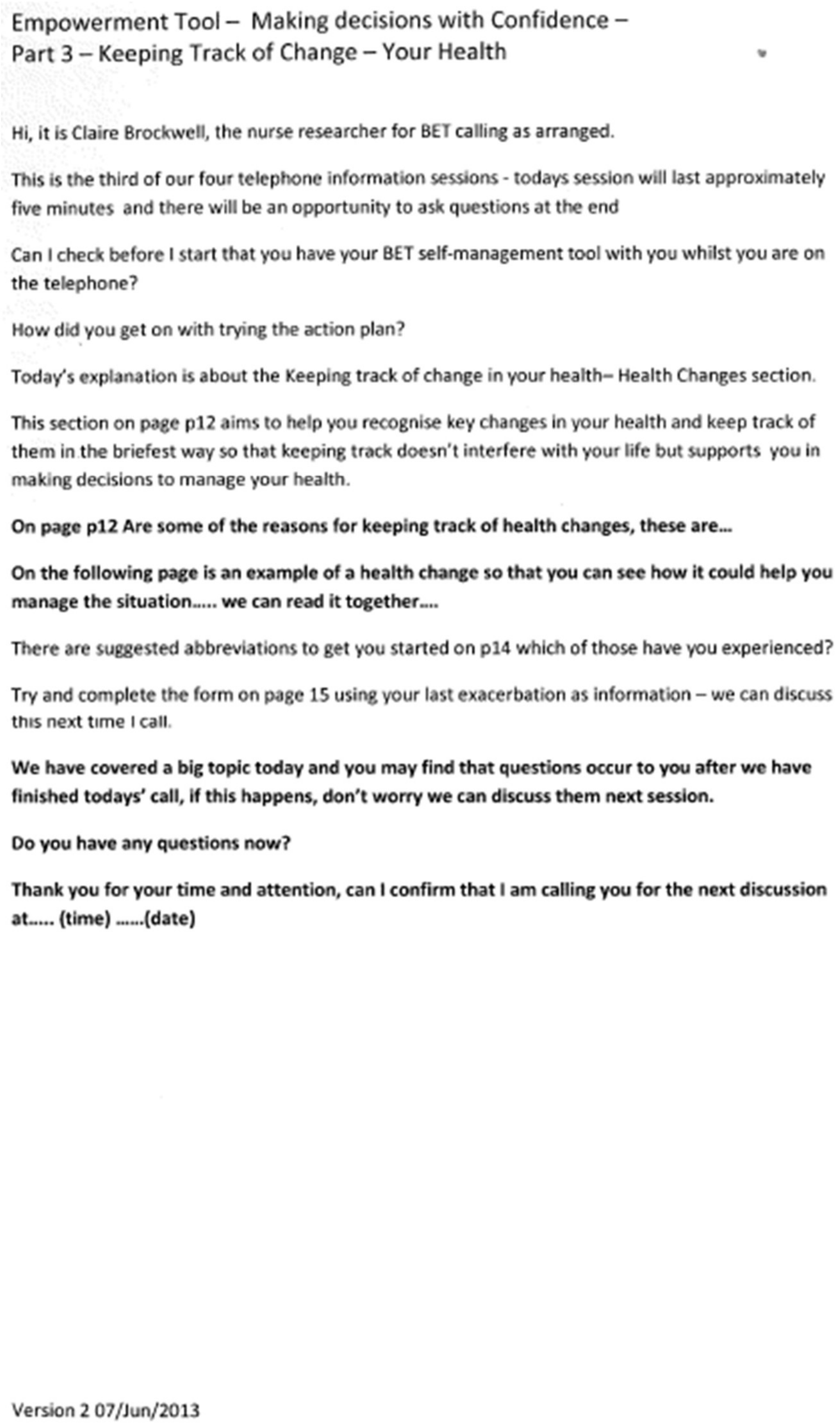
1. Change in colour
2. Change in volume (more of it)
3. Change in texture (more sticky or viscous)

On page …. Is a crib sheet and then some pages where you can keep track, it isn't a daily diary and we don't want it to be a chore, just the minimum so that you can remember progress and spot patterns.
Further in this section there are boxes to keep track of how your antibiotics are working for you. Page…. Insert the name of the infection you have if you know it and also what antibiotic you took and whether you improved when taking the antibiotic? This should help you when discussing and planning with your healthcare team.
Finally it is important to send sputum samples when things change, although they may not always grow and tell us more about the specific infection that you have, it helps your clinician build a picture of what is happening. Try if possible to rinse your mouth before performing your airway clearance and huffing a visible sample. Asking your GP or consultant to provide you with labels and paperwork will ensure that the lab can process them – MAKE SURE THAT YOU ADD THE DATE AND COLLECTION TIME. It is ideal if you can produce the sample and drop it off as near the collection and processing time as possible (if this is not possible seal your sample carefully in a bag and keep it refrigerated until you hand it in).

Do you have any questions? If something occurs to you over night we can discuss it tomorrow

Thank you for your time and attention, can I confirm that I am calling you for the next discussion at…. (time) …..(date)

Version 3 10/Jun/2013



Empowerment Tool – Making decisions with Confidence – Part 3 – Keeping Track of Change – Your Health

Hi, it is Claire Brockwell, the nurse researcher for BET calling as arranged.

This is the third of our four telephone information sessions - todays session will last approximately five minutes and there will be an opportunity to ask questions at the end

Can I check before I start that you have your BET self-management tool with you whilst you are on the telephone?

How did you get on with trying the action plan?

Today's explanation is about the Keeping track of change in your health– Health Changes section.

This section on page p12 aims to help you recognise key changes in your health and keep track of them in the briefest way so that keeping track doesn't interfere with your life but supports you in making decisions to manage your health.

On page p12 Are some of the reasons for keeping track of health changes, these are…

On the following page is an example of a health change so that you can see how it could help you manage the situation….. we can read it together….

There are suggested abbreviations to get you started on p14 which of those have you experienced?

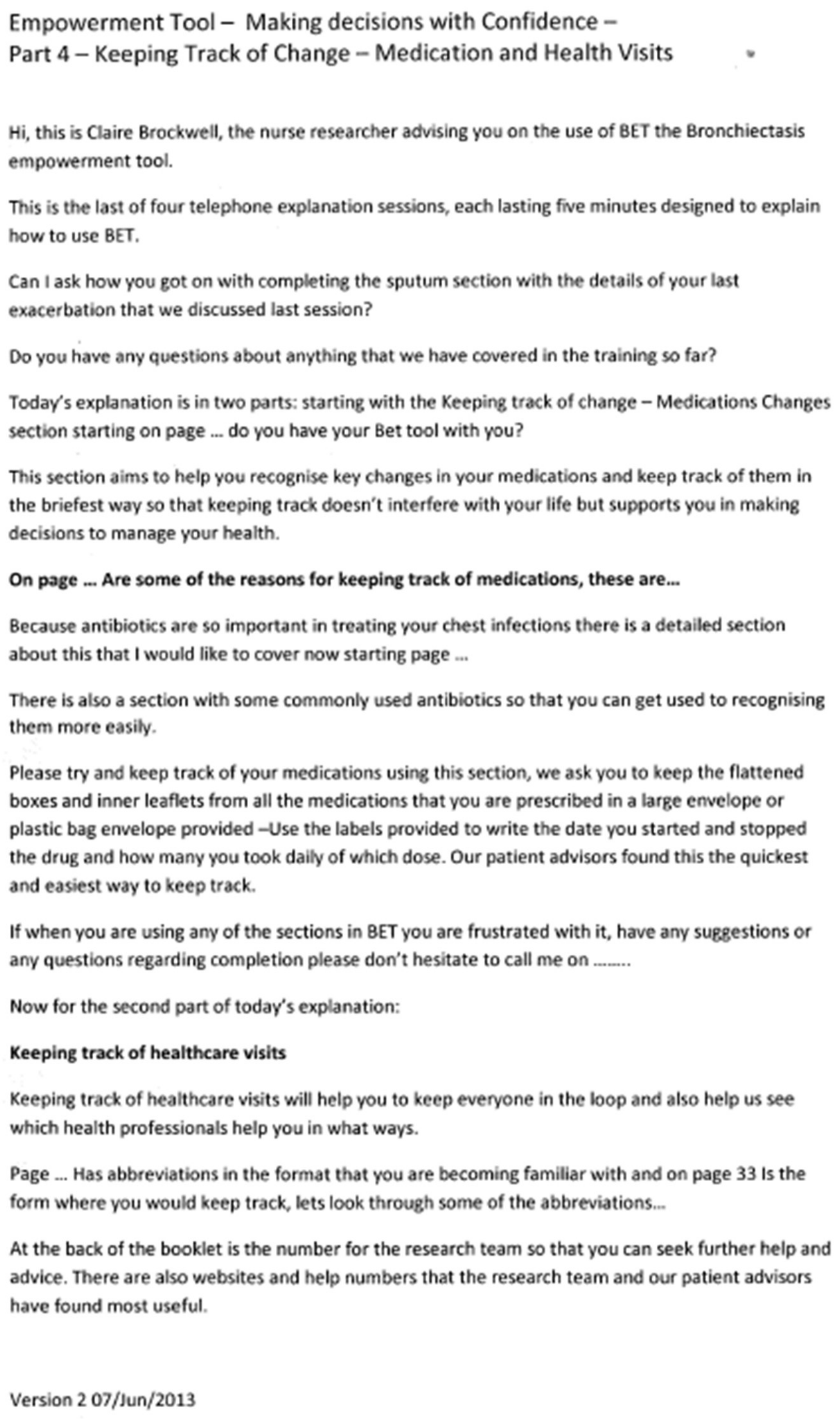
Try and complete the form on page 15 using your last exacerbation as information – we can discuss this next time I call.

We have covered a big topic today and you may find that questions occur to you after we have finished todays' call, if this happens, don't worry we can discuss them next session.

Do you have any questions now?

Thank you for your time and attention, can I confirm that I am calling you for the next discussion at….. (time) ……(date)

Version 2 07/Jun/2013



Empowerment Tool – Making decisions with Confidence –
Part 4 – Keeping Track of Change – Medication and Health Visits

Hi, this is Claire Brockwell, the nurse researcher advising you on the use of BET the Bronchiectasis empowerment tool.

This is the last of four telephone explanation sessions, each lasting five minutes designed to explain how to use BET.

Can I ask how you got on with completing the sputum section with the details of your last exacerbation that we discussed last session?

Do you have any questions about anything that we have covered in the training so far?

Today's explanation is in two parts: starting with the Keeping track of change – Medications Changes section starting on page ... do you have your Bet tool with you?

This section aims to help you recognise key changes in your medications and keep track of them in the briefest way so that keeping track doesn't interfere with your life but supports you in making decisions to manage your health.

On page ... Are some of the reasons for keeping track of medications, these are...

Because antibiotics are so important in treating your chest infections there is a detailed section about this that I would like to cover now starting page ...

There is also a section with some commonly used antibiotics so that you can get used to recognising them more easily.

Please try and keep track of your medications using this section, we ask you to keep the flattened boxes and inner leaflets from all the medications that you are prescribed in a large envelope or plastic bag envelope provided –Use the labels provided to write the date you started and stopped the drug and how many you took daily of which dose. Our patient advisors found this the quickest and easiest way to keep track.

If when you are using any of the sections in BET you are frustrated with it, have any suggestions or any questions regarding completion please don't hesitate to call me on ....

Now for the second part of today's explanation:

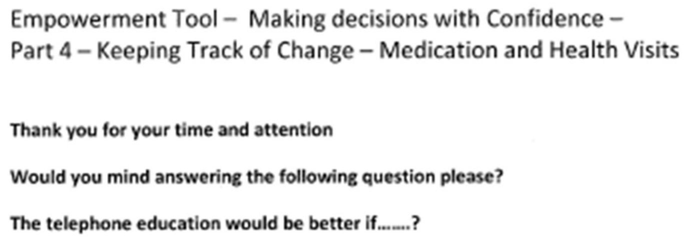
Keeping track of healthcare visits

Keeping track of healthcare visits will help you to keep everyone in the loop and also help us see which health professionals help you in what ways.

Page ... Has abbreviations in the format that you are becoming familiar with and on page 33 Is the form where you would keep track, lets look through some of the abbreviations...

At the back of the booklet is the number for the research team so that you can seek further help and advice. There are also websites and help numbers that the research team and our patient advisors have found most useful.

Version 2 07/Jun/2013



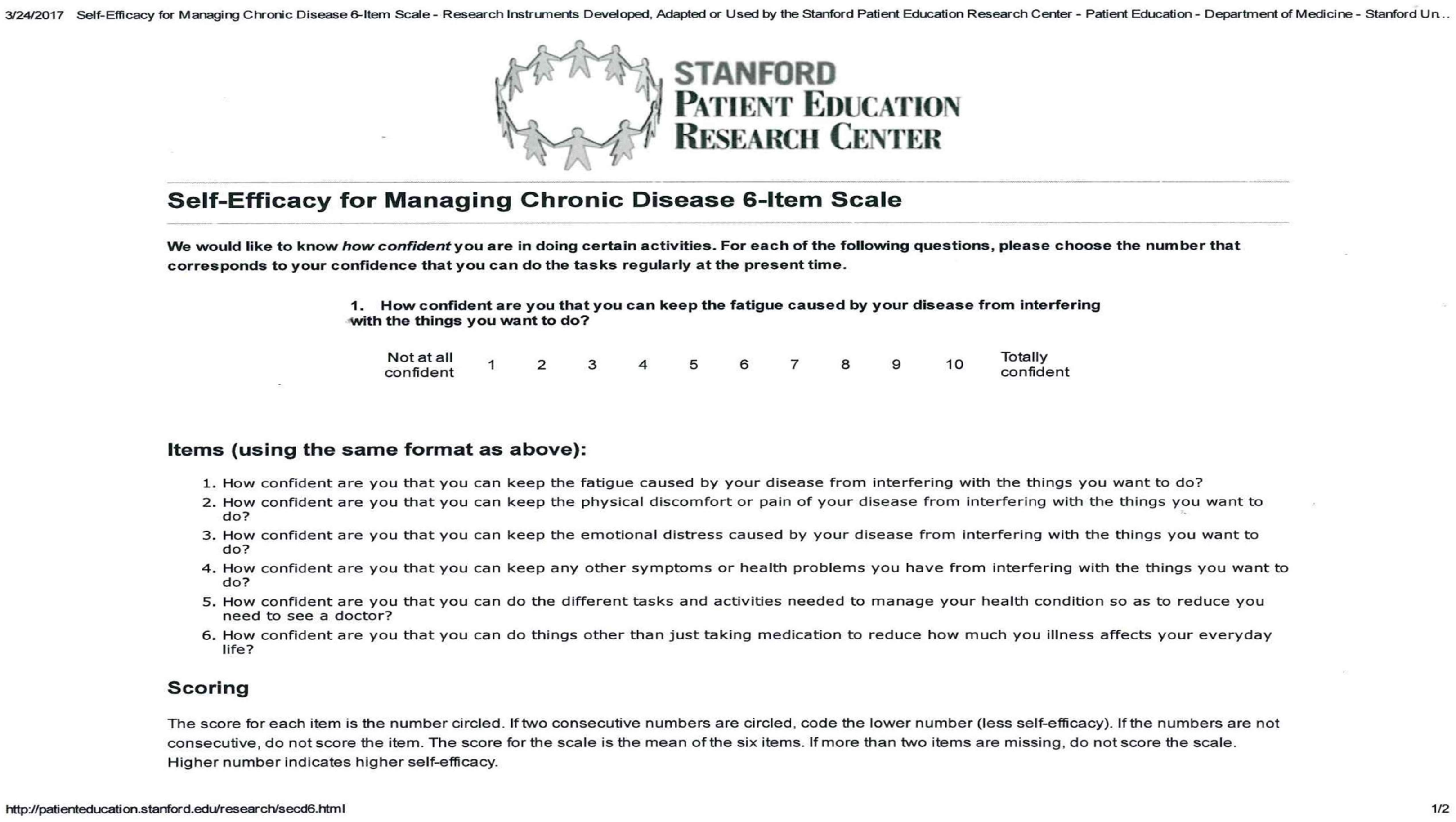
Empowerment Tool – Making decisions with Confidence –
Part 4 – Keeping Track of Change – Medication and Health Visits

Thank you for your time and attention

Would you mind answering the following question please?

The telephone education would be better if.......?

Appendix 15: SEMCD Primary Outcome for BET



3/24/2017 Self-Efficacy for Managing Chronic Disease 6-Item Scale - Research Instruments Developed, Adapted or Used by the Stanford Patient Education Research Center - Patient Education - Department of Medicine - Stanford Un...

STANFORD
PATIENT EDUCATION
RESEARCH CENTER

Self-Efficacy for Managing Chronic Disease 6-Item Scale

We would like to know *how confident* you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all confident	1	2	3	4	5	6	7	8	9	10	Totally confident

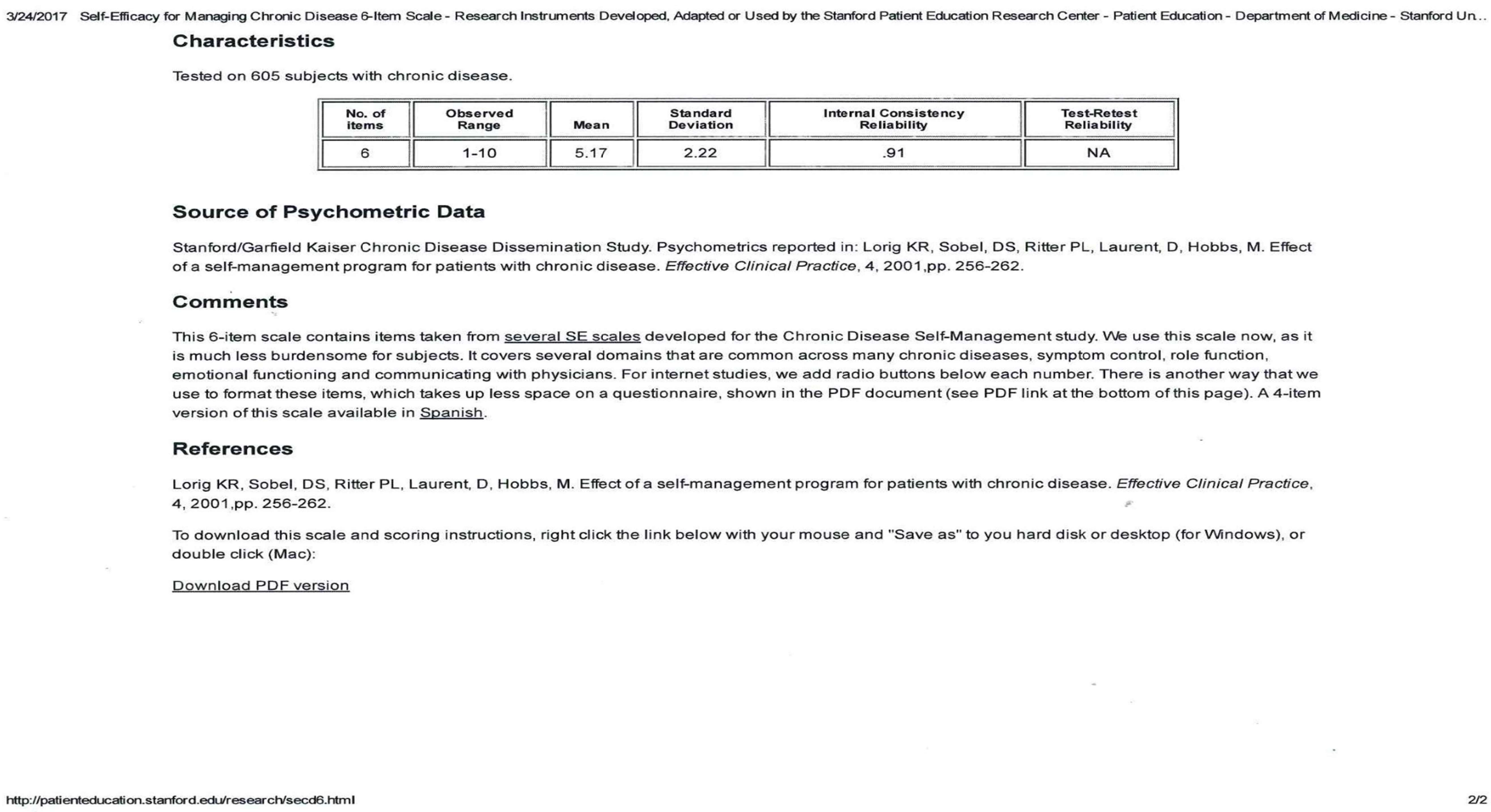
Items (using the same format as above):

1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?
2. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
3. How confident are you that you can keep the emotional distress caused by your disease from interfering with the things you want to do?
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
5. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce you need to see a doctor?
6. How confident are you that you can do things other than just taking medication to reduce how much you illness affects your everyday life?

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for the scale is the mean of the six items. If more than two items are missing, do not score the scale. Higher number indicates higher self-efficacy.

http://patienteducation.stanford.edu/research/secd6.html 1/2



Characteristics

Tested on 605 subjects with chronic disease.

No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
6	1-10	5.17	2.22	.91	NA

Source of Psychometric Data

Stanford/Garfield Kaiser Chronic Disease Dissemination Study. Psychometrics reported in: Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

Comments

This 6-item scale contains items taken from several SE scales developed for the Chronic Disease Self-Management study. We use this scale now, as it is much less burdensome for subjects. It covers several domains that are common across many chronic diseases, symptom control, role function, emotional functioning and communicating with physicians. For internet studies, we add radio buttons below each number. There is another way that we use to format these items, which takes up less space on a questionnaire, shown in the PDF document (see PDF link at the bottom of this page). A 4-item version of this scale available in Spanish.

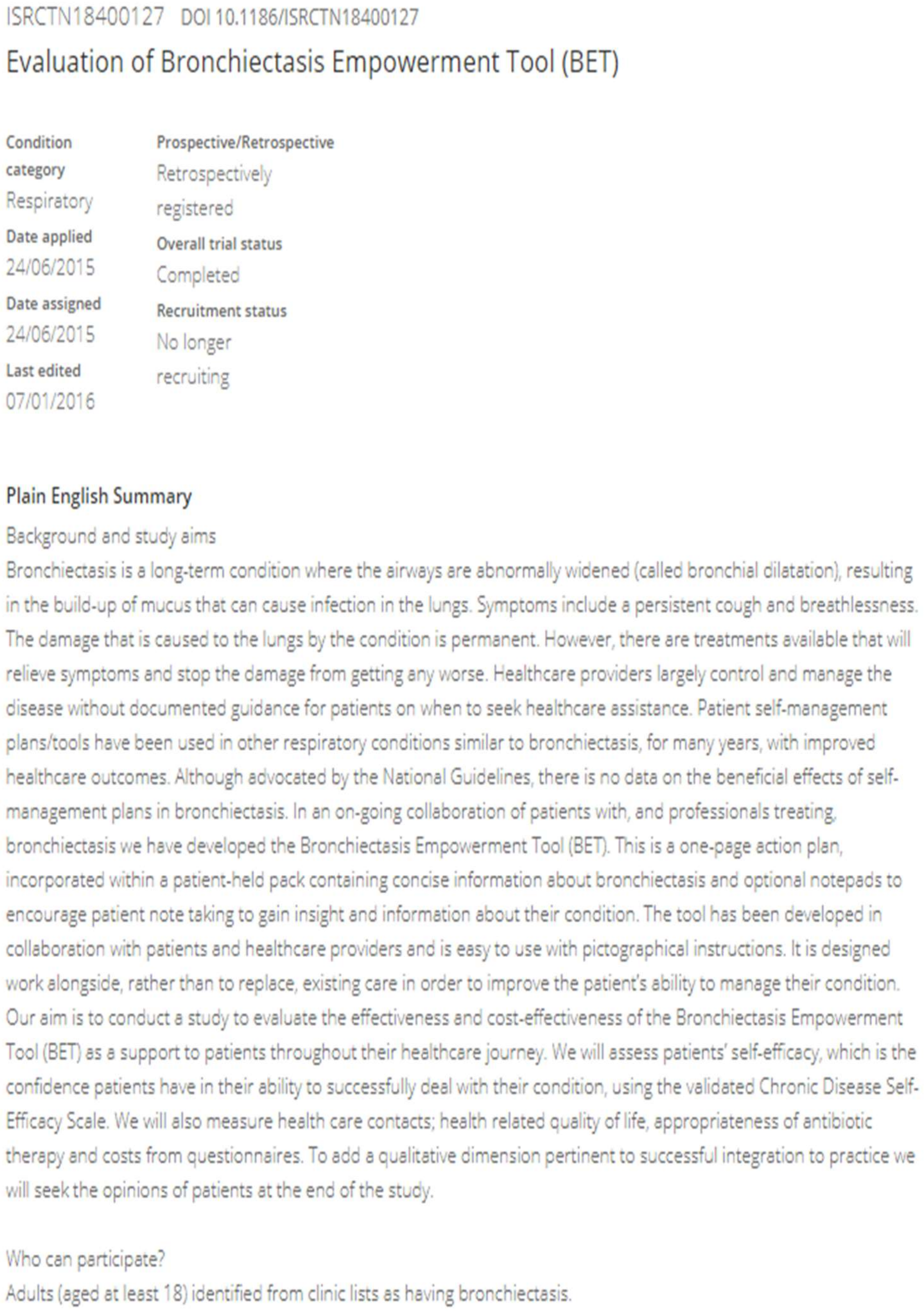
References

Lorig KR, Sobel, DS, Ritter PL, Laurent, D, Hobbs, M. Effect of a self-management program for patients with chronic disease. *Effective Clinical Practice*, 4, 2001,pp. 256-262.

To download this scale and scoring instructions, right click the link below with your mouse and "Save as" to you hard disk or desktop (for Windows), or double click (Mac):

Download PDF version

Appendix 16 ISRCTN Registration



ISRCTN18400127 DOI 10.1186/ISRCTN18400127

Evaluation of Bronchiectasis Empowerment Tool (BET)

Condition category
Respiratory

Date applied
24/06/2015

Date assigned
24/06/2015

Last edited
07/01/2016

Prospective/Retrospective
Retrospectively registered

Overall trial status
Completed

Recruitment status
No longer recruiting

Plain English Summary

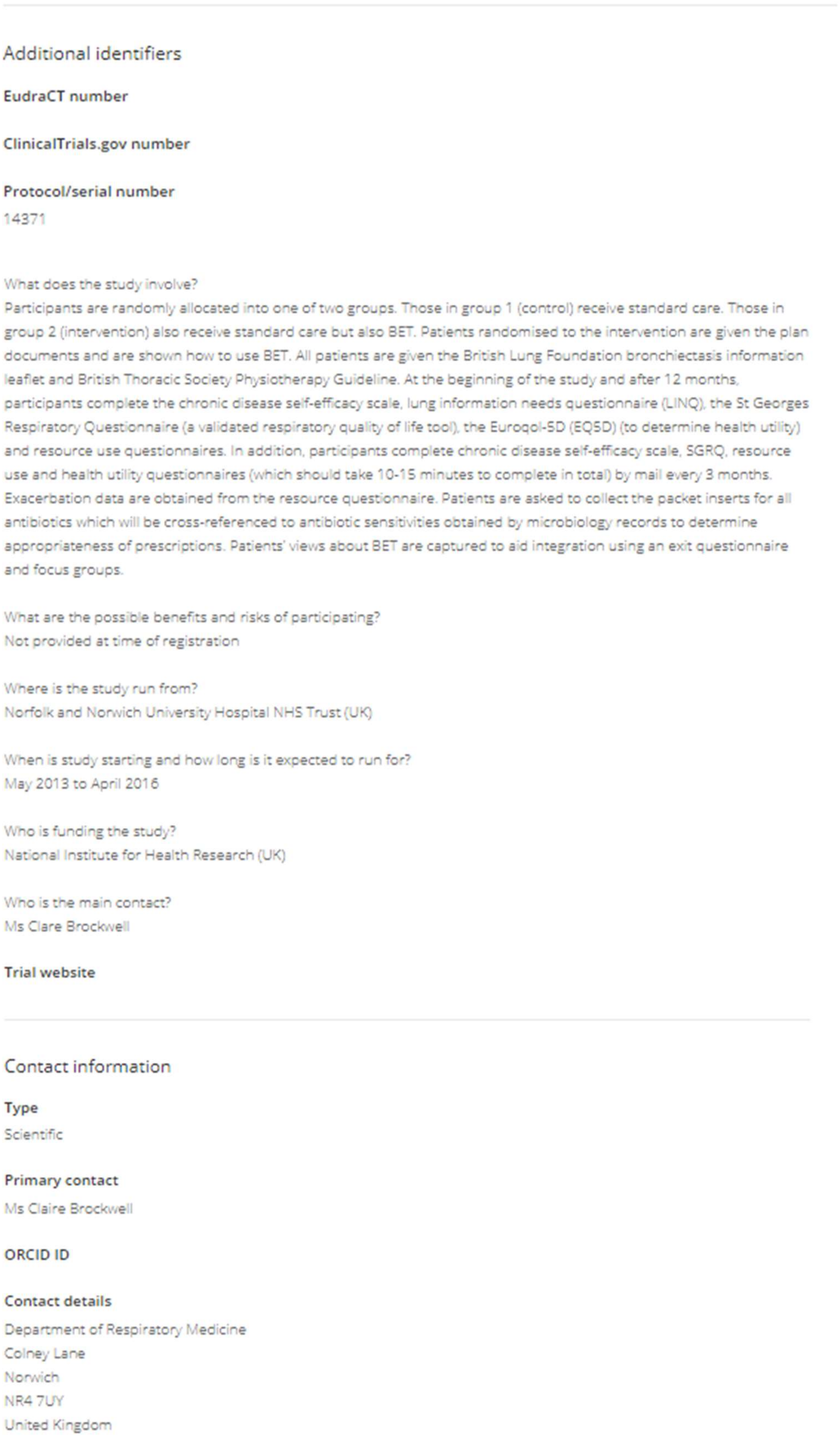
Background and study aims

Bronchiectasis is a long-term condition where the airways are abnormally widened (called bronchial dilatation), resulting in the build-up of mucus that can cause infection in the lungs. Symptoms include a persistent cough and breathlessness. The damage that is caused to the lungs by the condition is permanent. However, there are treatments available that will relieve symptoms and stop the damage from getting any worse. Healthcare providers largely control and manage the disease without documented guidance for patients on when to seek healthcare assistance. Patient self-management plans/tools have been used in other respiratory conditions similar to bronchiectasis, for many years, with improved healthcare outcomes. Although advocated by the National Guidelines, there is no data on the beneficial effects of self-management plans in bronchiectasis. In an on-going collaboration of patients with, and professionals treating, bronchiectasis we have developed the Bronchiectasis Empowerment Tool (BET). This is a one-page action plan, incorporated within a patient-held pack containing concise information about bronchiectasis and optional notepads to encourage patient note taking to gain insight and information about their condition. The tool has been developed in collaboration with patients and healthcare providers and is easy to use with pictographical instructions. It is designed work alongside, rather than to replace, existing care in order to improve the patient's ability to manage their condition. Our aim is to conduct a study to evaluate the effectiveness and cost-effectiveness of the Bronchiectasis Empowerment Tool (BET) as a support to patients throughout their healthcare journey. We will assess patients' self-efficacy, which is the confidence patients have in their ability to successfully deal with their condition, using the validated Chronic Disease Self-Efficacy Scale. We will also measure health care contacts; health related quality of life, appropriateness of antibiotic therapy and costs from questionnaires. To add a qualitative dimension pertinent to successful integration to practice we will seek the opinions of patients at the end of the study.

Who can participate?

Adults (aged at least 18) identified from clinic lists as having bronchiectasis.

ISRCTN page 1 of 2



Additional identifiers

EudraCT number

ClinicalTrials.gov number

Protocol/serial number

14371

What does the study involve?
Participants are randomly allocated into one of two groups. Those in group 1 (control) receive standard care. Those in group 2 (intervention) also receive standard care but also BET. Patients randomised to the intervention are given the plan documents and are shown how to use BET. All patients are given the British Lung Foundation bronchiectasis information leaflet and British Thoracic Society Physiotherapy Guideline. At the beginning of the study and after 12 months, participants complete the chronic disease self-efficacy scale, lung information needs questionnaire (LINQ), the St Georges Respiratory Questionnaire (a validated respiratory quality of life tool), the Euroqol-5D (EQ5D) (to determine health utility) and resource use questionnaires. In addition, participants complete chronic disease self-efficacy scale, SGRQ, resource use and health utility questionnaires (which should take 10-15 minutes to complete in total) by mail every 3 months. Exacerbation data are obtained from the resource questionnaire. Patients are asked to collect the packet inserts for all antibiotics which will be cross-referenced to antibiotic sensitivities obtained by microbiology records to determine appropriateness of prescriptions. Patients' views about BET are captured to aid integration using an exit questionnaire and focus groups.

What are the possible benefits and risks of participating?
Not provided at time of registration

Where is the study run from?
Norfolk and Norwich University Hospital NHS Trust (UK)

When is study starting and how long is it expected to run for?
May 2013 to April 2016

Who is funding the study?
National Institute for Health Research (UK)

Who is the main contact?
Ms Clare Brockwell

Trial website

Contact information

Type

Scientific

Primary contact

Ms Claire Brockwell

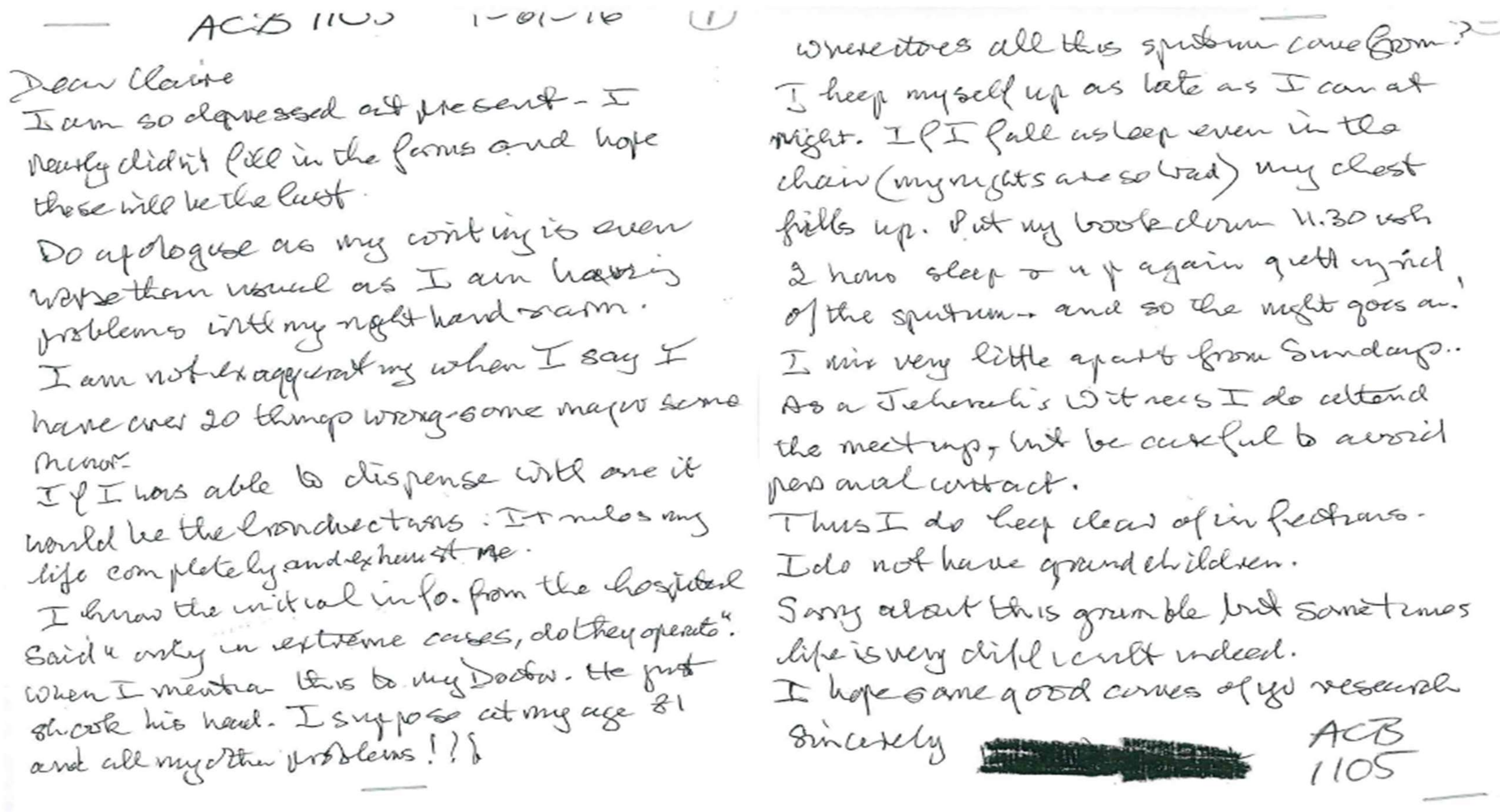
ORCID ID

Contact details

Department of Respiratory Medicine
Colney Lane
Norwich
NR4 7UY
United Kingdom

ISRCTN page 2 of 2

Appendix 17 Impact of disease, depression and questionnaires



ACB 1105 1-01-16 ①

Dear Claire
I am so depressed at present - I nearly didn't fill in the forms and hope these will be the last.

Do apologise as my writing is even worse than usual as I am having problems with my right hand & arm.

I am not exaggerating when I say I have over 20 things wrong - some major some minor.

If I was able to dispense with one it would be the bronchiectasis: It rules my life completely and exhaust me.

I know the initial info. from the hospital said " only in extreme cases, do they operate". When I mention this to my Doctor. He just shook his head. I suppose at my age 81 and all my other problems !?!

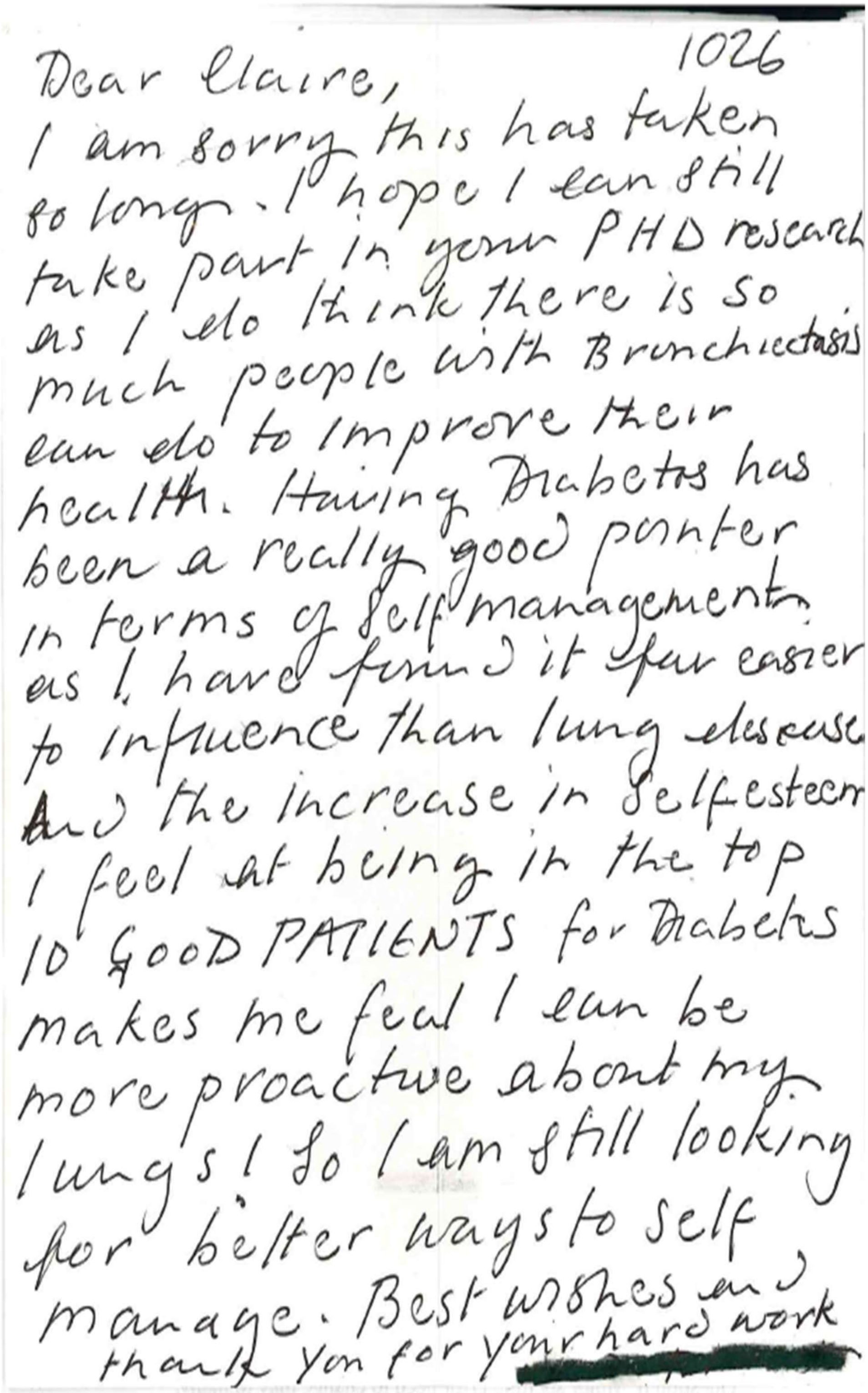
Where does all this sputum come from ?

I keep myself up as late as I can at night. If I fall asleep even in the chair (my nights are so bad) my chest fills up. Put my book down 11.30 wish 2 hours sleep & up again getting rid of the sputum - and so the night goes on.

I mix very little apart from Sundays..
As a Jehovah's Witness I do attend the meetings, but be careful to avoid personal contact.
Thus I do keep clear of infections.
I do not have grandchildren.
Sorry about this grumble but sometimes life is very difficult indeed.
I hope some good comes of yo research

Sincerely [redacted] ACB 1105

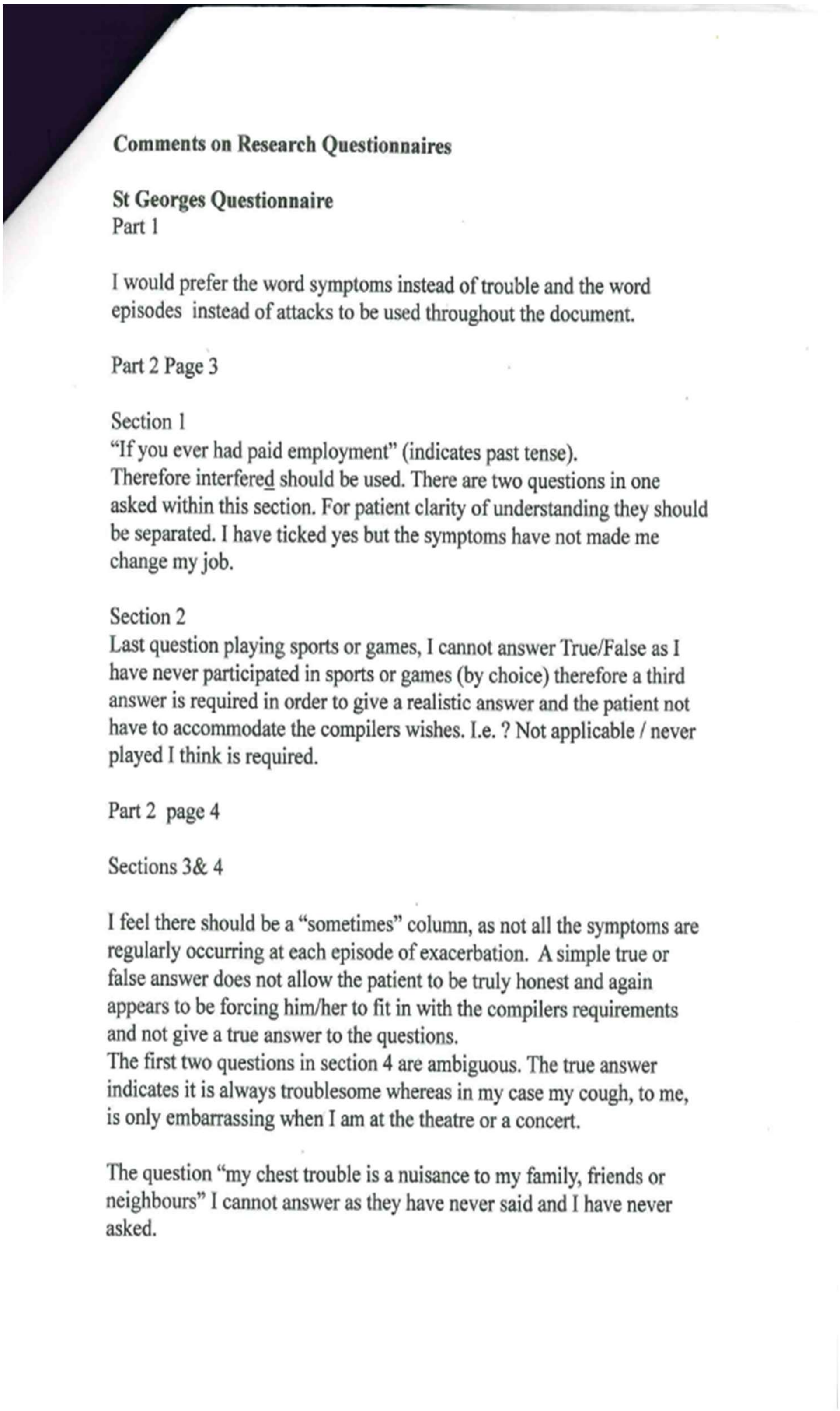
Appendix 18 Patient letter re self-management



1026

Dear Claire,
I am sorry this has taken
so long. I hope I can still
take part in your PHD research
as I do think there is so
much people with Bronchiectasis
can do to improve their
health. Having Diabetes has
been a really good pointer
in terms of self management
as I have found it far easier
to influence than lung disease
And the increase in selfesteem
I feel at being in the top
10 GOOD PATIENTS for Diabetes
makes me feel I can be
more proactive about my
lungs! So I am still looking
for better ways to self
manage. Best wishes and
thank you for your hard work [redacted]

Appendix 19 Participant comments re questionnaires



Comments on Research Questionnaires

St Georges Questionnaire
Part 1

I would prefer the word symptoms instead of trouble and the word episodes instead of attacks to be used throughout the document.

Part 2 Page 3

Section 1
"If you ever had paid employment" (indicates past tense).
Therefore interfered should be used. There are two questions in one asked within this section. For patient clarity of understanding they should be separated. I have ticked yes but the symptoms have not made me change my job.

Section 2
Last question playing sports or games, I cannot answer True/False as I have never participated in sports or games (by choice) therefore a third answer is required in order to give a realistic answer and the patient not have to accommodate the compilers wishes. I.e. ? Not applicable / never played I think is required.

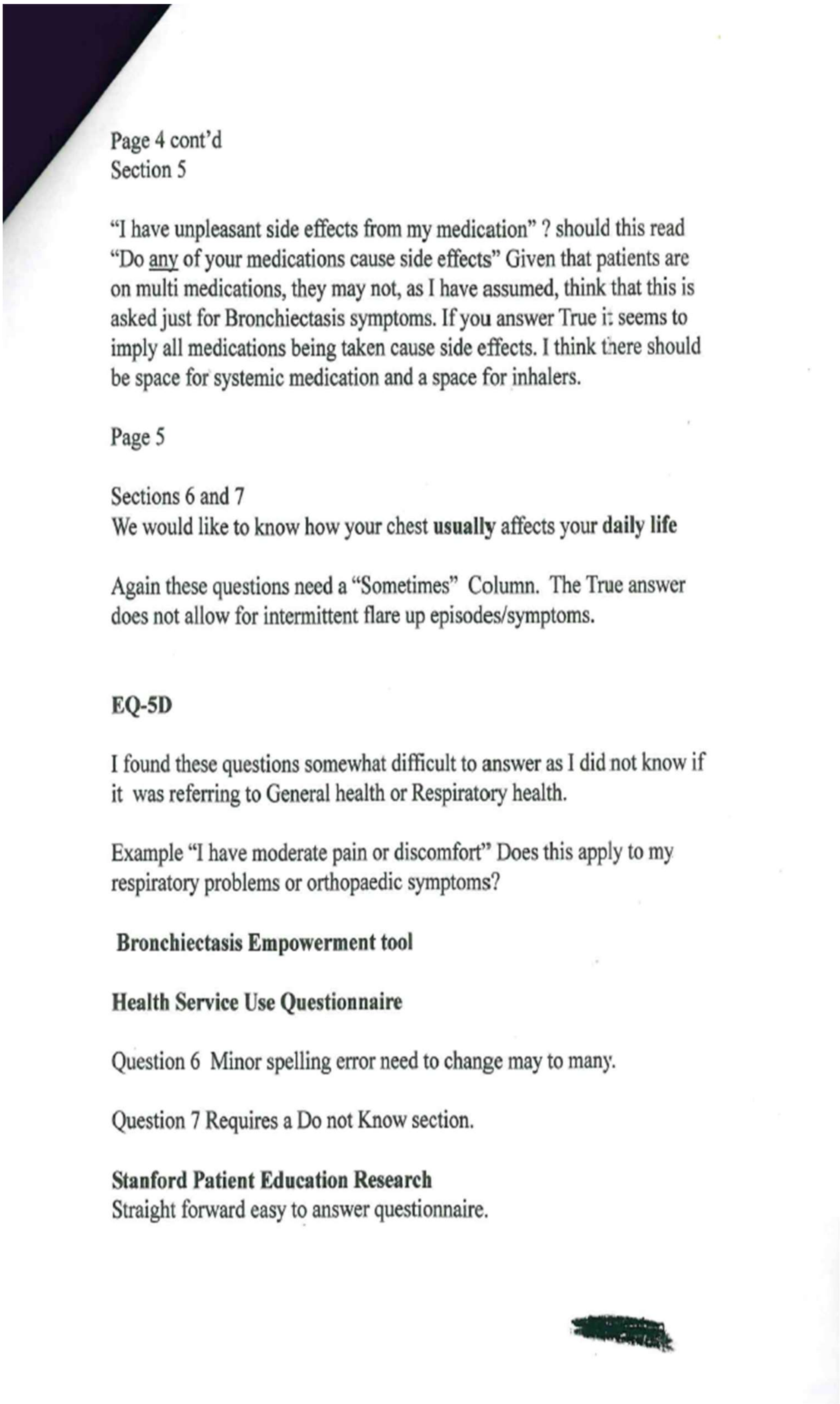
Part 2 page 4

Sections 3& 4

I feel there should be a "sometimes" column, as not all the symptoms are regularly occurring at each episode of exacerbation. A simple true or false answer does not allow the patient to be truly honest and again appears to be forcing him/her to fit in with the compilers requirements and not give a true answer to the questions.
The first two questions in section 4 are ambiguous. The true answer indicates it is always troublesome whereas in my case my cough, to me, is only embarrassing when I am at the theatre or a concert.

The question "my chest trouble is a nuisance to my family, friends or neighbours" I cannot answer as they have never said and I have never asked.

Participant eval of Qrres1 of 2



Page 4 cont'd
Section 5

"I have unpleasant side effects from my medication" ? should this read "Do any of your medications cause side effects" Given that patients are on multi medications, they may not, as I have assumed, think that this is asked just for Bronchiectasis symptoms. If you answer True it seems to imply all medications being taken cause side effects. I think there should be space for systemic medication and a space for inhalers.

Page 5

Sections 6 and 7
We would like to know how your chest **usually** affects your **daily life**

Again these questions need a "Sometimes" Column. The True answer does not allow for intermittent flare up episodes/symptoms.

EQ-5D

I found these questions somewhat difficult to answer as I did not know if it was referring to General health or Respiratory health.

Example "I have moderate pain or discomfort" Does this apply to my respiratory problems or orthopaedic symptoms?

Bronchiectasis Empowerment tool

Health Service Use Questionnaire

Question 6 Minor spelling error need to change may to many.

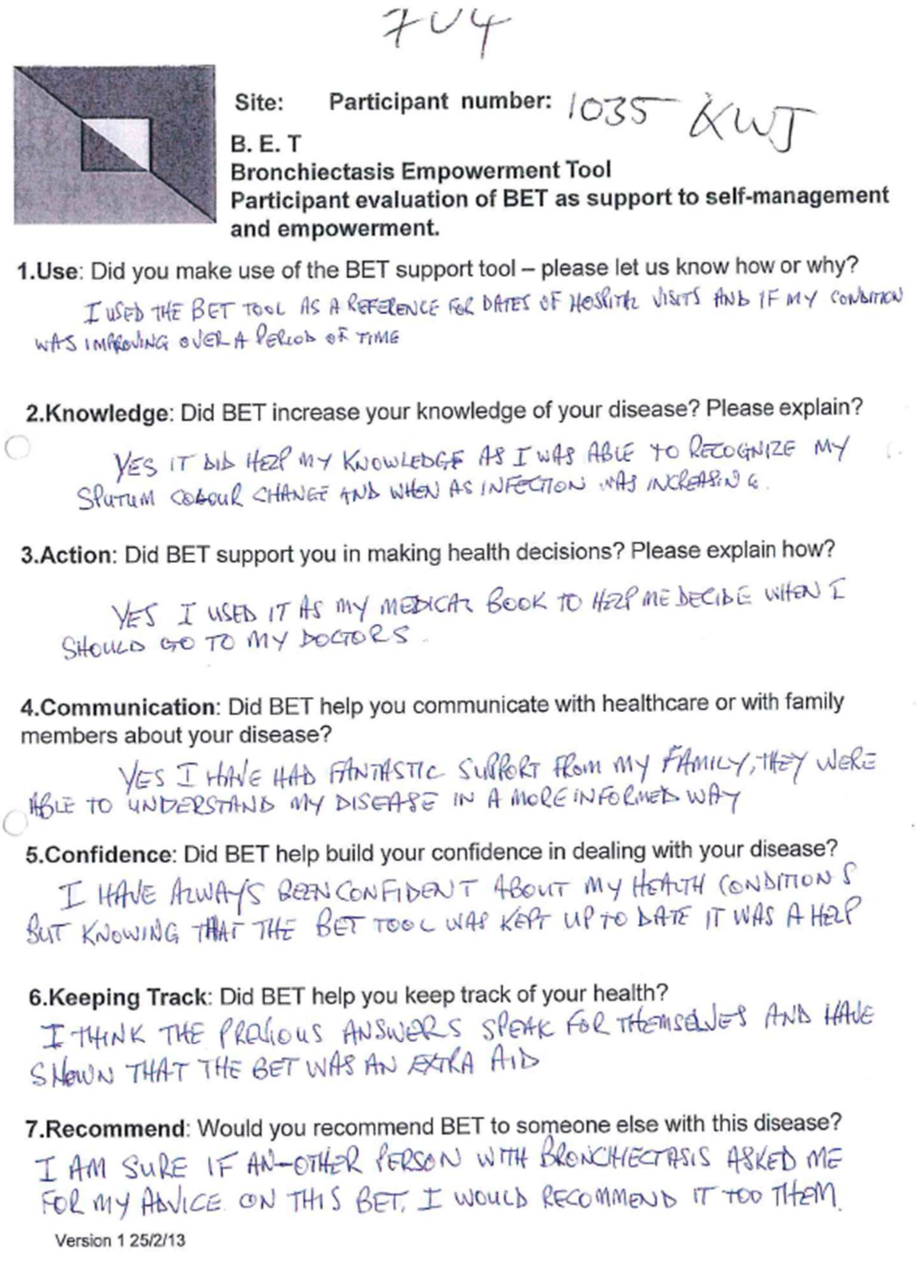
Question 7 Requires a Do not Know section.

Stanford Patient Education Research
Straight forward easy to answer questionnaire.

[redacted]

Participant eval of Qrres 2 of 2

Appendix 20 Non-validated BET intervention evaluation



7U4

Site: Participant number: 1035 KWJ

B. E. T
Bronchiectasis Empowerment Tool
Participant evaluation of BET as support to self-management and empowerment.

1.Use: Did you make use of the BET support tool – please let us know how or why?

I USED THE BET TOOL AS A REFERENCE FOR DATES OF HOSPITAL VISITS AND IF MY CONDITION WAS IMPROVING OVER A PERIOD OF TIME

2.Knowledge: Did BET increase your knowledge of your disease? Please explain?

YES IT DID HELP MY KNOWLEDGE AS I WAS ABLE TO RECOGNIZE MY SPUTUM COLOUR CHANGE AND WHEN AS INFECTION WAS INCREASING.

3.Action: Did BET support you in making health decisions? Please explain how?

YES I USED IT AS MY MEDICAL BOOK TO HELP ME DECIDE WHEN I SHOULD GO TO MY DOCTORS.

4.Communication: Did BET help you communicate with healthcare or with family members about your disease?

YES I HAVE HAD FANTASTIC SUPPORT FROM MY FAMILY, THEY WERE ABLE TO UNDERSTAND MY DISEASE IN A MORE INFORMED WAY

5.Confidence: Did BET help build your confidence in dealing with your disease?

I HAVE ALWAYS BEEN CONFIDENT ABOUT MY HEALTH CONDITIONS BUT KNOWING THAT THE BET TOOL WAS KEPT UP TO DATE IT WAS A HELP

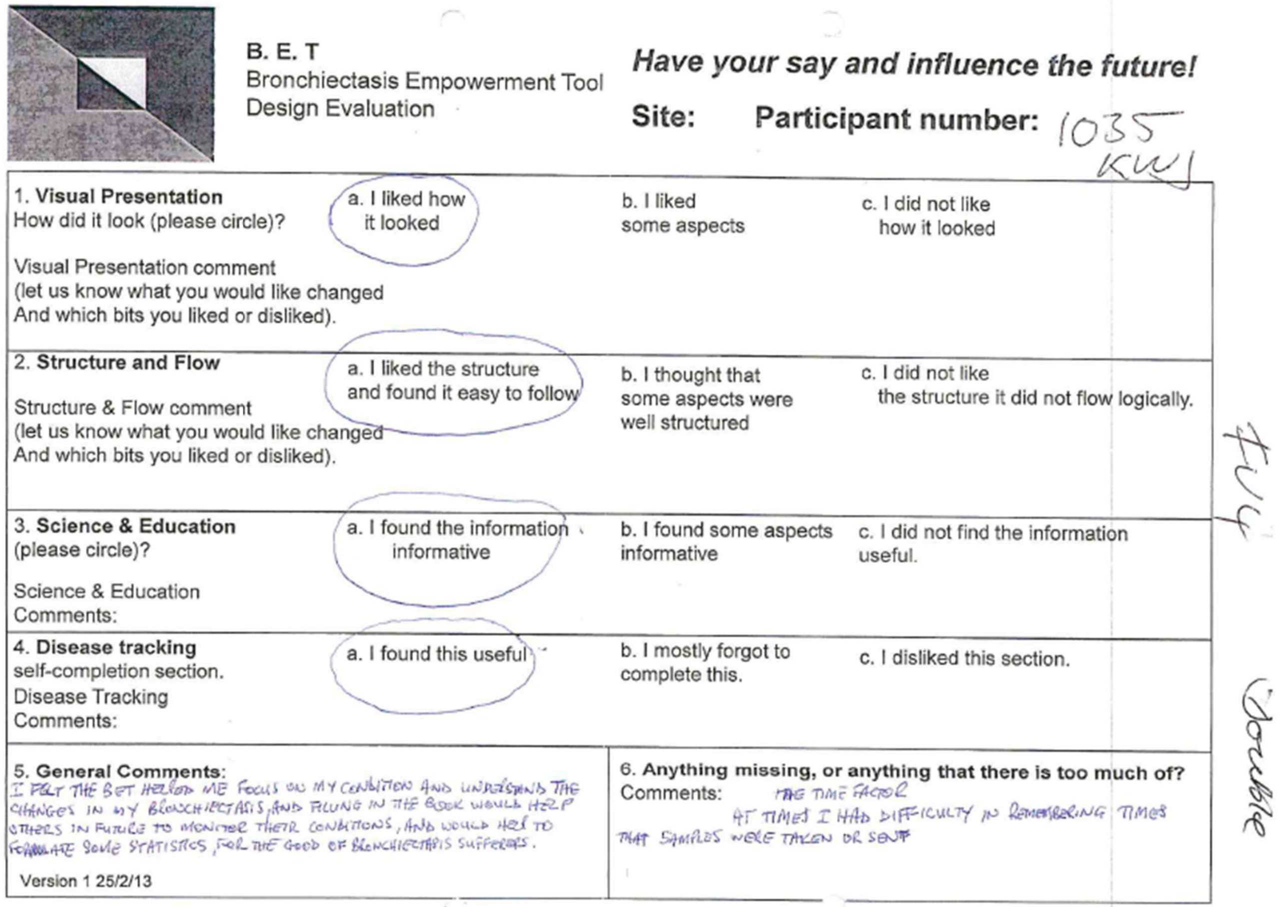
6.Keeping Track: Did BET help you keep track of your health?

I THINK THE PREVIOUS ANSWERS SPEAK FOR THEMSELVES AND HAVE SHOWN THAT THE BET WAS AN EXTRA AID

7.Recommend: Would you recommend BET to someone else with this disease?

I AM SURE IF AN-OTHER PERSON WITH BRONCHIECTASIS ASKED ME FOR MY ADVICE ON THIS BET, I WOULD RECOMMEND IT TOO THEM.

Version 1 25/2/13



B. E. T
Bronchiectasis Empowerment Tool
Design Evaluation

Have your say and influence the future!

Site: **Participant number:** 1035
KWJ

FU4

Double

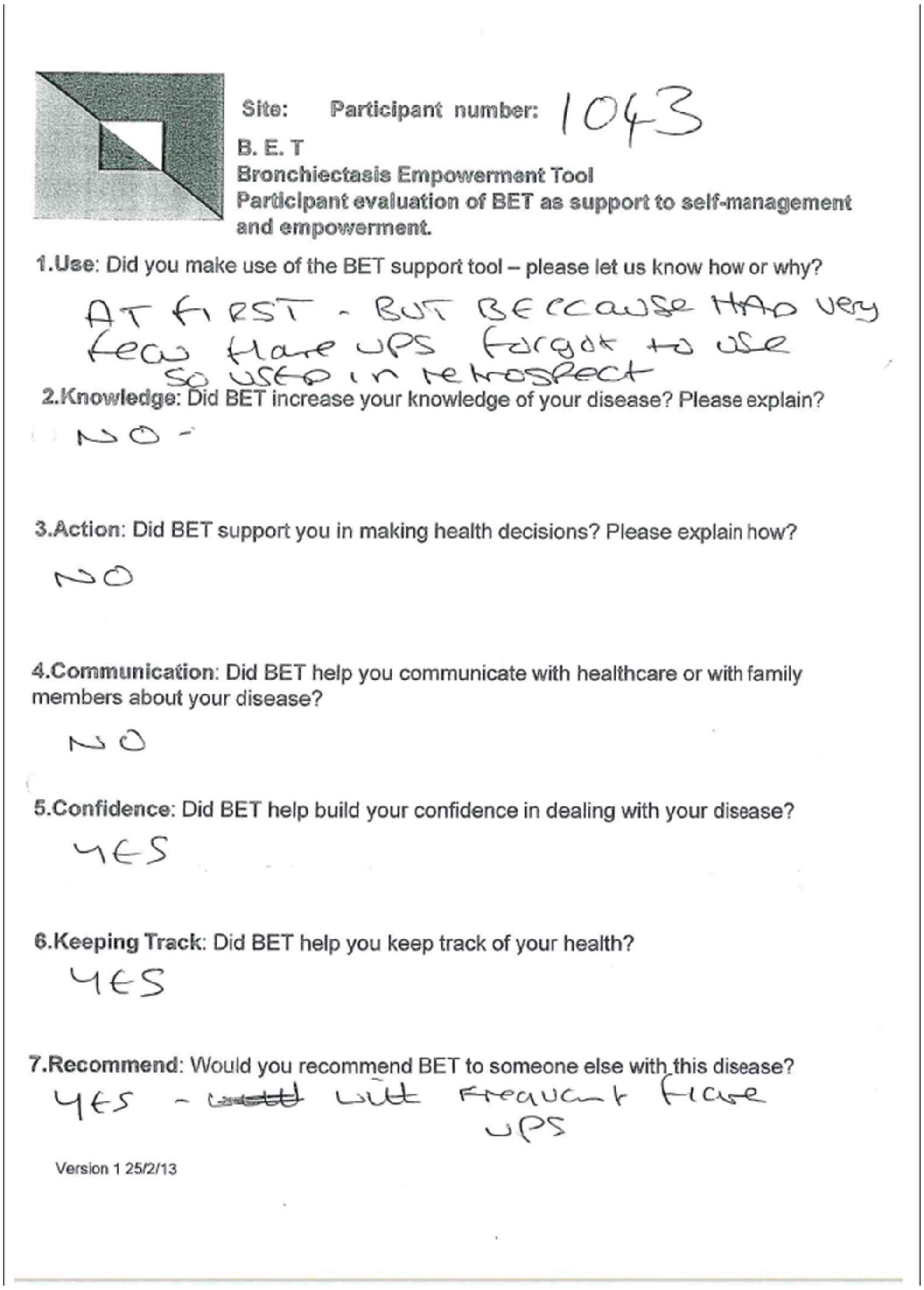
1. **Visual Presentation** How did it look (please circle)? Visual Presentation comment (let us know what you would like changed And which bits you liked or disliked).	[✓ a. I liked how it looked]	b. I liked some aspects	c. I did not like how it looked
2. **Structure and Flow** Structure & Flow comment (let us know what you would like changed And which bits you liked or disliked).	[✓ a. I liked the structure and found it easy to follow]	b. I thought that some aspects were well structured	c. I did not like the structure it did not flow logically.
3. **Science & Education** (please circle)? Science & Education Comments:	[✓ a. I found the information informative]	b. I found some aspects informative	c. I did not find the information useful.
4. **Disease tracking** self-completion section. Disease Tracking Comments:	[✓ a. I found this useful]	b. I mostly forgot to complete this.	c. I disliked this section.

5. **General Comments:**
I FELT THE BET HELPED ME FOCUS ON MY CONDITION AND UNDERSTAND THE CHANGES IN MY BRONCHIECTASIS, AND FILLING IN THE BOOK WOULD HELP OTHERS IN FUTURE TO MONITOR THEIR CONDITIONS, AND WOULD HELP TO FORMULATE SOME STATISTICS, FOR THE GOOD OF BRONCHIECTASIS SUFFERERS.

Version 1 25/2/13

6. **Anything missing, or anything that there is too much of?**
Comments: THE TIME FACTOR
AT TIMES I HAD DIFFICULTY IN REMEMBERING TIMES THAT SAMPLES WERE TAKEN OR SENT

Page 2 of 6 Non val BET eval



Site: **Participant number:** 1043

B. E. T
Bronchiectasis Empowerment Tool
Participant evaluation of BET as support to self-management and empowerment.

1.Use: Did you make use of the BET support tool – please let us know how or why?

AT FIRST - BUT BECCAUSE HAD very few flare UPS forgot to use SO USED in retrospect

2.Knowledge: Did BET increase your knowledge of your disease? Please explain?

NO -

3.Action: Did BET support you in making health decisions? Please explain how?

NO

4.Communication: Did BET help you communicate with healthcare or with family members about your disease?

NO

5.Confidence: Did BET help build your confidence in dealing with your disease?

YES

6.Keeping Track: Did BET help you keep track of your health?

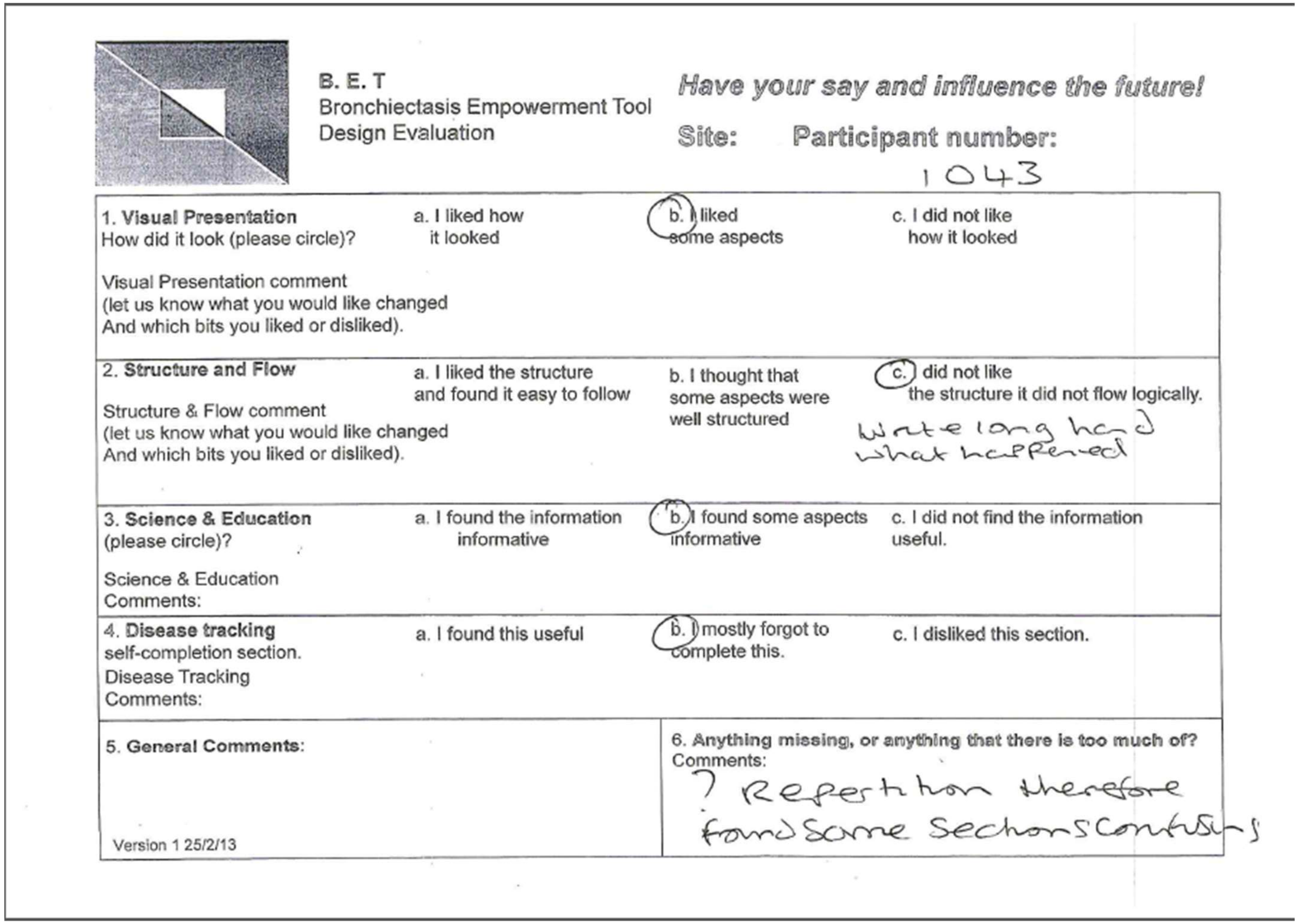
YES

7.Recommend: Would you recommend BET to someone else with this disease?

YES - [illegible] with Frequent flare UPS

Version 1 25/2/13

Page 3 of 6 Non val BET eval



B. E. T
Bronchiectasis Empowerment Tool
Design Evaluation

Have your say and influence the future!

Site: **Participant number:** 1043

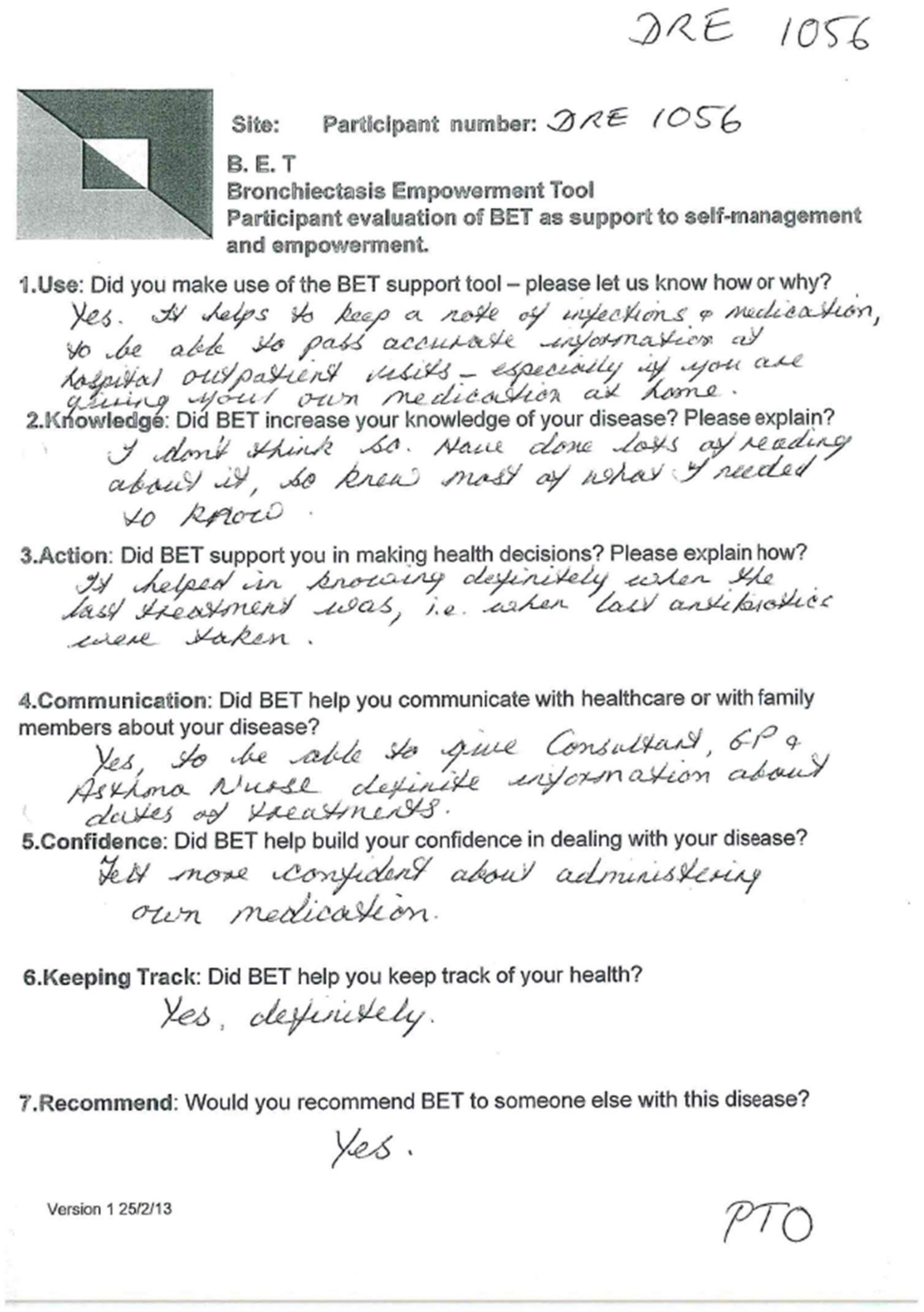
1. **Visual Presentation** How did it look (please circle)? Visual Presentation comment (let us know what you would like changed And which bits you liked or disliked).	a. I liked how it looked	[✓ b. I liked some aspects]	c. I did not like how it looked
2. **Structure and Flow** Structure & Flow comment (let us know what you would like changed And which bits you liked or disliked).	a. I liked the structure and found it easy to follow	b. I thought that some aspects were well structured	[✓ c. I did not like the structure it did not flow logically.] Write long hand what happened
3. **Science & Education** (please circle)? Science & Education Comments:	a. I found the information informative	[✓ b. I found some aspects informative]	c. I did not find the information useful.
4. **Disease tracking** self-completion section. Disease Tracking Comments:	a. I found this useful	[✓ b. I mostly forgot to complete this.]	c. I disliked this section.

5. **General Comments:**

Version 1 25/2/13

6. **Anything missing, or anything that there is too much of?**
Comments:
? Repetition therefore found some sections confusing

Page 4 of 6 Non val BET eval



DRE 1056

Site: **Participant number:** DRE 1056

B. E. T
Bronchiectasis Empowerment Tool
Participant evaluation of BET as support to self-management and empowerment.

1.Use: Did you make use of the BET support tool – please let us know how or why?

Yes. It helps to keep a note of infections & medication, to be able to pass accurate information at hospital outpatient visits – especially if you are giving your own medication at home.

2.Knowledge: Did BET increase your knowledge of your disease? Please explain?

I don't think so. Have done lots of reading about it, so knew most of what I needed to know.

3.Action: Did BET support you in making health decisions? Please explain how?

It helped in knowing definitely when the last treatment was, i.e. when last antibiotics were taken.

4.Communication: Did BET help you communicate with healthcare or with family members about your disease?

Yes, to be able to give Consultant, GP & Asthma Nurse definite information about dates of treatments.

5.Confidence: Did BET help build your confidence in dealing with your disease?

Felt more confident about administering own medication.

6.Keeping Track: Did BET help you keep track of your health?

Yes, definitely.

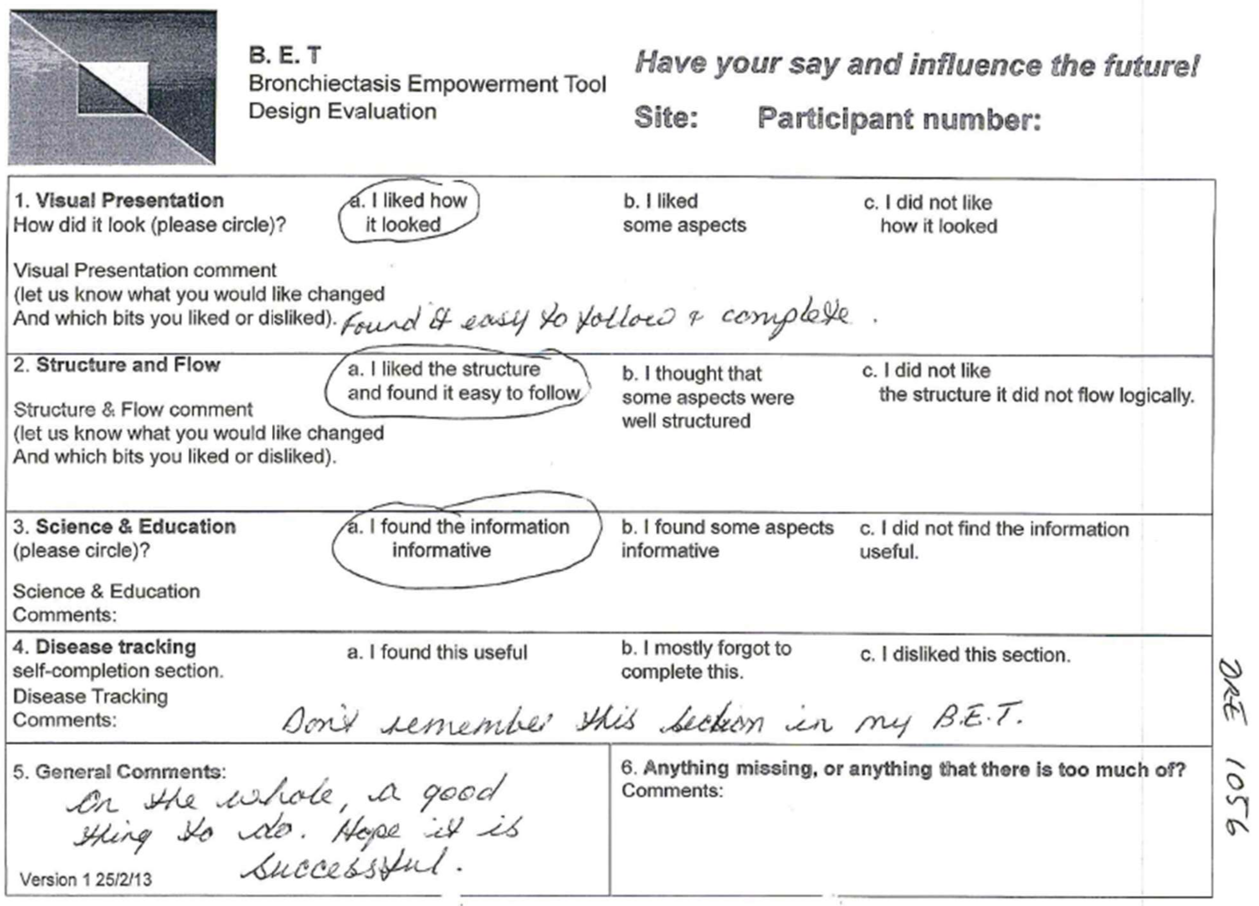
7.Recommend: Would you recommend BET to someone else with this disease?

Yes.

Version 1 25/2/13

PTO

Page 5 of 6 Non val BET eval



DRE 1056

B. E. T
Bronchiectasis Empowerment Tool
Design Evaluation

Have your say and influence the future!

Site: **Participant number:**

1. **Visual Presentation** How did it look (please circle)?	[✓ a. I liked how it looked]	b. I liked some aspects	c. I did not like how it looked
Visual Presentation comment (let us know what you would like changed And which bits you liked or disliked).	Found it easy to follow & complete.		
2. **Structure and Flow**	[✓ a. I liked the structure and found it easy to follow]	b. I thought that some aspects were well structured	c. I did not like the structure it did not flow logically.
Structure & Flow comment (let us know what you would like changed And which bits you liked or disliked).			
3. **Science & Education** (please circle)?	[✓ a. I found the information informative]	b. I found some aspects informative	c. I did not find the information useful.
Science & Education Comments:			
4. **Disease tracking** self-completion section.	a. I found this useful	b. I mostly forgot to complete this.	c. I disliked this section.
Disease Tracking Comments:	Don't remember this section in my B.E.T.		

5. **General Comments:**
On the whole, a good thing to do. Hope it is successful.

Version 1 25/2/13

6. **Anything missing, or anything that there is too much of?**
Comments:

Page 6 of 6 Non val BET eval