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Emergency care patient driven solutions for severe asthma

Author 1: Karen Newell, BA (Hons), RGN, MSc. Clinical Nurse Specialist. Respiratory, Medicine and Allergy, Guys and St Thomas NHS Foundation Trust, London, UK, Telephone: 020 7188 7188, e-mail: karennewell@hotmail.com

Author 2: Chris Corrigan, MA MSc PhD FRCP, Professor of Asthma, Allergy & Respiratory Science, Respiratory Medicine and Allergy, Kings College London, UK, Telephone: 020 7188 0599, e-mail: Chris.Corrigan@kcl.ac.uk

Author 3: Geoff Punshon, BSc Hons, Visiting Fellow, School of Health and Social Care, London South Bank University, London, UK, Telephone: 020 7815 7815, e-mail: punshong@lsbu.ac.uk

Author 4: Alison Leary, PhD RN, Professor of Healthcare Modelling, School of Health and Social Care, London South Bank University, London, UK, Telephone: 020 7815 7815, e-mail: alisonleary@yahoo.com

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Corresponding author: Alison Leary.

Corresponding author's e-mail: alisonleary@yahoo.com

Abstract

Purpose: Patients with severe asthma were choosing not to use the emergency department (ED) in extremis and were self-medicating when experiencing severe asthma, putting their lives at risk. This local issue reflected a nationwide situation. Our aim was to better understand the reasons behind this reluctance to attend the ED and consider practical solutions in a structured way.

Design/Methodology/approach: Systems thinking (soft systems methodology) was used to examine the issues resulting in this reluctance to attend the ED. Once this tame problem was revealed, a potential solution was developed in co-production with patients.

Findings: Patients feared attending the ED and felt vulnerable while in the ED for a number of reasons. This appeared to be a well-defined and solvable problem. The solution proposed was an Asthma Patient Passport (APP), which increased patient's confidence in their ability to communicate their needs while in severe distress. The APP decreased (from twelve to five steps) the work patients had to do to achieve care. The APP project is currently being evaluated.

Practical implications: The APP should be offered to all people with severe asthma,

Originality/Value: By revisiting systems thinking and identifying problems, a solution was identified. Although methods such as soft systems methodology have limitations when used in 'wicked' (difficult or impossible to resolve) problems, such methods still have merit in tame problems and were applicable in this case to fully understand the issues and design practical solutions.

Keywords: Asthma; Emergency; Systems thinking; Soft System Methodology; Patient passport.

Article Classification: Case study

Background

Approximately 1,200 people with asthma die in the UK each year and 90% are preventable (Asthma UK, 2014). The UK has a higher asthma death rate than similar countries and numbers have not reduced significantly in recent years (Levy *et al.*, 2014). The *Why Asthma Still Kills: The National Review of Asthma Deaths (NRAD) Confidential Enquiry Report* was published in 2014 (Royal College of Physicians, 2014). Its aim was to identify avoidable factors and recommend changes to improve care and reduce asthma deaths. The NRAD authors concluded that there are factors associated with the disease, its medical management and the patient's behaviour or psychosocial status, which contribute to death. Most deaths occurred before admission to hospital and most fatalities had chronically severe asthma (British Thoracic Society, 2014).

Local context

In conjunction with NHS Improvement, some work was undertaken around asthma re-attendance in the Emergency Department (ED) at one large London NHS Foundation trust during 2010-2011. A local initiative (audit cycle) using increased general practitioner (GP) and general practice nurse (GPN) communication, forming an action plan with patients and an ED pro forma for emergency care was initiated over a year. The initiative included the patient experience team who facilitated work that elicited reasons for re-attendance. This initial improvement project yielded a 45% decrease in 30-day asthma re-attendance (75 patients re-attended 143 times between May 2010 and April 2011 out of 888 adult attendances). Admissions were reduced by 60%. Reducing asthma re/attendance and admissions indicates better asthma control and quality of life (British Thoracic Society, 2014).

Severe asthma patients were excluded from the original NHS Improvement work because they had different needs. Asthma is known as severe when a patient has a confirmed asthma diagnosis and ongoing symptoms despite adherence to treatment. It is recognised by one or more near-fatal asthma episodes; e.g., previous ventilation or respiratory acidosis, previous admission for asthma especially in the last year, requiring three or more asthma medication classes, heavy β_2 agonist use and repeated ED attendances for asthma care (British Thoracic Society, 2014). Severe asthma cases in the Trust are fully medically optimised and are supported by specialist asthma clinic staff. They all have bespoke asthma action plans, which are drawn up between themselves and the asthma clinical nurse specialist (CNS). The plan outlines how to titrate asthma treatments according to symptom and when to access medical assistance.

To evaluate these plans locally, interviews were conducted with service users. The interviews showed that patients valued the asthma action plan, but there was usually awkwardness around when and how to access emergency medical care. Exploration revealed that patients were putting their lives at risk because they had such a difficult time in ED and they preferred to stay at home and take high bronchodilator therapeutic doses. Patients said they avoided the ED, even in extreme respiratory distress, for several reasons:

- Feeling vulnerable or fear in the ED when they are least able to talk; i.e., when unable to say what they needed, which caused more distress.
- They are asked the same questions many times and felt that they are not always listened to.
- Treatment isn't always escalated as quickly as they felt it needed to be.
- Patients had no choice about which ED the ambulance service staff took them; consequently, they elected to use either their own or public transport even when in severe respiratory distress.

Understanding this experience structured the problem and therefore this study. A soft systems thinking approach (Checkland, 2001) was taken to identify the specific problem and then construct a satisfactory and sustainable solution. Soft Systems Methodology (SSM) was chosen as it helps conceptualise, define and address problems and is particularly useful in people oriented systems, and allows issues to be considered from a more holistic whole systems perspective. Once possible solutions had been identified a plan, do, study, act (PDSA) cycle was used as a quality improvement approach (Langley *et al.*, 2009).

Methods

To understand the problem more fully, SSM was applied (Langley *et al.*, 2009; Checkland 1981). An overview can be seen in Figure 1. Soft system methodology originated in systems engineering and has been in use for over thirty years and attempts to foster learning and understanding of a problem situation through a group of stakeholders instead of attempting to solve a pre-determined problem. Initially, meetings and interviews are held in order to obtain an understanding of the problem situation and identify relevant systems after which conceptual models of the systems are generated. These models are then used as a basis for debate and can lead to feasible and desirable changes which can be actioned. Whilst it is commonly considered that general systems thinking has not delivered the anticipated changes in healthcare, applying systems thinking to tame problems has been beneficial in many areas (Checkland, 2001)

Figure 1 here.

Results

Identifying the problem locally

Step 1: Situation considered problematic

From local interviews, patients with severe asthma did not appear to be seeking emergency medical help when they needed to. This behaviour is associated with avoidable harm/death (Levy *et al.*, 2014). The NRAD report into avoidable asthma deaths (British Thoracic Society, 2014) states that 45% (87) of the 195 people who died did so without seeking medical help or before emergency medical care could be provided. Previous hospital admission for asthma occurred in 47% (90 of 190). Nineteen (10%) of the 195 died, within 28 days of discharge from hospital after asthma treatment. At least 40 (21%) who died had attended an ED with asthma at least once in the previous year and 23 had attended twice or more. Thirty-nine percent appeared to have severe asthma. The NRAD report (British Thoracic Society, 2014) and local patient experience work underlined having a personal asthma action plan. During the co-creating an asthma action plan process, the asthma CNS often felt resistance from severe asthma patients around when and how to access emergency medical care, which needed exploring. The asthma CNS felt that patients were putting their lives at risk because they had such a difficult time in the ED. Owing to the difficult time in the ED, they preferred to stay at home and take high doses of bronchodilator therapy (Asthma UK, 2004). The reasons behind this decision had not been considered systematically within this service. Trust staff currently care for around 800 severe asthma patients per year. Defining the problem revealed that it had characterised a tame problem (Rittel and Webber, 1973) in that the problem can be articulated with a clearly desired outcome - that distressed patients feel able to go to the ED. The problem can be stated as a gap between *what is* and *what ought* to be – the latter agreed by professionals and patients.

Step2: Problem situation described

Soft system methods help to formulate and structure thinking about problems in complex human situations by applying systems thinking about things that happen in the real world. It is most usefully carried out by the people immersed in the problem situation, in this case, people with severe asthma and the asthma CNS who provides expert help to guide and facilitate the process. The asthma CNS facilitated a focus group with the patients and the allergy CNS to gain a situational insight. The findings from the group echoed the asthma plan evaluation themes:

- Feeling vulnerable and afraid
- Asked the same questions repeatedly when least able to talk
- Unable to say what they need when least able to talk
- Feeling that they are not always listened to
- Life-saving treatments aren't always escalated as quickly as necessary
- Healthcare staff do not always appreciate the attack's severity
- Individual fears; i.e., being left alone in a cubicle when they think they are dying

Owing to the initial meeting, process mapping was introduced to explore the issues (Newell *et al.*, 2014). The process mapping revealed that twelve separate actions were required to gain treatment when self-presenting to the ED and thirteen if brought by ambulance and these are listed in Appendix 1 (Newell *et al.*, 2015)

Step 3: Root definitions

It was agreed by the co-production group that 'something needed to be done', thus a project team was established to set out a shared purpose and vision. The project's aim was that patients with severe asthma would seek emergency help appropriately. A further aim was that when patients with asthma went to the ED, they should feel that they were being taken seriously and be able to work with staff to achieve the best outcomes. Returning to SSM to help achieve these aims several questions are posed.

1. What the system will do?
2. How it is done?
3. Why it is being done (long term aim)?

Underpinning this is a transformation process in which something is changed or transformed into something else, which revealed the study question/system requirement: *A system to encourage people with 'severe asthma to go to the ED when they need to for the right treatment, in the right place, at the right time without fear.* Once the problem has been defined, the SSM CATWOE checklist (Checkland, 2001) was used to solve problem:

Customers - it was the asthma CNS's duty to listen carefully to what patients with severe asthma had to say about seeking emergency help and contribute to enabling ED and London Ambulance Service (LAS) staff to understand patients' needs.

Actors - those involved in the situation and in partnership with them, to act on what had been discussed. How might they react? What is their stake in improving the situation?

Transformation - so that the patient group would change their behaviour and go to ED when they needed to. Staff reacted in a way that reassured and met patients' needs rather than increase distress and fear.

Weltanschauung (this is the right thing to do) - because not to do so put patients at risk - they say they are already at risk and want to do something about it.

Owners of the process - all the stakeholders and included: patients with severe asthma, ED clinical staff, ED reception staff, London Ambulance Service (LAS) staff, asthma Professor, Patient Experience Team, Communications and Patient Publications.

Environmental constraints - NRAD (British Thoracic Society, 2014) describes how people with asthma were needlessly dying because patients failed to recognise the asthma attack's severity, healthcare staff's failure to recognise attack severity and inappropriate or under-treatment. It was fundamental that any plan took these constraints into account.

Step 4: Conceptual models of systems described in root definitions

Drawing out a conceptual model highlights the many reasons why the patient group weren't going to ED without losing sight of how component parts fit together (Figure 2).

Figure 2 here

Designing the intervention - the Asthma Patient Passport (APP)

Patients aren't necessarily local to the Trust and therefore need to use different EDs and so a local arrangement wasn't an obvious solution. Another option was to have a national database of people with severe difficult to manage asthma so that the ambulance service and the various UK EDs had all the necessary information about the patient, but this was impractical. Establishing such a system would be resource intensive because there is no common information technology infrastructure in the UK. Other long-term condition groups, such as people with learning difficulties and mental health problems and palliative care needs, were already using a Patient Passport as a collaborative communication tool and this had been found to be helpful in accessing services (Abbot *et al.*, 2015). A local Chronic Obstructive Pulmonary Disease (COPD) Passport was being used and it was felt that the design had been well evaluated. The COPD Passport is a credit card sized z-card (a z-card is a piece of paper with a number of panels of information on it that folds down into a credit-card sized card that can easily be stored in a wallet or purse) and simply records relevant demographic and clinical information. Where the Asthma Patient Passport (APP) would differ from the COPD Passport is that it would be designed by patients for patients and would also consider ambulance service and the ED staff needs. The other important factor was the decision to use the model for improvement as a way for implementing health service change (NHS Institute for Improvement, 2014). Every time a patient used the APP, their experience was fed back by the patient or other user (e.g., LAS) to the group and any suggestions were incorporated into the APP:

- Putting the emergency information at the beginning of the document
- Adding a box for the Asthma Physician's signature to lend credibility
- Changing the word 'severe' to 'brittle' as it is more commonly understood in those who do not specialise in asthma treatment
- Having an explicit statement about what to do if arterial blood gases (ABG) are needed (as ED staff felt that gaining permission to undertake ABG's can be challenging at times)
- Adding a review date
- Having a pre-hospital treatment section for the ambulance journey
- Highlighting and dating previous ITU/HDU admissions
- Adding a triggers section
- Designing watermarks that provide subliminal awareness information on crucial safety factor such as the silent asthmatic

These suggestions won commitment from various health staff groups and patients.

Step 5: Comparing models with the real world

The problem examined was APP development and to compare this model with the real world. The APP made the patient journey through the ED more efficient. Patients brought in by ambulance went through a 13-stage process before the APP was introduced. With the APP in place, there are now only nine steps. Self-presenting patients also went through 12 steps before the APP was introduced and five afterwards (see Appendix 1). The APP streamlined the process by improving communication allowing improved access and flow through emergency care. This reduced delays and ensuring treatment is individualised and right the first time, thereby improving quality and possibly lowering costs (Newell *et al.*, 2015).

Step 6: Changes - systematically desirable, culturally feasible?

Does the solution work?

The APP was developed and piloted for three months with 15 patients. During this period, it was used 15 times by seven patients. After a positive feedback and some minor alterations based on the feedback, the APP was trialled for one year. During this time, regular meetings and consultations were held with partners (patients, specialist nurses, ED and LAS staff and the medical consultant) who were consulted extensively throughout the trial period using this approach. Finally, an APP document (Figure 3) was devised that provided this patient group with the confidence to attend ED when appropriate, and assisted healthcare staff in treating them (Newell *et al.*, 2014).

Figure 3 here

Is it worthwhile?

The APP addressed four key areas most important to patients: (i) being left alone; (ii) being unable to communicate needs; (iii) feeling frustrated at not being listened to; (iv) being asked the assessment questions repeatedly at a time when they are too breathless to talk) and in doing so improving; treatment timeliness, decision making, patient experience (the APP's original aims) (Newell *et al.*, 2014). The APP also appeared to meet a London Ambulance Service staff need, captured in this comment ... *the patient doesn't have the pressure of having to give their story to the ambulance crew (which) takes the pressure out of the situation.*

Does the solution achieve its goals?

As patients have a better experience, they report that they are more likely to access emergency services in a timely manner and receive correct treatment (Newell *et al.*, 2014). The APP now features regularly in clinical practice at the London NHS Foundation trust we studied.

Step 7: Action to improve the problem situation

The action taken was to implement the APP for patients with severe asthma at one large London NHS Foundation trust. There are plans to undertake a multi-centre study using a mixed-methods approach, which will include an impact evaluation.

Discussion

There is breadth and value in the SSM approach and the PDSA cycle in tame (well-defined) problems. Patient passports are common in other long term conditions (National Quality Forum, 2015). The APP was specifically co-designed to meet an expressed need and it was

the patients and asthma CNS that drove the development process. The core group included patients, asthma and allergy CNSs, and it was the collaborative approach adopted by patients and wider team (including ambulance and ED staff) that helped to get it right. Inextricably connected with this was learning by doing so that every time a patient used the APP, it was discussed with the asthma CNS and the APP was improved. The same problem was that severe asthma patients weren't accessing emergency healthcare when they needed to. The patient's perspective is highly relevant to efforts to improve healthcare quality and effectiveness (Frew *et al.*, 2011) and because all parties were involved in the creation process, all parties benefited – a win, win, win' patients, clinicians and healthcare system. The patients feel more secure and are more likely to go to the ED and get the right treatment, in the right place, at the right time. Healthcare staff have all the necessary information, which is individualised and easy to follow. The healthcare provider benefits because the process is leaner and outcomes are improved, which indicates a cost saving (was not assessed during the study). The APP implementation is undergoing evaluation.

Conclusion

Systems thinking and SSM have limited applicability in the NHS because the methods have been applied to wicked (complex and unanswered) problems. Our work shows that there is some benefit to be gained from SSM application in tame, well defined problems to help understand and solve the problem.

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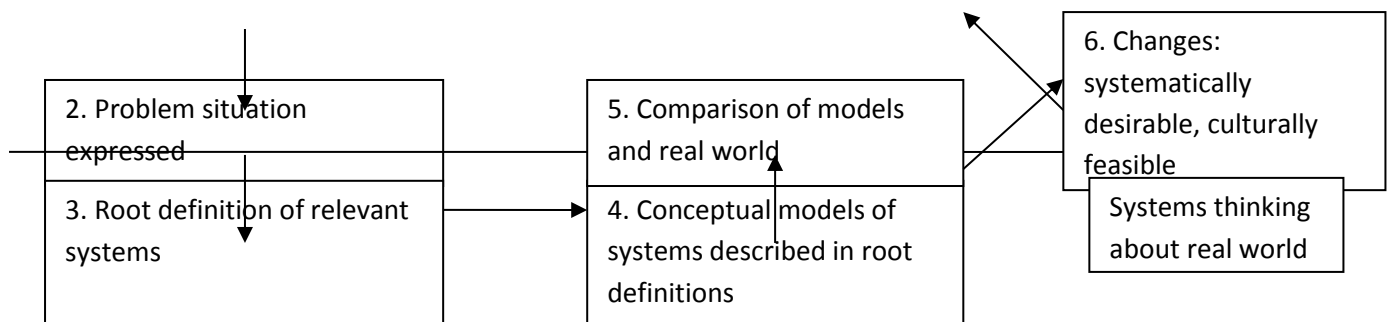
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Figure 1: Soft systems methodology - Checkland's 7 stage overview



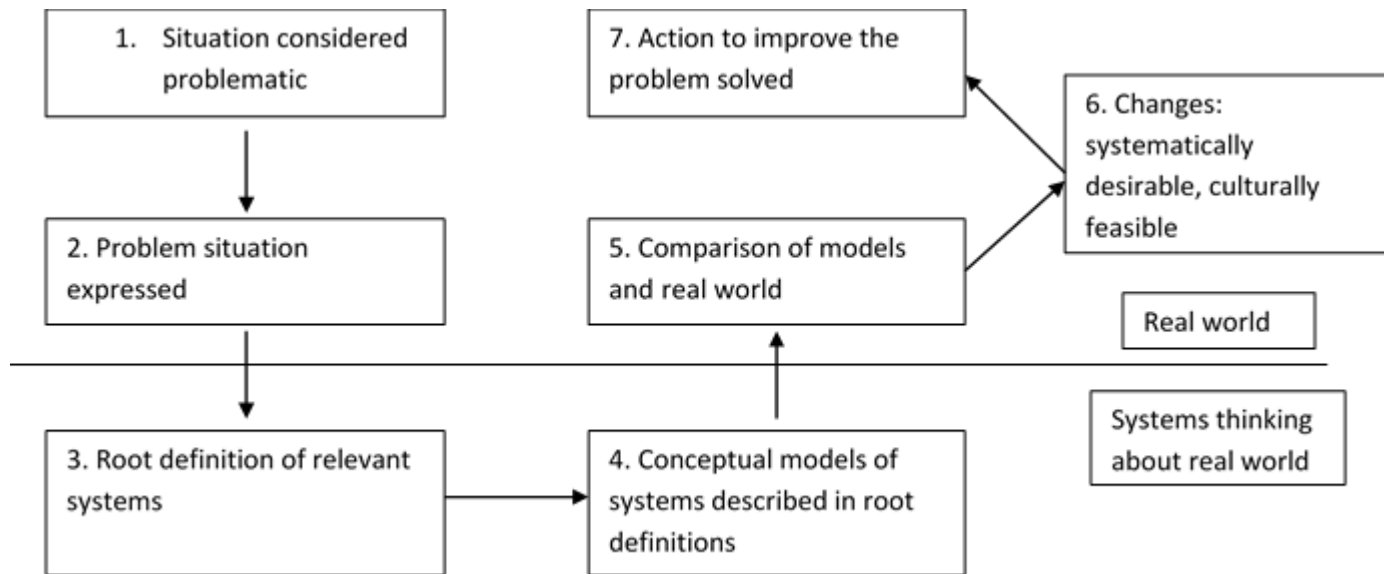


Figure 2: Reasons why severe asthma patients were not going to ED when they needed to.

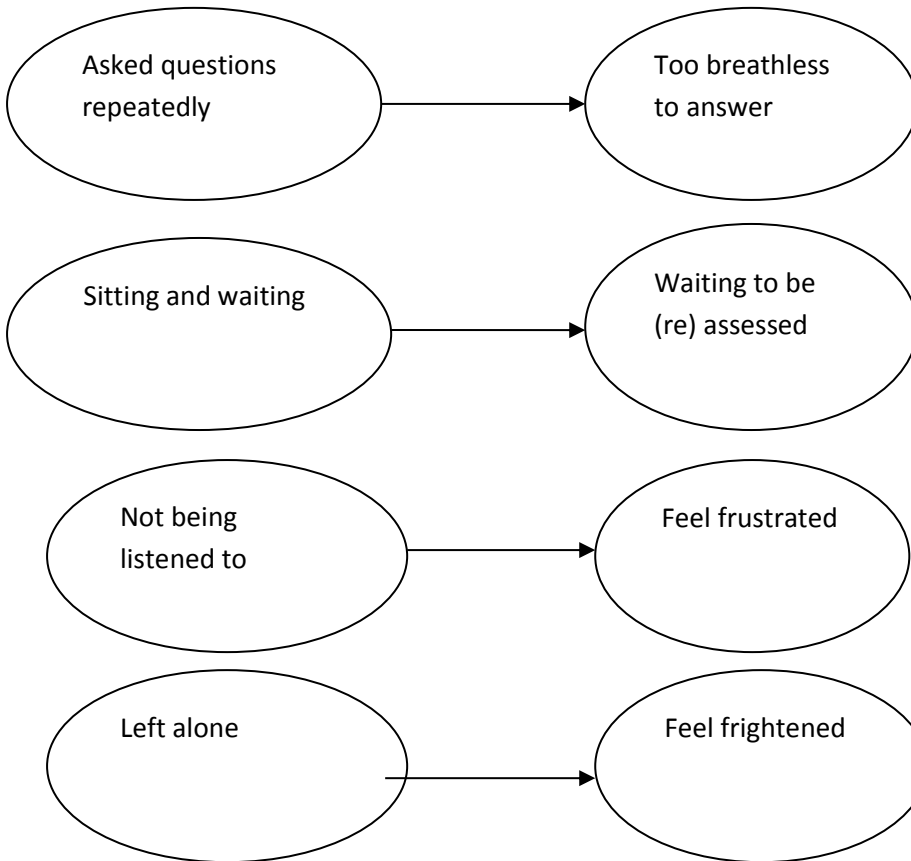
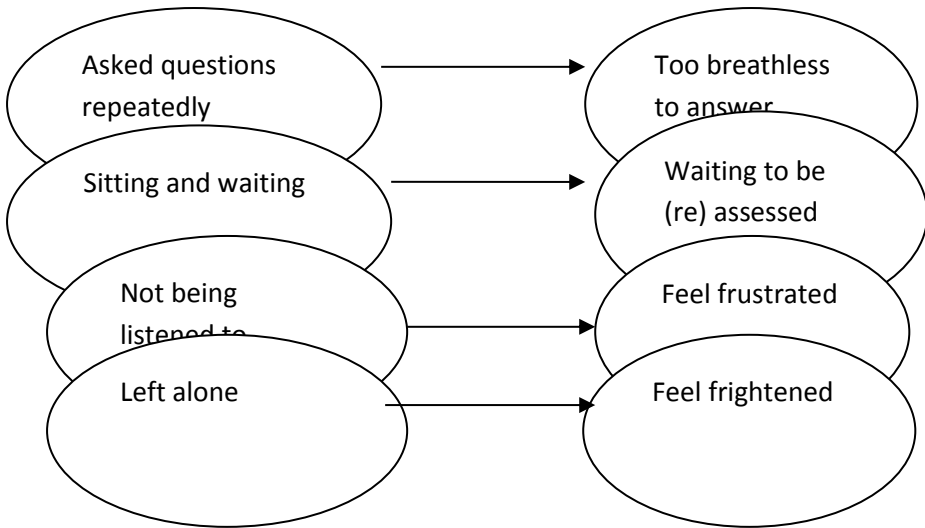


Figure 3: The Asthma Patient Passport

I have brittle asthma. Please direct me straight to the resuscitation unit. I may be unable to talk/answer your questions. Please see below:

Contact details:

Name _____

Date of birth _____ Age _____ NHS number _____

Address _____

Telephone _____

Next of kin _____

Relationship _____ Telephone _____

GP Practice _____

GP's name _____ Telephone _____

Consultant's name _____

Drug allergy/Adverse reaction: _____

Pre-hospital treatment: _____

Previous admissions:

ITU: _____ Y / N _____ Date _____

with intubation: Y / N _____ Date _____

HDU: _____ Y / N _____ Date _____

This asthma passport was agreed by me

and _____

on _____

Review date _____

Triggers: _____

Best peak flow/FEV1 reading: _____

If I need an arterial blood gas please: _____

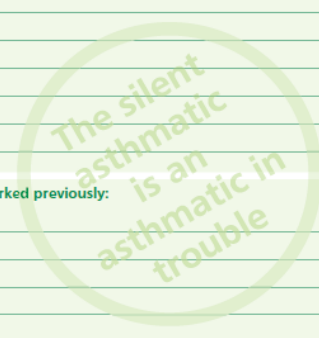
My signs and symptoms in an asthma emergency:

- _____
- _____
- _____

What has worked previously:

- _____
- _____
- _____

This asthma passport is intended as a guide only. Always use clinical judgement and maintain patients privacy and dignity.



I have brittle asthma. Please direct me straight to the resuscitation unit. I may be unable to talk/answer your questions. Please see below:

Contact details:

Name _____

Date of birth _____ Age _____ NHS number _____

Address _____

Telephone _____

Next of kin _____

Relationship _____ Telephone _____

GP Practice _____

GP's name _____ Telephone _____

Consultant's name _____

Drug allergy/Adverse reaction: _____

Pre-hospital treatment: _____

Previous admissions:

ITU: _____ Y / N _____ Date _____

with intubation: Y / N _____ Date _____

HDU: _____ Y / N _____ Date _____

This asthma passport was agreed by me

and _____

on _____

Review date _____

Triggers: _____

Best peak flow/FEV1 reading: _____

If I need an arterial blood gas please: _____

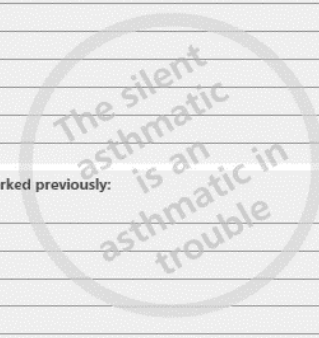
My signs and symptoms in an asthma emergency:

- _____
- _____
- _____

What has worked previously:

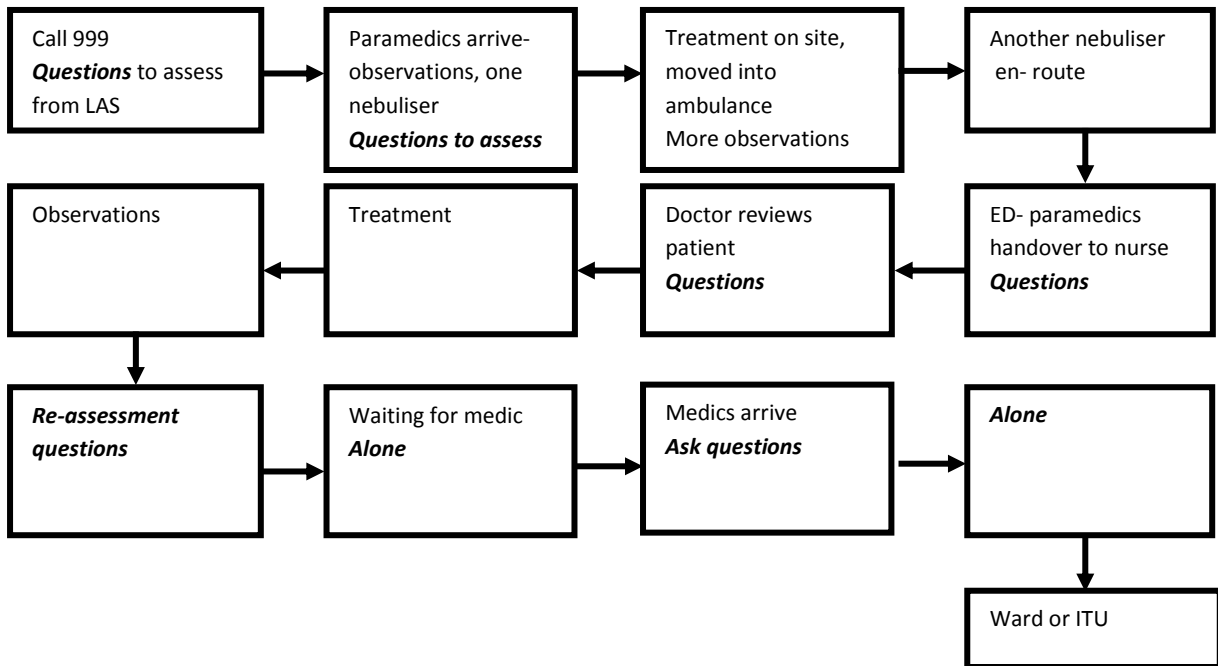
- _____
- _____
- _____

This asthma passport is intended as a guide only. Always use clinical judgement and maintain patients privacy and dignity.

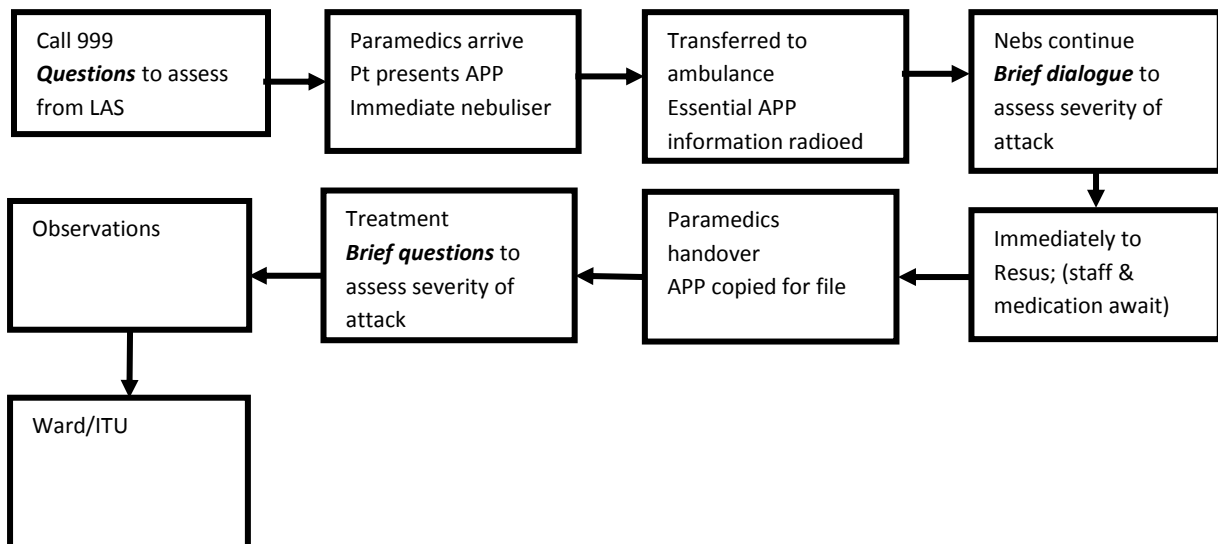


Appendix 1:

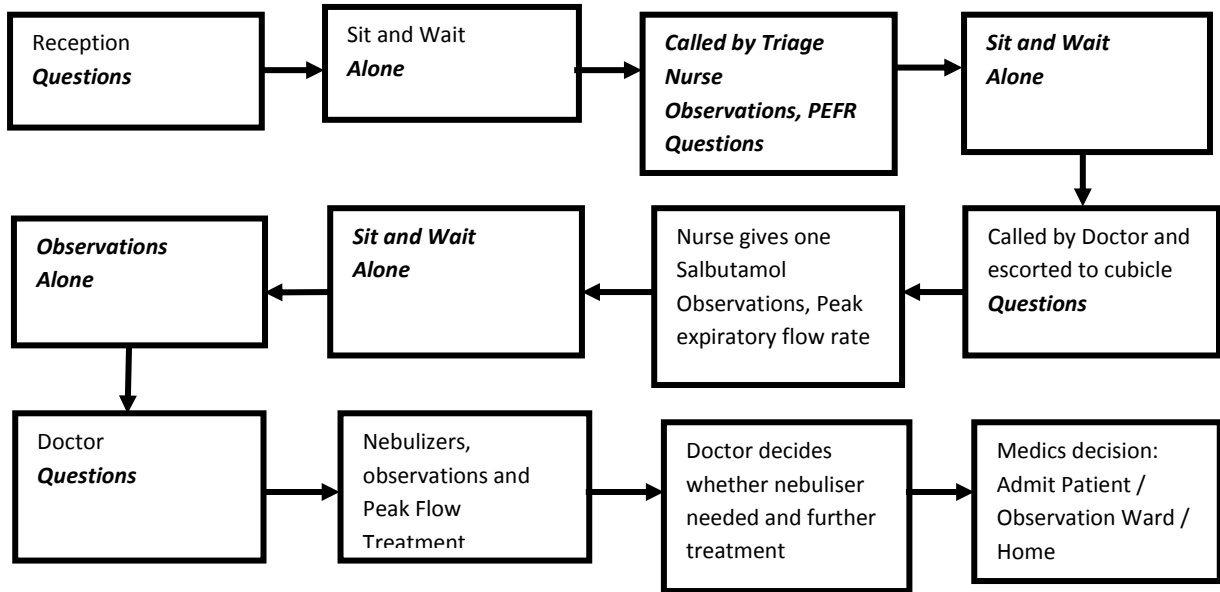
Ambulance process mapping before the introduction of the APP



Ambulance process mapping after the introduction of the APP



Self-presenting at the Emergency Department process mapping before the APP



Self-presenting at the Emergency Department process mapping after the introduction of the APP

