

# Early Sepsis in Children Assessment by Parents: an Evaluation



The **ESCAPE** project

Final Report

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## **Conflict of Interest**

The project team members have no conflict of interest to declare.

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## PUBLIC SUMMARY

Sepsis is one of the leading causes of death in children worldwide. The death rate among children caused by sepsis is around 10-20% globally. No figures are available in the UK about the number of deaths in children who suffered from sepsis. However, fever often indicates the onset of an infection or sepsis in children. Current figures indicate that parent-reported symptoms of fever in their child range between 20-40% and fever is the second most common cause of a child's hospital admission. Although most children with fever suffer from a viral infection, it could be possible that a child is suffering from a serious bacterial infection (sepsis). Thus, early recognition of signs and symptoms of sepsis is crucial and influences the survival of children.

Two interventions have been developed to improve early sepsis recognition in children: the Sepsis Assessment & Management (SAM) leaflet for parents and the Desktop SAM application for General Practitioners (GPs). Both tools have been designed to connect the observations of the parents to the observations of the GPs and to support a common language understanding each other observations. The SAM leaflet uses amber and red fields to look for signs and symptoms: (1) Colour, (2) Activity, (3) Breathing, (4) Circulation, (5) Temperature & Body, and (6) Vomiting, Diarrhoea and Hydration. The leaflet also provided details regarding who to contact in case symptoms appear in the amber or red areas. Similar features are incorporated in the Desktop SAM. Both interventions were based on the NICE guideline 'Feverish illness in children' and developed with a large group of stakeholders, including parents.

This project aimed to evaluate the feasibility and pilot the implementation of the SAM leaflet and the Desktop SAM. Specifically, the objectives were to evaluate the use of the SAM leaflet by parents and GPs, and to evaluate the application and effectiveness of the Desktop SAM at GP practices. The methods used in the project were online surveys for parents and GPs and interviews with GPs. The survey for parents included questions about the experiences of using the SAM leaflet, their experiences with a GP visit, and also a standard questionnaire about the empowerment of families related to the health services of their children. The survey of the GPs asked questions about the use of the Desktop SAM application, the content, and how it helped them in making decisions about diagnosis and management of the sick child.

In total, 77 parents completed the online survey. Of these, 12 parents completed the questions related to the SAM leaflet, 66 parents completed the GP questions and 49 parents

completed the questions about family empowerment. The parents were positive about the SAM leaflet and found the leaflet useful, as one parent wrote: '*Very useful for deciding whether to get further advice or not*'. The majority of the parents were satisfied with their GP visit and they were treated with respect and given enough time. The parents who responded to the family empowerment questions felt fairly confident about their child health services. However, 24% of the parents stated '*sometimes*' when asked if they know what services their child needs. This was in line with the question if parents have a good understanding of the health service system for their child; only 18% of the parents stated '*very often*' on this topic. Therefore, the SAM leaflet might provide guidance to parents to contact the right health service at the right time, in order for their child to receive the right care.

The GP survey revealed a positive attitude toward the Desktop SAM. Nearly 70% of the GPs found that the Desktop SAM contributed to their clinical assessment. More than 60% of the GPs were positive about the Desktop SAM and thought this application assists them in clinical decision-making. Some suggestions were made to improve the Desktop SAM, which were mostly related to adding space for notes of the overall history taking and management plan. The interviews with the GPs revealed that there was an overall positive experience about the usability of the Desktop SAM. The application was found to be easy for data entry and was seen as a good 'prompt' tool. Also, the GPs found that the Desktop SAM provided a good reference for supporting parents, particularly the option to print the SAM leaflet directly from the application and discuss the leaflet with the parent.

Although this project has some limitations, such as the number of parents and GPs responding to the surveys, it is believed that the SAM leaflet and Desktop SAM can play a key-role in recognising early sepsis and timely treatment of sick children. Therefore, the recommendations are related to further implementation of the SAM leaflet and the Desktop SAM on a regional and national level.

#### Recommendations for SAM leaflet:

1. Develop a strategy to implement the SAM leaflet with a clear pathway to increase the awareness of the leaflet in the wider public, with a special focus on parents.
2. Develop an educational strategy for parents and healthcare professionals to increase the knowledge and understanding of the SAM leaflet.
3. Evaluate the SAM leaflet by assessing the effectiveness, understanding the change when using the SAM leaflet, and assess the cost-effectiveness.

Recommendations for Desktop SAM:

1. Develop a strategy to implement the Desktop SAM in healthcare settings.
2. Develop an educational strategy for healthcare professionals to increase the knowledge and understanding of the Desktop SAM.
3. Evaluate the Desktop SAM by assessing the effectiveness, understanding the decision-making processes, and assess the cost-effectiveness.

The development of the SAM leaflet and Desktop SAM was prompted by the tragic death from sepsis of a 3 year old child called Sam. The wider implementation and dissemination of the SAM leaflet and Desktop SAM needs to be undertaken by a collaborative network of parents, healthcare professionals, and other stakeholders. After all, parents, healthcare professionals, the NHS, the public, and politicians do not want to experience a so-called 'never event' again with the result of an unnecessary death of a child.

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## INTRODUCTION

On 23 December 2010, three-year-old Sam died due to several failures in a rapid diagnosis and treatment of sepsis by several healthcare services.<sup>1</sup>

Sepsis is a leading cause of death among patients globally. Patient mortality caused by sepsis can reach up to 30 to 50% depending on the severity of illness and healthcare settings.<sup>2</sup> In children, mortality rates from sepsis are much lower than in adults; current global estimates indicate that mortality rates of sepsis in children range between 10-20%.<sup>3-4</sup>

In the UK, approximately 37,000 patients die each year as a result of an infection and sepsis. Unfortunately, no data is available for children. However, since fever often indicates the onset of an infection or sepsis among children, evidence indicates that parent-reported symptoms of fever of their child range between 20-40%.<sup>5</sup> About one third of the visits of parents consulting a primary care site such as the Out-of-Hours Doctor, Walk-in-Centre, GP surgery or an Emergency Department are related to their child's fever.<sup>6</sup> Consequently, feverish children are the second most common cause of a hospital admission.

Given the impact of sepsis on patients and families, several initiatives have been developed by organisations over the past few years. The Global Sepsis Alliance (GSA) initiated the World Sepsis Day in 2012, an annual event to increase awareness of sepsis among the public and healthcare professionals. The GSA website provides information for the public, professional toolkits, and information about actions taken by countries and regions.<sup>7</sup> In the UK, several initiatives have been established by the public and healthcare professionals. The UK Sepsis Trust is a non-profit organisation and aims to increase the awareness of sepsis.<sup>8</sup> From a healthcare professional's point of view, the 2008 sepsis guidelines were revised in 2013.<sup>9</sup>

September 13 2015 | World Sepsis Day

**Paediatric Sepsis 6**  
 Sepsis is a CLINICAL EMERGENCY. Signs and symptoms of sepsis in children can be subtle. Ask doctors to check early. Early treatment of sepsis improves outcomes.

**Recognition:**  
 If a child with suspected or proven infection AND has at least 2 of the following:  
 • Core temperature < 36°C or > 38°C  
 • Inappropriate tachycardia (Refer to local criteria / APLS Guidance)  
 • Abnormal mental state (including: Irritability / lethargy / Responsiveness)  
 • Reduced peripheral perfusion (Prolonged capillary refill)

**Think: could this child have SEPSIS or SEPTIC SHOCK?**

**Response with Paediatric Sepsis 6:**

Action	Time taken
1. Give high flow oxygen	
2. Obtain intravenous/intramuscular access & take blood tests	
a. Blood culture	
b. Blood glucose - treat low blood glucose	
c. Blood gas (+ FBC, lactate & CRP if able for testing)	
3. Give IV or IO antibiotics	
Broad spectrum cover as per local policy	
4. Consider fluid resuscitation	
Aim to restore normal circulating volume and physiological parameters	
Titrate 20ml/kg boluses. Fluid over 2 - 10 ml, and repeat if necessary	
Cautions with fluid overload > 30ml/kg by prescription & hypotension	
5. Involve senior clinicians / specialists early	
6. Consider inotropic support early	
If normal physiological parameters are not restored after 2-40 ml/kg fluids, 20-40ml/kg dopamine may be given via peripheral IV or IO access	

Record any reasons for variation from Paediatric Sepsis 6 overhead

These guidelines, the *Surviving Sepsis Campaign Guidelines for Management of Severe Sepsis and Septic Shock*, are mainly focused on clinical in-hospital interventions. For the paediatric population the UK Sepsis Trust developed the Paediatric Sepsis 6 protocol (depicted left), which has been widely advertised among clinicians, community healthcare professionals and is also available for the public on their website. The protocol describes the signs and symptoms of sepsis in children to promote early recognition of sepsis by junior doctors and nurses, including six

important interventions for early initiation of treatment to improve outcomes among sick children.<sup>10</sup>

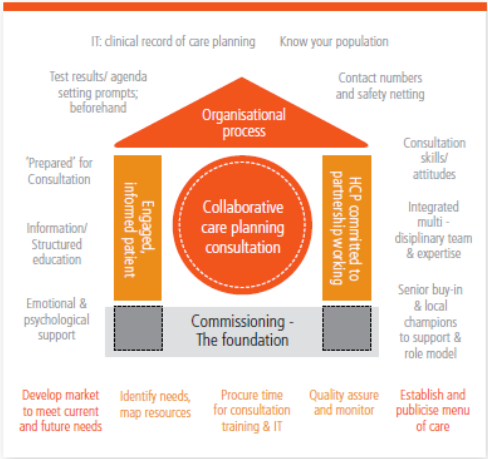
All initiatives have been developed over the past few years. Unfortunately, epidemiologic data documenting any improvement in the care of sick children with fever and sepsis are not yet available. The timeline might be too short, but the recurrent call for interventions to improve outcome is timely.

Despite the global and regional initiatives of the past few years, little data are available demonstrating improved outcomes of children with sepsis. Therefore, infections leading to sepsis remain the leading cause of death in children below 5 year of age. Interventions of early sepsis recognition mainly focus on the clinical settings. Further, the report ‘*Time to Act*’ by the Health Service Ombudsman seems to focus on the care failings that occur mainly in the first few hours in the hospital.<sup>11</sup> Regrettably, little attention is given to identify sepsis at the early stages of its onset; the home situation and community health services.

Clearly, sepsis in children does not start in a clinical setting but occurs and develops often rapidly in a home situation. Therefore and regardless of all initiatives by (clinical) healthcare professionals, it might be considered a serious omission to ignore the early assessment and recognition of sepsis in the community. Parents are the initial carers at the onset of a possible critical illness of their child. They often have a parental instinct of the intensity and progression of the sickness of their child. Although guidelines of early sepsis recognition are available on various websites, these might be complex and are not always written in clear layman language, thus difficult to use for parents.

NHS England envisions a transformation of patients and carers participation in health and care (depicted below). The aim is to ensure that “public, patient and carer voices are at the

centre of our healthcare services, from planning to delivery”.<sup>12</sup> With this strategic vision, it is timely to develop an early paediatric sepsis assessment tool by parents and for parents: a tool that is recognised by the front line healthcare professionals such as GPs and Pharmacists, and is integrated in the pathway of a sick child from community to hospital.



[www.selfmanagementsupport.health.org.uk](http://www.selfmanagementsupport.health.org.uk)



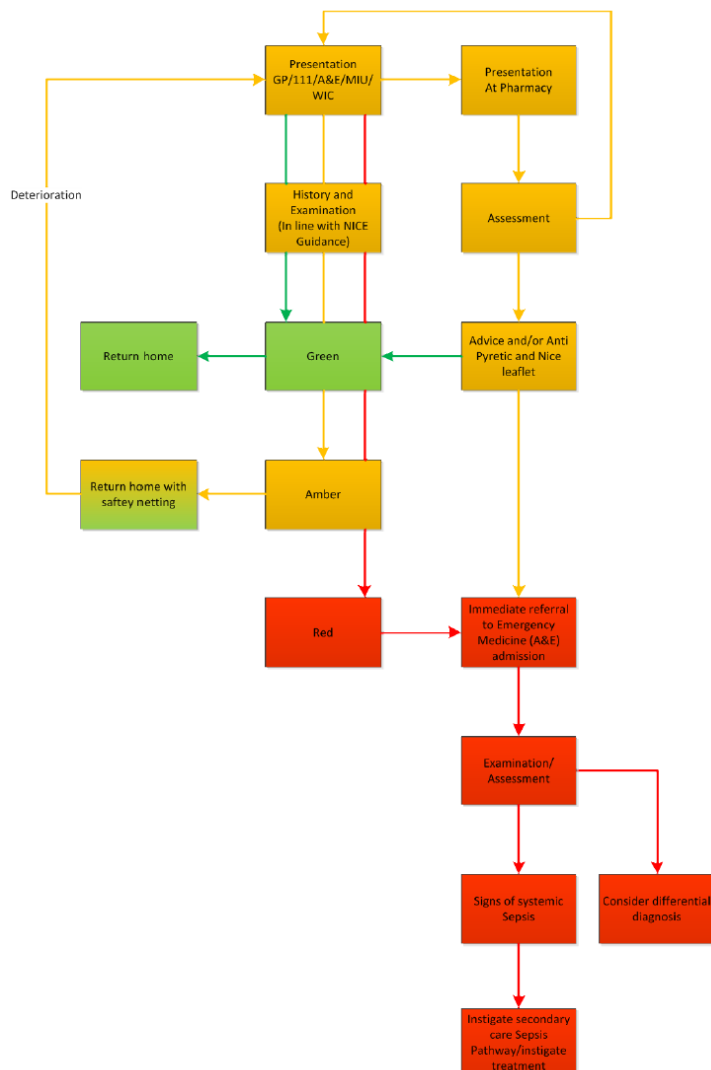
## PREVENTING SEPSIS IN CHILDREN

A child presenting with fever might alert the parents and healthcare professionals to an underlying infection. Fever is common in children, particular under 5 years of age. Between 20 to 40% parents report their child's fever annually and it is the most common reason to consult a doctor.<sup>5</sup> Often, parents are concerned about their child's fever and increased anxiety levels have been documented.<sup>13-15</sup> While most cases of children with fever might suffer from a viral infection, it may be possible that the child is suffering from a serious bacterial infection.<sup>16-17</sup> Therefore, early recognition of signs of a serious infection or sepsis is crucial and influences the outcomes of survival in children.<sup>14 18</sup>

A pathway for children with fever has been outlined (see right) using the NICE traffic light system (green, amber, red). The presentation of the child to a doctor starts either via a 111 call or at a GP surgery, MIU, WIC, or Emergency Department (ED). Parents could also seek advice at a pharmacy. All healthcare professionals should take a history and examine the child. The pharmacy should assess the child and provide the parents possibly anti-pyretic and information for further guidance. The child might return home on advice of the healthcare professional or may be referred to the ED for further examination.

The first place of consultation by the parents is often the GP. Unfortunately, evidence suggests that GPs working in primary out-of-hours care are more conservative

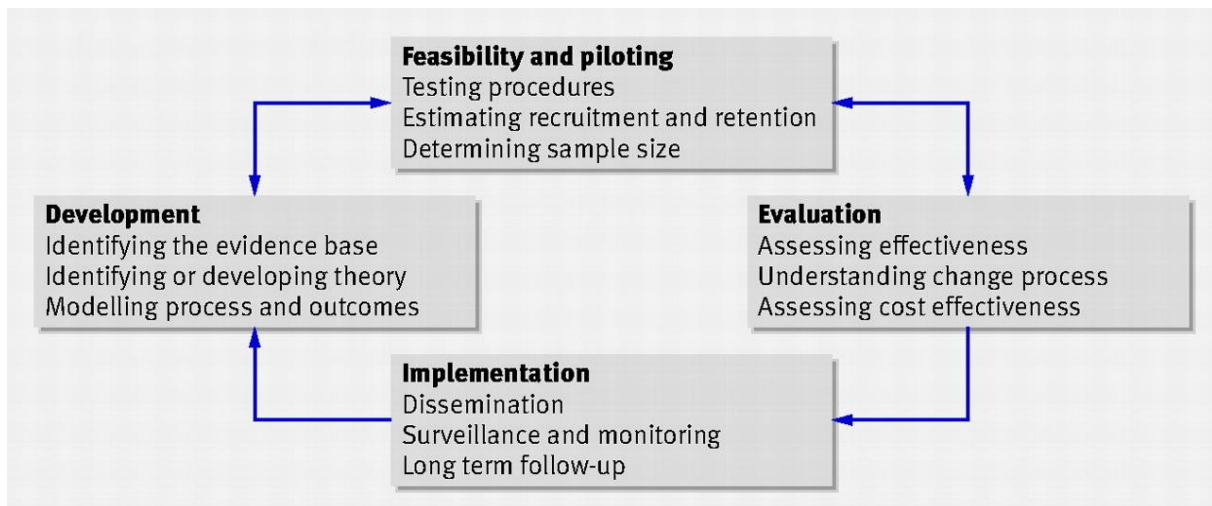
### Sepsis Pathway Ver.3



Susan Bracefield  
NHS England, DCIOS Area Team, Sepsis Working Group

in referring children with fever to ED, particularly if only one or two signs of serious infection are present.<sup>19</sup> Of the 3424 children with a positive referral indication, only 19% were referred to ED. Alarm features were absent in 20% of the referred children, suggesting that other factors might be important in decisions about referral of febrile children to ED. Subsequently to the available evidence and current practices, there is a need to improve early recognition, assessment, and urgent treatment of children with fever.

It is recognized that interventions to improve outcomes of the sepsis pathway might be complex. Therefore the Medical Research Council (MRC) guidelines for developing and evaluating complex interventions will be applied.<sup>20-21</sup> The key elements of the MRC guidelines are Development, Feasibility and Piloting, Evaluation, and Implementation.



Two interventions have been developed to improve the process of early sepsis recognition in children. The new interventions are primarily focused on the recognition of signs and symptoms of sepsis in the home situation and following the pathway in community healthcare settings. The interventions are for parents, GPs and acute physicians. The interventions have been designed to link together, with the philosophy that parents and healthcare professionals use the same common language. Understanding the concerns and observations of the parents will allow healthcare professionals to better assess and treat a child with an infection and possibly a sepsis.

### **SAM Leaflet**

The first intervention has two purposes: to empower parents in the care of their sick child and to assist parents in the consultation with healthcare professionals. A specific tool has been

developed to assess early sepsis symptoms in children. The name of the tool is SAM; Sepsis Assessment & Management. The rationale for developing the SAM leaflet was based on the report of the Parliamentary and Health Services Ombudsman; 'An avoidable death of a three-year-old child from sepsis'.<sup>1</sup> The report recognised that there were no good safety-netting tools available for parents. The Sepsis Working Group and the parents of Sam started to develop the SAM leaflet taking the current evidence into account such as the NICE guideline 'Feverish illness in children'.<sup>5</sup> The vision of the parents within the Sepsis Working Group expressed their wishes not to develop a safety-netting instrument but rather a leaflet that would help parents in making informed decisions. Representatives of mumsnet ([www.mumsnet.com](http://www.mumsnet.com)), the UK's largest network for parents, were involved and reviewed the SAM leaflet in terms of understanding and practicality. Initially, the SAM leaflet used the NICE traffic light system for the signs and symptoms. However, parents preferred to include only signs and symptoms belonging to the amber and red sections. Therefore, the normal signs and symptoms in the green section were deleted. The final version of the SAM leaflet uses the amber and red fields to recognise signs in six major physical topics: (1) Colour, (2) Activity, (3) Breathing, (4) Circulation, (5) Temperature & Body, and (6) Vomiting, Diarrhoea and Hydration. Guidance is provided to contact the appropriate health service based on the amber or red areas.

### Desktop SAM

The second intervention has been developed to facilitate uniform assessment by GPs. A desktop application - Desktop SAM - has been developed with the similar outline of the SAM leaflet. Dr. Paul Johnson and Dr. John McCormack, GPs, developed the Desktop SAM. The NICE guideline of children with fever was used to create the template of signs and symptoms. The content of the Desktop SAM and the SAM leaflet have been designed to a comparable set of signs and symptoms with the vision to provide both tools speaking the same language i.e. between parents and GPs.

The Desktop SAM runs under the IT application “SystemOne” that was introduced at GP practices in South West Devon and Torbay area. The Desktop SAM was also made available at the ADAstra system for out-of-hours GPs in Devon. Although SystemOne already includes a child fever assessment application, the Desktop SAM application provides a clear overview using the NICE traffic light colours and provides further actions based on the completion of the online assessment.

## IMPLEMENTATION PROCESS

Implementation of the paediatric sepsis pathway has followed a number of processes:

1. Dissemination of the SAM leaflet via: the Red Book (child health record held by parents), a media campaign through local newspapers (series of stories about sepsis, interviews parents, advertorials, etc), social media, and the NHS England website (Devon and Cornwall page).
2. Implementation of the Desktop SAM application at GP practices (n=12) that are on SystemOne in Torbay and South Devon:
  - Workshops with GPs to encourage them to embed the Desktop SAM in their assessment of a feverish child and ask parents about their SAM assessment of their child
  - IT implementation of the Desktop SAM application on all desktop computers at 12 GP practices in Torbay and South Devon.

The key-evaluation points

<b>Intervention</b>	<b>Key-evaluation points</b>	<b>Expected outcomes</b>
SAM leaflet	Parents: <ul style="list-style-type: none"> <li>• Evaluate with parents (survey)</li> </ul>	<ul style="list-style-type: none"> <li>• Parents use SAM leaflet at home</li> <li>• Parents use SAM leaflet when communicating with GPs about their feverish child and feel empowered</li> <li>• Public awareness of SAM leaflet</li> </ul>
Desktop SAM	GPs: <ul style="list-style-type: none"> <li>• Evaluate with GPs (survey, interviews)</li> </ul>	<ul style="list-style-type: none"> <li>• Application available and used at GPs practices</li> <li>• Child managed appropriately, according to the parental guidance, SAM, Desktop SAM</li> </ul>

## AIMS AND KEY QUESTIONS

The aim of the project was to evaluate the feasibility and pilot the implementation of the SAM leaflet and the Desktop SAM.

The objectives were:

1. To evaluate the use of the SAM leaflet by parents and GPs
2. To evaluate the application and effectiveness of the Desktop SAM at GP practices

The key evaluation questions were:

- 1.1 Is SAM an effective tool to allow parents to make informed decisions?
- 1.2 Is SAM an effective tool to support shared decision-making between parents and GPs?
- 2.1 Is the Desktop SAM at GP practices an effective tool to guide GP decisions?

## METHOD OF EVALUATION

This feasibility project used a mixed methods design. The mixed methods included qualitative methods (interviews with GPs) and quantitative measures (surveys with parents and GPs). The data collection period was between April 2015 and November 2015.

### Population and recruitment

The recruited parents and GPs were from Torbay and South Devon. Recruitment took place after ethical approval by the Human Research Ethics Committee of Plymouth University.

**Parent survey recruitment:** A convenience sample was employed for the parent survey. It was anticipated to receive around 100 responses; ideally one group of parents who have used the SAM leaflet (n=50) and one group of parents who did not use the SAM leaflet (n=50). Recruitment of parents took place via various strategies. The first approach was to invite parents via the practice manager at the GP practices. The aim was for the practice manager to invite parents orally and hand over a written invitation and patient information sheet. The second approach was via an information flyer. The information leaflets, 10,000 printed, were distributed to GP practices, pharmacists, hospitals, ambulance services, out-of-hours, nurseries and pre-schools. The third approach was informing parents via the media. An article was published, alongside the information leaflet, in the HERALD EXPRESS on Wednesday, April 29, 2015.

## Parents asked to help shape NHS care for future

PARENTS across South Devon and Torbay are being asked to help assess the effectiveness of a colour-coded symptom-checker which helps to safeguard children from a bloodstream infection which can cause damage to vital organs and even kill.

Thousands of SAM (sepsis awareness and management) leaflets were distributed late last year across South Devon and Torbay as part of a pilot scheme, following the case of three-year-old Sam Morrish, from Newton Abbot, who died from sepsis in December, 2010.

The sepsis awareness campaign involved South Devon and Torbay Clinical Commissioning Group, Torbay Hospital, Public Health, GP practices, pharmacies and other local organisations.

It will be rolled out across the region and then the country when it has been evaluated.

This comes as sepsis rises up the national agenda, especially in the light of Sam's case and of a report by the NHS Ombudsman which called for action against a condition which claims 37,000 lives annually.

Most deaths involve adults, but children die every year and more are left with disabilities.

Susan Bracefield, who has led work on the project for NHS England, said it is important parents of children who have had sepsis share their views on the system-checker.

She added: "There was a lot of enthusiasm among parents when they came across the SAM leaflets, especially as sepsis was often completely new to them.

"But the acid test is whether they were useful when children did develop potential symptoms. Were they easy to understand and did they help parents take the right action? Are there things we could improve or should change before making similar information available to parents elsewhere?"

"Only parents really know, so their insights will be crucial in making sure we do the right thing in future. It's their chance to make a real difference, based on their own experiences."

Part of the problem with sepsis in children is the early, feverish symptoms can easily be mistaken for common and less-serious conditions. There is no single test as there is for meningitis, for example.

The SAM leaflet has been designed for parents to take away after seeing the doctor or getting other NHS advice, so they can look out for other potential signs of sepsis, such as drowsiness, vomiting or dehydration.

Sepsis is still very unlikely, but parents need to be on the lookout and to act quickly if necessary.

The leaflet is a key element in a broader care 'pathway' across the entire healthcare system in South Devon and Torbay.

Nothing like this exists in the NHS — nor in the rest of the world.

The aim is to ensure parents are always asked the right questions and those children who do have severe sepsis always go on to get the right treatment, whatever their point of contact with the NHS.

Any parent who has used the symptom-checker is therefore being asked to complete an online survey and/or to take part in a short interview — face to face or by phone — so their experience can help others in the future.

The survey is available at [www.research.nhs.uk/sepsis-project/nhs.net](http://www.research.nhs.uk/sepsis-project/nhs.net)

Parents who want to take part in the interview process can call 0113 824 8778 or email [sepsis.project@nhs.net](mailto:sepsis.project@nhs.net)



## Have you used the SAM sepsis leaflet?



**Tell us about your experience – and help save lives**

Late in 2014, thousands of SAM leaflets were circulated in South Devon and Torbay to help parents protect their children from sepsis – a response to severe infection that can cause damage to vital organs and even kill.

Have you used it to check symptoms? If so, did it help? And how could we make it better?

Please share your experience so others can benefit in the future, by:

- Completing our online survey at: [www.research.nhs.uk/sepsis-project/nhs.net](http://www.research.nhs.uk/sepsis-project/nhs.net)
- Or, if you are happy to take part in a phone or face-to-face interview, call: 0113 824 8778 or email: [sepsis.project@nhs.net](mailto:sepsis.project@nhs.net)

What you say will help shape NHS care here and elsewhere, as we seek to reduce the toll from sepsis

Thank you





Despite the three approaches to invite parents to participate in the survey, responses were very low. Therefore, a fourth approach was deployed: Twitter™. Messages about the SAM leaflet and related survey were tweeted. The tweets used are listed in Box 1 below. In total, 77 parents completed the survey.

### **Box 1.** Twitter messages

- Have you used the SAM leaflet? Would you be interested in talking to us about it?
- Do you live in South Devon and have you used the SAM leaflet? If so please take our survey
- Sepsis in children. If you have seen the SAM leaflet could you please take our short survey
- Aware of Sepsis Assessment in children? Please take our short survey
- Sepsis and the SAM leaflet. Have you used it? Please take our survey
- Has your child had a fever? Info here about Sepsis Assessment Measure for children
- Look out for the signs of Sepsis with the SAM leaflet available here
- Do you know what to look for if your child has a temperature and you are concerned?
- Do you know about Sepsis in children? Further information here
- #sepsis #sepsisassessment #sepsisresearch #sepsisawareness #research #awareness #childhealth #fever #SAMleaflet #symptoms

**GP interview recruitment:** Sample size of the GPs was based on the participating GP practices in Torbay and South Devon. Around 80 GPs are based at the 12 participating GP practices. For the interviews with the GPs, a purposive sampling strategy was employed. The sample size follows the guidelines of qualitative research and generally between 5 to 25 participants is sufficient to reach data saturation (the point at which no new themes emerge).<sup>22</sup> There were 12 GPs invited for the interview; eight GPs agreed and were interviewed.

**GP survey recruitment:** The sample for the questionnaires was all GPs of the participating GP practices.<sup>24</sup> Totally, 80 GPs were invited by an invitation letter and 21 GPs completed the survey.

### ***Instruments***

**Parent survey:** The questionnaire for parents included three sections. The first section contained questions related to the use and content of the SAM leaflet. The second section used questions from the GP survey to ask about their most recent contact with the GP practice. The third section was the Family Empowerment Scale (FES)<sup>23</sup>. The FES was included in the survey to explore whether parents who used the SAM leaflet were already 'empowered'. The FES was developed in 1997 and originally designed for assessing the



empowerment of parents whose children have emotional disabilities. The 34-item FES has three domains (family, service system, community/political). Empowerment is operationalized by attitudes, knowledge and behaviour. The FES has adequate psychometric properties<sup>23</sup>.

**GP survey:** A bespoke questionnaire was designed for the GP survey. The 12 questions were related to the practice of using the Desktop SAM, the content, and how it facilitates decisions about diagnosis and management, including safety-netting for the child.

**GP interviews:** An interview guide was developed for the semi-structured interviews with the GPs. The interview questions were related to the structure (IT issues), process (operation of application) and outcome (decision-making and communication with parents) of the Desktop SAM and the SAM leaflet.

### ***Data analysis***

The quantitative analysis of the surveys was performed by IBM/SPSS version 22 (IBM Corp. Released 2013.). Descriptive statistics using counts and percentages were applied. Data is presented as percentages at item level of the surveys.

The qualitative analysis aimed to explore the experiences of GPs. The interviews were analysed using thematic analysis. This method included an analysis strategy suitable for identifying themes and subthemes.<sup>25</sup> The first step concerned the familiarization of the narratives and two researchers independently read the transcripts. In the next step, two researchers independently coded the text by allocating the text fragments to codes. In the following step the two researchers discussed the results of the individual codes and reached consensus. After this, the codes were reviewed and themes were formulated. The final step was the determination of meaningful text fragments, codes (sub-themes) and themes.

## RESULTS

### *Parent Survey*

A total of 77 parents completed the online questionnaire between 13 July 2015 and 19 November 2015. However, not all of the questions were answered by all parents. Results are presented below related to: experience using SAM (n=12 respondents), experience with the GP (n=66 respondents) and completion of the Family Empowerment Scale (n=49 respondents).

The majority of respondents were female (n=70, 91%). The age ranged between 20 to 55 years. The majority of respondents were aged 36-40 (n=23, 61%), followed by 31-35 age group (n=17, 23%). The majority of respondents stated their ethnic group as white (n=71, 92%). Respondents had 0-3 children living in the household, with the majority having 2 children living at home (n=25, 33%). Of the respondents, 35 (47%) were in paid employment of 30+ hours per week; 18 (23%) respondents were in part-time employment of <30hours per week; 11 (14%) respondents were looking after the home. Only 40% (n=31) were residing in South Devon.

Awareness of the SAM leaflet was fairly low, with only 16% (n=12) of respondents stating that they were aware of it and only 8% (n=6) had actually used the SAM leaflet. However, given that only 40% (n=31) lived in the area where the leaflet was distributed, this percentage is more accurately reflected as 39%. Of the six people who had used the SAM leaflet; two mentioned that they had obtained it from a GP, one from a newspaper and one from the Red Book.

Parents wrote several comments at the open-ended question to share the experiences of the SAM leaflet. These comments were mostly related to the usefulness of the SAM leaflet:

- *'On the 30th July my son had abdominal pains. Later that evening he started to vomit and it contained a small amount of blood. He went a funny colour and he had a pin prick rash around his eyes. The following day, 31st July, we called the doctor who came and examined my son saying it looked like gastroenteritis and to keep fluids up. The rash around his eyes, we were told, was to do with him straining to vomit. Later on, that afternoon, he started having diarrhoea and his stomach pains were getting no better. On the 1st Aug my son was still in lots of pain, not keeping fluids down, very weak, no appetite and hadn't passed urine for 12 hours. We called 111 and got an appointment to see the doctor on call, at the local hospital. The doctor examined him and confirmed gastroenteritis. We were advised to keep fluids going and was prescribed a stronger pain killer. The doctor did also advise us, if pain got worse to take him to A&E. When we got back*

home I gave my son the painkillers and i had a look at the SAM leaflet. It occurred to me that my son had 4/5 features on the red high risk page. I had just put the leaflet down when my son started screaming and almost going unconscious with pain, that was when we dialled 999. Later that day, 1st Aug, my son had an operation. The surgeons found that he had a burst gangrenous appendicitis and peritonitis. It was at this point I stressed my concerns about sepsis, I was reassured he would be on a iv antibiotics to protect him. My son remained very poorly for 4 days before slowly improving. I don't know if my son was septic or not, but I am so pleased I was aware of it'

- 'I was given the leaflet from my GP when my toddler has an infection. I found it very informative'
- 'Very useful for deciding whether to get further advice or not'
- 'Just put it on my fridge for me to worry more. I'm already aware of most of the signs to look out for. And your gut instinct I find is always right'
- 'I've looked at it and thought it was useful to keep handy for when I am worried. It has helped me know what to look out for and start monitoring. But I haven't needed to refer to it yet'

One parent wrote about the distribution of the SAM leaflet saying: 'health professional publicising the leaflet'.

Parents were asked about their experience at their most recent appointment with a doctor at their GP surgery or health centre and rated a number of statements. (Table 1)

**Table 1.** Experiences of most recent contact with GP or health centre

	Very Good Good	Neither Good nor Poor	Poor Very Poor	Doesn't Apply
Giving you enough time (n=66)	76%	12%	11%	1%
Asking about your symptoms (n=66)	74%	14%	11%	1%
Listening to you (n=66)	70%	14%	15%	1%
Explaining tests and treatments (n=65)	52%	20%	19%	9%
Involving you in decisions about your care (n=66)	55%	24%	18%	3%
Treating you with care and concern (n=66)	69%	21%	9%	1%
Taking your problems seriously (n=66)	64%	14%	21%	1%

Overall, parents responded positively and rated the statements as 'Very Good' (26.9%) and 'Good' (38.6%), compared with only 3.91% who rated the statements as 'Very Poor'.

When asked whether they had confidence in the doctor they saw, 40.9% (n=27) said 'Yes, definitely' and 45.5% (n=30) said 'Yes, to some extent. Conversely, only 12.1% (n=8) said 'No, not at all'.

The majority of parents were satisfied with the care that they had received at their GP surgery or health centre. (Table 2)

**Table 2.** Satisfaction with GP surgery or health centre

How satisfied are you with the care that you got at your GP surgery or health centre?	Response (n=64)
Very Satisfied	39%
Fairly Satisfied	36%
Neither Satisfied or Dissatisfied	13%
Fairly Dissatisfied	11%
Very Dissatisfied	1%

A total of 13 parents made comments in relation to their experience at their GP surgery or health centre.

Some comments were positive:

- *'respectful understood about your medical conditions meds etc. kind caring'*
- *'The Dr was much better than the Dr's at urgent care'*

The negative comments related mainly to access:

- *'Visiting a GP for referrals is nigh on impossible. My 3.5 yr old needs speech therapy'*
- *'Very hard to make an appointment'*
- *'Rarely get to see the doctor as they won't let you make an appointment. All by phone which is worrying with a child'*

Other feedback provided was related to communication:

- *'Although we did receive good/excellent care throughout my sons treatment. I sometimes feel that doctors think we are over reacting parents. I knew my son was really really poorly and it's hard to get that across'*
- *'Most of the GPs we see are very patient and kind and helpful, unfortunately we have a new GP who is less so. Speaks over you, and doesn't come across as caring or compassionate'*
- *'My doctor sent me home. The next day I took my new-born to A&E & he was admitted into hospital'*
- *'Unrelated to the original problem, my son was asked if he gets an itchy throat, my son said sometimes. The doctor then said he suffered from hay fever and told us to buy an over the counter'*

*remedy! He's never suffered from it before and I felt that this suggestion was uncalled for as my son now thinks he has hay fever!*

- *'Prefer a doctor to talk rather than give out leaflets for every condition known to man. They are professionals and will individualise care to a patient rather than say the same thing to every person - which is what a leaflet does'*

### **Family Empowerment Scale (FES)**

The answer option for every statement was a 5-point scale; 1=never; 2=seldom; 3=sometimes; 4=often; 5=very often. Scores for the FES are given below in percentages. In detail, the individual statements of the three subscales are presented in percentages in Tables 3.1 to 3.3.

**Table 3.1.** Family Empowerment Scale: subscale About Your Family

About Your Family	Never %	Seldom %	Sometimes %	Often %	Very often %	n
When problems arise with my child, I handle them pretty well	0	0	14	41	45	49
I feel confident in my ability to help my child grow and develop	0	2	6	45	47	49
I know what to do when problems arise with my child	0	2	14	51	33	49
I feel my family life is under control	0	0	16	55	29	49
I am able to get information to help me better understand my child	0	2	10	49	39	49
I believe I can solve problems with my child when they happen	0	0	18	51	31	49
When I need help with problems in my family, I am able to ask for help from others	0	2	14	49	35	49
I make efforts to learn new ways to help my child grow and develop	0	0	4	47	49	49
When dealing with my child, I focus on the good things as well as the problems	0	0	6	51	43	49
When faced with a problem involving my child, I decide what to do and then do it	0	0	12	49	39	49
I have a good understanding of my child's disorder	15	0	15	35	35	46
I feel I am a good parent	0	2	13	54	31	48

**Table 3.2.** Family Empowerment Scale: subscale About Your Child's Services

About Your Child's Services	Never %	Seldom %	Sometimes %	Often %	Very often %	n
I feel that I have a right to approve all services my child receives	0	6	11	40	43	47
I know the steps to take when I am concerned my child is receiving poor services	0	20	30	37	13	46
I make sure that professionals understand my opinions about what services my child needs	2	2	24	48	24	46
I am able to make good decisions about what services my child needs	0	4	13	52	31	46
I am able to work with agencies and professionals to decide what services my child needs	6.5	6.5	22	43	22	46
I make sure I stay in regular contact with professionals who are providing services to my child	7	4	28	39	22	46
My opinion is just as important as professionals' opinions in deciding what services my child needs	2	4	13	35	46	46
I tell professionals what I think about services being provided to my child	4	13	13	46	24	46
I know what services my child needs	4	0	24	41	31	46
When necessary, I take the initiative in looking for services for my child and family	2	0	13	47	38	45
I have a good understanding of the service system that my child is involved in	4	4	20	54	18	46
Professionals should ask me what services I want for my child	2	4	18	35	41	46

**Table 3.3.** Family Empowerment Scale: subscale About Your Involvement in the Community

About Your Involvement in the Community	Never %	Seldom %	Sometimes %	Often %	Very often %	n
I feel I can have a part in improving services for children in my community	17	15	30	23	15	47
I get in touch with my MP when important legislation or policy issues concerning children are pending	53	23	13	9	2	47
I understand how the service system for children is organized.	15	24	31	26	4	46
I have ideas about the ideal service system for children	19	19	28	30	4	47
I help other families get the services they need.	30	25.5	25.5	13	6	47
I believe that other parents and I can have an influence on services for children	11	13	38	25	13	47
I tell people in agencies and government how services for children can be improved.	41	22	11	17	9	46
I know how to get agency administrators or legislators to listen to me	38	32	21	9	0	47
I know what the rights of parents and children are under the special education laws.	26	35	24	13	2	46
I feel that my knowledge and experience as a parent can be used to improve services for children and families	17	17	13	33	20	46

At the end of the Family Empowerment Scale, parents were asked if they had any further comments to make. Seven parents responded and provided valuable suggestions:

- *'I don't think info is readily available, and every time we have taken our child to GP or hospital when very very ill, nothing has been done-even with. 41 degree temp she wasn't ever seen by Dr at hops as they didn't have time'*
- *'I have found in the area were I lived I was never listened to by professionals in meeting or respected about knowing my own children or trying to get them support or help. Often in meetings I was bullied by professionals and made to feel worthless not only as a parent but as a human being. They didn't support me or my children and often the meetings went round in circles and often nothing was resolved in any support for the children or myself. At times staff were disrespectful and put me down and humiliated me in front of other professionals and then other professionals would get together and bully me. They would often say I needed more support and then say children should be on child protection often I didn't know what I did wrong and I thought I was a really bad parent. Then eventually they started to tell me there was no evidence of me being a bad parent but I was a great parent. I am not a perfect parent and often make loads of mistakes but I try my best sometimes I make or say the wrong things to my kids but I don't; believe that I deserve or my kids to be treated this way by professionals who work with children. I now don't trust professionals who work with children because of the damage they have done to my kids and the harm my children have gone through. Professionals also came into my home supposed to work and help my children but bullied and humiliated them as well this is not acceptable from any professional who works with any child to treat a child in this dehumanising way. To me every child matters in this country and in this world we live in'*
- *'I do feel professionals need to listen more to the whole family...'*
- *'Getting clinical help from GP's or hospitals is more self-explanatory but getting community help for development needs is like working in treacle. School nurses are inaccessible and even the teachers would not recognise them. GPs won't refer to psychologists or developmental physios'*
- *'I am a primary school teacher. Professionally I know more than I do as a parent'*
- *'Professionals are professionals - parents who read the odd internet blog are not. This is against the current mood I know but I would rather trust a professional than a self-selected patient/parent "expert" often with a personal agenda'*
- *'My daughter has ALL so we have a lot of contact with all the agencies and sepsis is a HUGE concern to us as parents'*

### Questionnaire GPs

A total of 21 GPs responded to the online questionnaire about the Desktop SAM. However, not all of the questions were answered by all practitioners. The majority of respondents were GPs (n=19, 91%) with the remaining respondents being a GP SpR, an IT lead, and a clinical champion for SystmOne.

Of the 21 respondents, 71% (n=15) had used the Desktop SAM in a clinical setting.

Reasons for not using the Desktop SAM stated by the remaining six respondents were:

- *'I did not feel it would add to how I currently deal with this clinical presentation'*
- *'I was unaware of the Desktop SAM'*
- *'I can never find the pathway to the desktop SAM on SystmOne'*
- *'The desktop SAM is far too longwinded and time-consuming to fill in and use in the consultation'*
- *'Felt quite clunky and then added a lot of read codes to the patient journal'*
- *'IT role only'*

Three specific questions were designed related to the Desktop SAM and relevance to clinical assessment. Totally, 15 respondents completed these questions (Table 4). The majority of GPs felt that the Desktop SAM helped them in the clinical assessment.

**Table 4.** Desktop SAM and difference to clinical assessment (n=15)

n=15	No to not at all	Yes to totally agree
Did the list of symptoms assist your history taking?	33%	67%
Did the list of signs assist your examination?	27%	73%
Did the list signs and symptoms assist you in including or excluding sepsis as a differential diagnosis?	33%	67%

In response to whether there was any other effect on clinical assessment not covered here (in the answer options), one person stated: *'useful tool to triage the unwell child, but sepsis has not been on my differential recently - v rare!'*

Four specific questions were designed related to the use of the Desktop SAM and decision-making or efficiency of the consultation. In total, 13 respondents completed these questions (Table 5). The majority of GPs responded positively to the Desktop SAM being helpful in making clinical decisions.



**Table 5.** Desktop SAM, decision-making and efficiency (n=13)

n=13	No to not at all	Yes to totally agree
Did the traffic light score assist you in making a diagnosis?	46%	54%
Did the traffic light score assist you in including or excluding sepsis as a differential diagnosis?	38%	62%
Did the traffic light score assist you in making your management decision?	38%	62%
Did the recording of the signs and symptoms assist in the efficiency of your consultation?	23%	77%

In response to whether there was any other effect on clinical decision making not covered in the questions, one respondent stated: *'The recording of details in the template is, in my opinion, often incomplete so missing details still need to be added into patient notes which can then be less easy to read as related bits of information are partly in template and partly elsewhere in patient notes'* Another respondent stated: *'doesn't help with diagnosis but does with 'triage' and decision to admit/ safety net'*

A total of 69% (n=9) had not referred the patient, while 4 GPs (31%) referred the patient. Those who referred the patients completed two specific questions (Table 6).

**Table 6.** Effect of Desktop SAM on referral of child (n=4)

n=4	No to not at all	Yes to totally agree
Did the traffic light score assist you in your decision to refer?	50%	50%
Did the referral letter assist in the efficiency of your referral?	50%	50%

When asked if there was anything they found particularly helpful or problematic, one respondent stated: *'I believe it is probably too risk averse, and another GP stated: concern re lad with found to have pneumonia on CXR who's score was amber - he had quite low sats and surprised this didn't show as red'*

Four GPs had made seven referrals within the last 30 days: four children following a red score on the Desktop SAM and three children after an amber score. A total of 10 (77%) respondents had provided safety netting advice in the last 30 days, however 7 (70%) had not given a SAM leaflet to parents.

Of the 10 respondents, only half had ever used the Desktop SAM link to print out a SAM leaflet for parents.

Two questions were raised about the functionality of the Desktop SAM related to safety-netting. (Table 7)

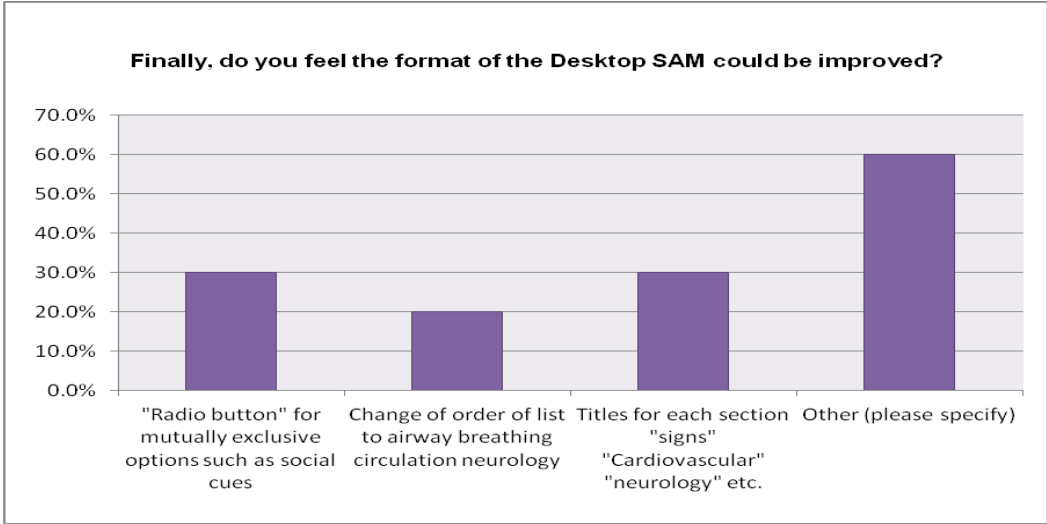
**Table 7.** Desktop SAM and safety-netting (n=10)

n=10	No to not at all	Yes to totally agree
Did the SAM Card link assist you in your decision to safety net?	60.0%	40.0%
Did the SAM Card link assist you in the efficiency of your safety-netting?	40.0%	60.0%

When asked if there was anything they found particularly helpful or problematic, one respondent stated: *'didn't use SAM card'* and another stated: *I have used the SAM card on occasion to help with safety netting, but I don't / wouldn't use it to help safety netting - in surgery we have system 1 version & Ddoc uses a different one - both electronic/ quicker & a means of documenting consultation'*

Respondents were asked whether they felt that the Desktop SAM could be improved, with 10 respondents selecting the following options (Figure 1).

**Fig 1.** Improvement of Desktop SAM



Those that ticked 'other' provided the following suggestions:

- *'Highlight the important symptoms and signs (according to available evidence). The signs section is huge and it would help to know which to focus on (eg temp, pulse, oxygen sats?)'*
- *'I understand the rationale for this but fear it may be too risk averse and put extra pressure on ED (a bit like 111!).'*

- *'More free text within template to avoid need to have to enter missing details separate from template in patient record'*
- *'Although the traffic light system follows the NICE guideline the parameters are not sufficiently age-specific to be reliably useful. For example, a 3 month old baby with a pulse of 158 / min and resp rate of 48 comes up as red on the traffic light system, but these are within published normal ranges for this age'*
- *'I prefer the DDoc version that gives ranges and not absolute numbers, the desktop one I think is a bit 'trigger happy' with regard to pulse- seems no difference in different age groups so amber & red when otherwise wouldn't be'*
- *'Better area for overall history taking and management plan'*

## GP Interviews

In total, eight GPs were interviewed. The mean age of the GPs was 40.5 years (SD 8.35; range 31-53 years). The mean years of GP experience was 10.5 years (SD 8.75; range 3-25 years). The GPs stated that they see, on a weekly basis, two to seven children with fever. However, several GPs stated that this number can be more than tripled during the winter months. Most GPs had experienced and managed a child with sepsis.

Thematic analysis of the interviews revealed three major themes:

1. Accessibility of the Desktop SAM
2. Usability of the Desktop SAM
3. Value of SAM leaflet to parents

### 1. Accessibility of the Desktop SAM

Two sub-themes were identified in this theme.

Some GPs experienced some **Challenges in accessing the Desktop SAM**. The challenges appear to be related to the start-up phase of using the Desktop SAM as one GP mentioned:

*"I started to use it but there were some glitches in how it was set up and how it had been transferred to the other practices initially and again this was in the early stages so I had a few technical problems getting it up and running"* [GP4]. Another GP expressed the concern about the easiness of accessing the SAM template on the computer which seems to be an IT issue. This GP said: *"So you have your notes and then down the side here you've got a whole load of templates, but sometimes it's a faff to be honest with you trying to find it..."* [GP3]. This was also evident from the survey data.

The second (contrasting) sub-theme was **Easy to access**. In contrast to the previous mentioned IT issues, how the desktop SAM is integrated in System One, one GP mentioned: *"it's easy to use, it pops up straight away, it's quick, it's not too detailed, the questions seem relevant, I like the fact that it will auto generate a letter..."* [GP7]. Seemingly, this GP has a better system to use the Desktop SAM in an easy and accessible way. During the interviews, one GP showed that it was possible to have an icon of the Desktop SAM on the desktop page of the computer to increase the accessibility.

### 2. Usability of the Desktop SAM

The majority of the interviews were focused on the use of the Desktop SAM, which revealed 10 sub-themes that the GPs had addressed.

The first sub-theme was **Easy for data entry**, where two GPs with experiences in using the Desktop SAM found it beneficial and efficient for their records and notes taking. They

mentioned: *"I felt like it was recording things much easier than me writing them"* [GP5] and *"...the advantage of this is that it records it on the patient notes"* [GP1].

The system was also valued by some GPs as a **Good prompt tool**. One GP said that the system helps in the accuracy of documenting the observations; *"I like the idea of having prompts to make sure that you've...observed and recorded the crucial things. I probably sometimes forget to write everything down so having a prompt is great..."* [GP6]. Another GP mentioned the positive side of the Desktop SAM as a tool that assist in the rigour of the observations; *"...it does remind you of certain things to ask which is quite helpful, especially for little kids you know and you might forget what the respiratory rate and temperature was, you know the red flag type symptoms really, so it's good for that."* [GP8].

The **Challenges in using the Desktop SAM** was another sub-theme. One GP addressed this with his current experience, but also recommended the system to be used in the consultation; *"...also to complete it to get the safety net you have to fill in the information with the patient sat there...I just fill in the history afterwards and just literally use it to get a colour code and then fill the rest in around it. It breaks the style of it (the consultation) so it'd be good if you could have it so it would embed into the right bits and it would flow with the natural flow of the consultation."* [GP5].

**Time factor using the Desktop SAM** was for some GPs a concern; *"If you're not sure, I mean you only get ten minutes don't you so you only get a snapshot, but if they're definitely not poorly, they're definitely not really well and they're kind of in the middle, so for those people it's quite useful."* [GP8]. However, other GPs felt that the Desktop SAM helps them to keep the consultation within time limits; *"So it documents everything, gives you the accurate NICE guidance and does it all in a way that helps you keep to time."* [GP1].

Although the reflection of only one GP created the sub-theme **Encouraging to use the Desktop SAM**, it appears to be relevant for the GP community to use the Desktop SAM in their GP surgeries; *"...it will be amazing if you can get people to use it regularly as part of their clinical, you know practise, that would be really good. It's just getting people to remember to use it I think and knowing that it's there and how they can use it..."* [GP8].

The sub-theme **Supports decision making** appeared in several interviews and was experienced positively towards the use of the Desktop SAM. Some GPs found the SAM application reassuring, *"It (desktop) didn't change my decisions it reinforced my general feelings that this was a child I could manage in the community"* [GP2], while others think that the Desktop Sam contributes to safe and reliable decision making, *"...you know it helps make us a bit more safe doesn't it really..."* [GP8] and *"...it helps to reassure that to admit it's the right thing to do if you're worried but also if you've got someone who's a bit borderline you think I'm just safety netting..."* [GP7].

Some GPs think that it is **Reassuring for parents when using the Desktop SAM** as said by one GP: *"I think it's reassuring to parents that you've taken the condition seriously and that you've used a tool that reinforces your clinical impression..."* [GP2].

The Desktop SAM challenged GPs by their daily work related to **Clinical intuition versus the use of the Desktop SAM**. As one GP stated clearly: *"I think it's intuitive isn't it, so an experienced GP usually...usually you can tell in the first 15-20 seconds whether that child is sick or not..."* [GP7]. More in detail, one GP expressed the complexity of the child and family circumstances that is also related to decision-making: *"...so I think when you are in the amber territory there is a lot of stuff that...the intelligence can't help you with and its all those other things it's the time...the geography... it's the family relation, the capability of the parents...the whole dynamics that will make you make a decision of whether or not you will admit them or not, or are you going to bring them back tomorrow morning"* [GP4].

Another sub-theme was the **Influence of risk parameters in the Desktop SAM**. The quote of a GP, *"...I think there are some parameters which are always going to trigger a red aren't they and you can't get away from that and it's using that, so for a newly qualified GP or a less experienced GP that could be really really helpful, just reminding them."* [GP7], reflects the content and outcome of the Desktop SAM specifically for new GPs. The last sub-theme related to the usability of the Desktop SAM was the **Safety netting with parents**. The Desktop SAM provides a link to the electronic version of the SAM leaflet for parents. This leaflet can be printed. The value of this system is expressed by a GP as *"I think it's more when you are not sending them in that the form becomes more relevant, more involved I think so it's about the safety netting questions...and sometimes you can show them what to look for."* [GP4].

### **3. Value of SAM leaflet to parents**

The interviews with the GPs also explored their experiences of the SAM leaflet for parents. This theme has six sub-themes.

The first sub-theme was related to **Parental intuition versus SAM leaflet**. Based on the experiences of the GP, they thought that it is a combination of the intuition of parents and the use of the SAM leaflet that makes them alert to contact the GP surgeries. As one GP addressed this clearly in *"because I think sometimes parents might think well my child doesn't have any of those features but I'm still worried about them and they might think that they shouldn't contact us"* [GP3].

**Parental responsibility to assess their child** was another sub-theme emerging from the interviews. One GP thought that *"...and this might also give the message that the doctor is giving me (the parent) responsibility for monitoring these things..."* [GP6]. The engagement of parents in assessing the sickness of their child seems to be recognised by GPs.

In terms of providing the SAM leaflet to the parents for future assessments a sub-theme appear to be related to the **Use of leaflet as a communication tool between GPs and Parents**. As one GP mentioned, the SAM leaflet might not always be beneficial for some parents: *"I might select the anxious parents a bit more...I've given it to people who I can see they're a little bit anxious..."* [GP7]. But the leaflet might also help to improve the communication and understanding of the situation: *"I suppose a thing you are going to give them to take away in terms of the leaflet, where it's a tangible thing that you can draw round and have a chat about rather than me do a presentation around my computer."* [GP4]. **Response to SAM leaflet** was a sub-theme providing evidence of how parents feel about receiving the SAM leaflet. As one GP stated: *"I think often when parents come in they're quite anxious aren't they, so anything we can give them they'll take and yeah nobody said, "oh no you're patronising I know what to look out for", they were all quite happy to have it..."* [GP8]. But it is also important to acknowledge that providing the SAM leaflet would imply also that parents need a certain explanation of the SAM leaflet on how to use it. This is highlighted by a GP speaking: *"...the first kind of couple of times I used it I think parents were a bit frightened by it, but as I've used it more, you know I think it's about how to explain it, I wouldn't just give it out."* [GP3].

The **Contacting health professionals based on the SAM leaflet** theme illustrates how the SAM leaflet was valued by the GP and mostly related to the benefit of providing parents with a decision tool when to contact the GP: *"...parents don't know and they leave it too late or they don't want to worry the GP...but it gives them something robust to say actually I should be contacting someone at this stage and I think that's helpful."* [GP1]. But the SAM leaflet also helps the communication between GPs and parents in terms of comforting parents; *"... so you can use that (the leaflet) as a focus around a conversation...you know or you are just worried or you feel that they are just not right then you need to come back and just see us and also there's not just us but there's Devon Doctors and this is how you access them"* [GP4].

The final sub-theme is related to **Parental education**. The value of the SAM leaflet is seen by GPs that it helps parents in their observations of their sick child and possibly provides reassurance. This was addressed by a GP: *"... my impression when I see them (parents) is that they don't know what to see the GP about and what not to and you will get some parents who will see their GP or seek help very early on in a child's illness and in a way the SAM leaflet will help them with a degree of reassurance, of managing some of the more minor illnesses themselves."* [GP1].

Another GP believes the SAM leaflet is a good educational tool for parents to learn the signs and symptoms of Sepsis: *"...but that's experience as well so sometimes they (the parents) need to come 10 times to get enough experience, enough confidence to know what to do but I use it (the leaflet) as an educational tool as well as a safety netting tool."* [GP4].

Additional data excerpts related to each sub-theme are presented at Appendix 1.

### **Use of Desktop SAM at 9 GP surgeries**

The Desktop SAM was introduced at nine GP surgeries on 5 December 2013. A total of 319 children were reviewed using Desktop SAM over a 6 month period. The results of the outcomes of the Desktop SAM have been reviewed in SystemOne. In Table 8 are the cases related to Green, Amber and Red outcomes.

**Table 8.** Outcome Desktop SAM at 9 GP surgeries (5 Dec 2013 – 11 May 2015)

<b>GP Surgery</b>	<b>Green</b>	<b>Amber</b>	<b>Red</b>	<b>Total</b>
GP surgery 1	8	2	0	10
GP surgery 2	8	21	3	32
GP surgery 3	4	6	0	10
GP surgery 4	3	0	2	5
GP surgery 5	90	98	24	212
GP surgery 6	4	2	0	6
GP surgery 7	10	6	0	16
GP surgery 8	4	6	1	11
GP surgery 9	7	9	1	17
<b>Total</b>	<b>138</b>	<b>150</b>	<b>31</b>	<b>319</b>



## WHAT THE RESULTS TELL US

The aim of the ESCAPE project was to evaluate the feasibility and piloting the implementation of the SAM leaflet and the Desktop SAM. The key evaluation questions were:

1. Is SAM an effective tool to allow parents to make informed decisions?
2. Is SAM an effective tool to support shared decision-making between parents and GPs?
3. Is the Desktop SAM at GP practices an effective tool to guide GP decisions?

### ***SAM leaflet: a tool for parents to make informed decisions***

Despite the many interventions to recruit parents to respond to the online questionnaire, the responses were small. However, the few parents who responded were pleased to have the SAM leaflet. They responded positively on their experiences of the SAM leaflet: *“I was given the leaflet from my GP when my toddler has an infection. I found it very informative”, “Very useful for deciding whether to get further advice or not...”, “I’ve looked at it and thought it was useful to keep handy for when I am worried. It has helped me know what to look out for and start monitoring...”*.

The SAM leaflet could be considered a good tool for parent. Particular looking at the larger group of parents who completed the FES questionnaire on the question if they know what to do when problem arises with their children. 14% replied sometimes, 51% often, and only 33% very often. This could indicate that support in terms of the SAM leaflet might increase the confidence of parent and to act timely in contacting the health services.

The SAM leaflet provides information on who to contact when symptoms occur in the amber or red section. This would help parents to contact the right services at the right time. The FES survey provided information that 24% of the parents stated ‘sometimes’ on the question if they know what services their child needs. A further 41% stated often and only 31% very often. This is in line with the question if parents have a good understanding of the health service system for their child; only 18% stated very often on this question. Therefore, the SAM leaflet might provide guidance to parents to contact the right health service at the right time and to receive the right care.

### ***SAM leaflet: a tool for parents to support shared decision-making with GPs***

From a parental perspective, the SAM leaflet seems to be supportive in communicating with GPs and other health professionals. However, given the small number of parent respondents who had used the SAM leaflet, the results of this evaluation do not provide clear evidence from the parents. It can be argued that the FES items in the survey do not provide sufficient evidence as to whether parents do appreciate shared decision-making with the GPs; as one parent stated in the online questionnaire: *“Professionals are professionals - parents who read the odd internet blog are not. This is against the current mood I know but I would rather trust a*

*professional than a self-selected patient/parent "expert", often with a personal agenda.*". Although the NHS promotes patients to be more autonomous in the health care system and possibly many patients do prefer shared-decision making with health care professionals, this might be different for parents who worry about their child. The emphasis should possibly be directed to careful 'listening' and acknowledging the parents' concerns by health care professionals. In terms of making the right decision by the health care professional, the SAM leaflet does provide a shared common language between parents and first line health professionals. This has been confirmed by the interviews of the GPs where six sub-themes occurred under the theme 'value of the SAM leaflet for parents'. The GP interviews addressed the issues of **parental intuition** and **parental responsibility** to assess their child. The SAM leaflet has been recognised as a **communication tool** between GPs and parents. When GPs provide the leaflet to parents, their **response to SAM leaflet** was positive. But at the same time the GPs recognise that the SAM leaflet needed oral explanation to parents before using and **contacting health professionals** based on SAM leaflet results. Overall, the SAM leaflet was received positive by GPs and many use the leaflet as a **parental education** tool or a safety netting tool to provide parents enough confidence to know what to do.

#### **Desktop SAM: a tool to guide GP decisions**

The Desktop SAM is an effective tool to guide GPs. The majority of the GPs (70%) who completed the survey found the Desktop SAM helpful in their clinical assessment and differentiating Sepsis in a child presented with fever. In addition, almost 70% of the GPs felt that the traffic light scores in the Desktop SAM helped them in making decisions and helped them in the efficiency of their consultation. However, according to the interviews with the GPs, the **accessibility of the Desktop SAM** was not standardised across the GP surgeries. Some GP practices arranged a link of the Desktop SAM on the desktop of their computer screen which provided a much easier access and alerted them to use the programme. The GPs also reported their experiences about the **usability of the Desktop SAM**: that it was easy for data entry, a good prompt tool, and supports decision making. However, the experience and intuition of the GPs were sometimes challenged by the Desktop SAM; *"I think it's intuitive isn't it, so an experienced GP usually...usually you can tell in the first 15-20 seconds whether that child is sick or not..."*. But, most GPs recognise the importance of documenting their observations and value the Desktop SAM in their daily clinical practice. The Desktop SAM provides the opportunity for GPs to print a SAM leaflet. This was appreciated by several GPs as they have addressed this as safety netting. Finally, most GPs advised to have the SAM leaflet in the Red Book, but would very much promote to have the SAM leaflet also discussed and explained to parents when they visit their GP during the 6-weeks post-partum visit.

## FUTURE DIRECTIONS

This project aimed to evaluate the feasibility and pilot the implementation of the SAM leaflet and the Desktop SAM. Based on the findings we recommend several future directions.

The SAM leaflet and the Desktop SAM were initiated by parents and healthcare professionals. Both interventions were designed to recognise early sepsis in children. The SAM leaflet and the Desktop SAM aimed to increase the communication between front-line health professionals and parents. Using the same common language when assessing the signs and symptoms of early sepsis in children in the home situation and at community healthcare settings might prevent delays in early treatment of sepsis and ultimately save lives of deteriorating sick children.

Although we recognise some limitations in this feasibility project, such as the number of parents and GPs responding to the surveys, we believe that both interventions can play a key-role in future efforts to combat paediatric sepsis. Therefore, our recommendations are related to the implementation of the SAM leaflet and the Desktop SAM on a regional and national level.

### Recommendations for SAM leaflet

- 1. Develop a strategy to implement the SAM leaflet with a clear pathway to increase the awareness of the leaflet in the wider public with a special focus on parents.**
  - a. The dissemination plan should include both healthcare settings and public locations such as schools, libraries, including the SAM leaflet in the Red Book.
- 2. Develop an educational strategy for parents and healthcare professionals to increase the knowledge and understanding of the SAM leaflet.**
  - a. The education plan should include the development of a Sepsis App including videos showing real life examples of the signs and symptoms of early sepsis.
  - b. The education plan should include a designated website with information and education, including videos, ability to download the SAM leaflet, and a feedback forum.
  - c. Parent education of the SAM leaflet and early sepsis recognition should be included in the 6-weeks post-natal visit.
  - d. Training days for healthcare professionals need to be organised, including training and information for reception staff at GP practices and other front-line healthcare settings to inform and educate parents about the use of the SAM leaflet.

- 3. Evaluate the SAM leaflet by assessing the effectiveness, understanding the change when using the SAM leaflet, and assessing the cost-effectiveness.**
  - a. Perform a wider evaluation in the NHS South West region to assess the feasibility and effectiveness of the SAM leaflet.

### **Recommendations for Desktop SAM**

- 1. Develop a strategy to implement the Desktop SAM at healthcare settings.**
  - a. The dissemination plan should include GP practices, walk-in-clinics, pharmacies, ambulance services, out-of-hours services, and other front-line healthcare organisations.
  - b. IT services need to collaborate in the implementation of the Desktop SAM application at various systems used at various healthcare settings.
- 2. Develop an educational strategy for healthcare professionals to increase the knowledge and understanding of the Desktop SAM.**
  - a. Training days for healthcare professionals need to be organised to use the Desktop SAM effectively.
- 3. Evaluate the Desktop SAM by assessing the effectiveness, understanding the decision-making processes, and assessing the cost-effectiveness.**
  - a. Perform a wider evaluation in the NHS South West region to assess the feasibility and effectiveness of the SAM leaflet.

### **Recommendations for success**

Although the recommendations are separated by the individual actions related to the SAM leaflet and the Desktop SAM, we recognise the importance of collaborating between both interventions as they are strongly linked to each other. Both interventions help the parents and the healthcare professionals to use a common language in communicating the signs and symptoms of children developing an early sepsis.

Linking the out-of-hospital and in-hospital health services is important to the success of combatting paediatric sepsis. The collective approach should be focused on creating a common language and understanding between several healthcare services. Only then can we ensure common understanding of the chain of the paediatric sepsis pathway and reduce mortality from sepsis.

Success is also related to the collaboration with other healthcare professionals and stakeholders working on interventions to increase awareness and prevent sepsis among children. Collaborative actions are needed and only the synergy between a range of

interventions designed for parents and professionals will make a difference. Several healthcare teams, organisations and other stakeholders are working on initiatives related to paediatric sepsis. These initiatives should be unified to increase the awareness of paediatric sepsis: Examples of recent initiatives include:

1. The upcoming NICE guideline related to Paediatric Sepsis is one of the initiatives that will provide directions of early recognition and treatment of paediatric sepsis.
2. The Paediatric Sepsis 6 tool developed by Dr Jeremy Tong and his team to support clinicians in emergency settings to detect and treat early sepsis in children (<https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2014/05/paediatric-sepsis-6-v10.pdf>).
3. Two paediatric consultants, Drs Amy Whiting and Sarah Bridges at Musgrove Park Hospital in Taunton, developed an app, the HANDi Taunton, to provide parents with information about common childhood illnesses and how to care for them. The app includes illness specific home assessment guidelines, signposting to the appropriate healthcare setting, and illness information (<http://www.musgroveparkhospital.nhs.uk/patients-and-visitors/innovation-projects/handi-paediatric-specialist-advice-when-and-where-you-need-it/>).
4. Dr Damian Roland from Leicester University and his team developed the Paediatric Observation Priority Score (POPS), an assessment measure to predict children to be discharged from hospitals (<http://www2.le.ac.uk/departments/cardiovascular-sciences/research/cardiovascular-physiology-and-pathophysiology/emergency-medicine-group/research/pemla/pops>).
5. The UK Sepsis Trust has been instrumental in increasing the awareness of sepsis among healthcare professionals and the public. The Trust “seeks to save lives and improve outcomes for survivors of sepsis by instigating political change, educating healthcare professionals, raising public awareness and providing support for those affected by this devastating condition” ([www.sepsistrust.org](http://www.sepsistrust.org)).
6. Many other organisations have supported initiatives to combat paediatric sepsis, such as parent organisations ([www.mumsnet.com](http://www.mumsnet.com)). NHS England is promoting paediatric sepsis initiatives via their directorates such as the National Patient Safety, the Patient Safety for Children, Young People and Maternity, and the Improving Patient Experience directorate.

In the political arena, the All-Party Parliamentary Group on Sepsis provides a platform through which parliamentarians, organisations and those affected by sepsis can discuss the current provision for patients, promote public understanding, and advocate interventions to be implemented across the NHS.

We might unintentionally have forgotten others working hard on paediatric sepsis initiatives. But we do recognise that the strongest partners in collaborating toward future successes to

prevent unnecessary deaths in children due to sepsis are the parents. In particular, the parents of Sam Morrish who were the driving force in developing the SAM leaflet.

## OPTIMISING THE IMPACT OF SAM

The impact of the SAM leaflet and Desktop SAM can be described in terms of children, parents, healthcare professionals, society and politicians.

Sick children deserve the best possible care. This starts often with tender love and care from the parents. However, parents might need support from the NHS to be prepared to act when their child is sick. Clear directions for informed decision making in the home situation make it possible for parents to be proactive. The same clear directions should be communicated and in line with the next step in the pathway of a child with fever and possible signs of sepsis.

This involves GPs and other health care professionals. These healthcare professionals need to use a common language to communicate with parents. This project evaluated the feasibility of two interventions to enhance the critical steps to be taken and understood by parents and health care professionals. The right decision at the right time and the right care can be achieved by the implementation of these interventions. Ultimately, the impact of the paediatric sepsis pathway is that children survive through early recognition of a possible sepsis. The impact on the society is that this project empowers the parents and carers of sick children. The NHS and politicians should acknowledge this project due to the impact of the pathway in terms of prevention measures taken by health care services. Providing public awareness of sepsis requires action on a number of fronts. Despite several initiatives, few pragmatic and easy-to-use and understandable tools are now developed for the public.

The project is based on a sad story of the death of a 3 year old child named Sam and is driven by many stakeholders, in particular parent organisations and groups. The dissemination of the interventions and possible success stories will be shared not only among healthcare professionals, but also with the public and politicians by means of scientific papers, stories in the newspapers, professional and organisational websites, social media, and other approaches. The aim is to disseminate the feasibility results of this project and implementation on national level is recommended. After all, parents, healthcare professionals, the NHS, the public, and politicians do not want to experience a 'never event' with the result of an unnecessary death of a child.

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## Appendix 1

### Themes, sub-themes and GP narratives

<b>THEME 1: Accessibility of the Desktop SAM</b>		
Challenges in accessing the Desktop SAM	So you have your notes and then down the side here you've got a whole load of templates, but sometimes it's a faff to be honest with you trying to find it...	GP3
	I started to use it but there were some glitches in how it was set up and how it had been transferred to the other practices initially and again this was in the early stages so I had a few technical problems getting it up and running	GP4
Easy to access	...it's easy to use, it pops up straight away, it's quick, it's not too detailed, the questions seem relevant, I like the fact that it will auto generate a letter...	GP7
<b>THEME 2: Usability of the Desktop SAM</b>		
Easy for data entry	I felt like it was recording things much easier than me writing them.	GP5
	...the advantage of this is that it records it on the patient notes.	GP1
Good prompt tool	I like the idea of having prompts to make sure that you've...observed and recorded the crucial things. I probably sometimes forget to write everything down so having a prompt is great...	GP6
	...it does remind you of certain things to ask which is quite helpful, especially for little kids you know and you might forget what the respiratory rate and temperature was, you know the red flag type symptoms really, so it's good for that.	GP8
Challenges in using the Desktop SAM	...what you've entered (the data) is actually jumbled up in a very unhelpful way not only for that particular consultation but I think if the child subsequently comes back to see someone else it's very difficult to see the core of what's happened...	GP6
	...also to complete it to get the safety net you have to fill in the information with the patient sat there...I just fill in the history afterwards and just literally use it to get a colour code and then fill the rest in around it. It breaks the style of it (the consultation) so it'd be good if you could have it so it would embed into the right bits and it would flow with the natural flow of the consultation.	GP5
Time factor using the Desktop SAM	If you're not sure, I mean you only get ten minutes don't you so you only get a snapshot, but if they're definitely not poorly, they're definitely not really well and they're kind of in the middle, so for those people it's quite useful.	GP8
	You see so many children, so many children with runny noses, with a temperature of 37.5, 37.6 and I don't do it for them, not because I don't think it's worth it I think it would be worth it, but I think just being realistic I don't have time and you can eyeball the child and think actually you're ok	GP3
	So it documents everything, gives you the accurate NICE guidance and does it all in a way that helps you keep to time.	GP1
Encouraging to use the Desktop SAM	...it will be amazing if you can get people to use it regularly as part of their clinical, you know practise, that would be really good. It's just getting people to remember to use it I think and knowing that it's there and how they can use it...	GP8
Supports decision making	It (desktop) didn't change my decisions it reinforced my general feelings that this was a child I could manage in the community	GP2
	...you know it helps make us a bit more safe doesn't it really	GP8
	...it helps to reassure that to admit it's the right thing to do if you're worried but also if you've got someone who's a bit borderline you think I'm just safety netting...	GP7
	...because it takes a lot of information it feels to me that the answer it pops out is, should be a reliable one, I would trust it you know...I would use it to you know, to influence what I would do...	GP3
	In a way for me the desktop SAM is the starting point, because in a way if it comes up with red then my decision's made and they're going into hospital.	GP1

Reassuring for parents when using the Desktop SAM	I think it's reassuring to parents that you've taken the condition seriously and that you've used a tool that reinforces your clinical impression...	GP2
	I think it can be very good to reassure parents that look, I've put all the things in and actually this is reassuring it's coming up as green and so that can be a very useful tool.	GP7
Clinical intuition versus the use of the Desktop SAM	I think it's intuitive isn't it, so an experienced GP usually...usually you can tell in the first 15-20 seconds whether that child is sick or not...	GP7
	I think it's choosing when to not follow the guidelines and having that confidence not to...if you were pretty sure from your initial assessment that the child didn't need to go in and there were no real concerns, I wouldn't have done the template, I would have just made that decision...	GP7
	I sort of thought to myself well, maybe it's amber now but maybe if I saw you in an hour it'd be red...	GP3
	...so I think when you are in the amber territory there is a lot of stuff that...the intelligence can't help you with and its all those other things it's the time...the geography... it's the family relation, the capability of the parents...the whole dynamics that will make you make a decision of whether or not you will admit them or not, or are you going to bring them back tomorrow morning	GP4
	..so if your gut instinct is to admit and you do this and it says yes admit, that's good, I suppose the problem may come if your gut instinct is not to admit and to observe and this is saying red.	GP7
	What I guess it helps us with is how they're physiologically coping with that infection and that is something that we have a gut instinct about as GPs, but what I've come to learn is that actually that gut instinct isn't robust enough...	GP1
	I would like to think I'm smarter than the computer or have more experience and be more able to make better decisions.	GP4
Influence of risk parameters in the Desktop SAM	...so will it end up with lots more kids being sent in who don't need to be sent in, because that the safest thing, so that's my main concern. I think it safety nets very well, but it could be, the algorithms that are used may be slightly risk averse, as any guidelines..	GP7
	...I think there are some parameters which are always going to trigger a red aren't they and you can't get away from that and it's using that, so for a newly qualified GP or a less experienced GP that could be really really helpful, just reminding them.	GP7
Safety netting with parents	(the leaflet is) automatically linked with the desktop SAM and it gives you an option, in fact it's hard not to print it off ... you have to work harder at not giving the information than you do to actually give it.	GP1
	I think it's more when you are not sending them in that the form becomes more relevant, more involved I think so it's about the safety netting questions...and sometimes you can show them what to look for.	GP4
<b>THEME 3: Value of SAM Leaflet to parents</b>		
Parental intuition versus SAM leaflet	...and I think the parent's biggest asset is their own intuition and their own knowledge of the child so the safety netting to my mind primarily needs to give them permission to ring again if they are worried...	GP6
	because I think sometimes parents might think well my child doesn't have any of those features but I'm still worried about them and they might think that they shouldn't contact us	GP3
Parental responsibility to assess their child	...and this might also give the message that the doctor is giving me (the parent) responsibility for monitoring these things...	GP6
	I thought of it (the card) as for parents to monitor their children as opposed to a..something I would use.	GP5

Use of leaflet as a communication tool between GPs/Parents	I might select the anxious parents a bit more...I've given it to people who I can see they're a little bit anxious...	GP7
	I suppose a thing you are going to give them to take away in terms of the leaflet, where it's a tangible thing that you can draw round and have a chat about rather than me do a presentation around my computer.	GP4
Response to SAM leaflet	I think often when parents come in they're quite anxious aren't they, so anything we can give them they'll take and yeah nobody said, on no you're patronising I know what to look out for, they were all quite happy to have it...	GP8
	...the first kind of couple of times I used it I think parents were a bit frightened by it, but as I've used it more, you know I think it's about how to explain it, I wouldn't just give it out.	GP3
Contacting health professionals based on SAM leaflet	...parents don't know and they leave it too late or they don't want to worry the GP...but it gives them something robust to say actually I should be contacting someone at this stage and I think that's helpful.	GP1
	... so you can use that (the leaflet) as a focus around a conversation...you know or you are just worried or you feel that they are just not right then you need to come back and just see us and also there's not just us but there's Devon Doctors and this is how you access them	GP4
Parental Education	... my impression when I see them (parents) is that they don't know what to see the GP about and what not to and you will get some parents who will see their GP or seek help very early on in a child's illness and in a way the SAM leaflet will help them with a degree of reassurance, of managing some of the more minor illnesses themselves.	GP1
	...but that's experience as well so sometimes they (the parents) need to come 10 times to get enough experience, enough confidence to know what to do but I use it (the leaflet) as an educational tool as well as a safety netting tool.	GP4