

# Single Care Plan: What do young people say?

Feedback from children and  
young people in  
Kirklees and Calderdale



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Your suggestions and contributions are an important part of ensuring that the changes that take place are the right ones.

### **Julie Walker**

**Kirklees Council - Commissioning & Health Partnerships**

[Julie.walker@kirklees.gov.uk](mailto:Julie.walker@kirklees.gov.uk)

### **Contributors to this report**

Sinead Boyle, Kirklees IYCE Team -

[sinead.boyle@kirklees.gov.uk](mailto:sinead.boyle@kirklees.gov.uk)

Anne Gomersall, Children & Young People's Voice & Influence, Calderdale –

[anne.gomersall@calderdale.gov.uk](mailto:anne.gomersall@calderdale.gov.uk)

Stephen Gregg, Asthma UK

[sgregg@asthma.org.uk](mailto:sgregg@asthma.org.uk)

## Introduction

The development and implementation of a Single Care Plan for children and young people is one of the projects identified by the Children’s Working Group within the Calderdale & Huddersfield Strategic Health Review.

A request for engagement was made to the Children and Young People’s Engagement & Communications sub group by Karen Poole, Children’s Commissioner with North Kirklees CCG.

The Briefing detail, Outline of request and Proposals for Engagement were agreed:

|  |  |
|--|--|
| Briefing detail                                | <p>All children, 0-18yrs, with ill health or conditions (eg Asthma) will have a single care plan.<br/>         The “patient” will hold the SCP and take to school, youth club, scout group<br/>         It will contain medical information<br/>         It will be paper based (at least in the first instance)<br/>         It will include “must do” info such as name, age, address, any allergy details, GP &amp; consultant details, information about treatment plan<br/>         To be piloted with children and young people who have Asthma</p>  |
| Outline of request                             | <p>KP has asked for involvement from children, young people and their parent/carers in order to determine how it looks and what will make it something the “patient” wants to use/carry.</p> <p>Children and young people will need to have a plan if they have a long-term condition – it would not be possible to “make” them carry it but Karen is hoping that whatever is developed locally, children and young people will understand the benefits of carrying it and chose to do so.<br/>         Ofsted have told schools that they must have a regularly up-dated plan for children with long-term conditions.</p> <p>Asthma UK have some possible examples of existing care plans</p> <p>KP would be keen to hear any ideas/suggestions that young people may put forward about what they’d like to see on the Care Plan – some of these ideas might be translated into reality but others would just be “blue sky thinking”.</p> |
| <b>Proposals for Engagement</b>                |  |
| Any previous relevant engagement?              | <p>Whilst there has been no local consultation with children and young people about the format they would prefer for the plan (eg paper, on-line), Karen advised that consultation with young people in London had suggested young people didn’t want any app on their phones. They preferred to have a paper plan. They said their phones were for fun and social activity.</p>   |
| What are the gaps, what do we need to ask now? | <p>What’s young people’s reaction to the SCP? Will they carry it? What will encourage them to carry it? Given that it will be paper format – what are their suggestions for shape/size etc? Do they have ideas for different formats?<br/>         What do parent/carers think about the SCP? Do they see their children carrying one?</p>   |

## **Feedback from Children and Young People in Kirklees**

Over 50 young people were involved in discussions on the Asthma Single Care Plan. The young people were aged 12 to 20 and were a mix of gender, ethnicity, socio-economic group. Some of these young people are ones who have ongoing involvement with IYCE projects, whilst others were as young people who access Youth clubs, schools, colleges and those in part time employment.

Almost half of the young people involved in the discussions have experienced symptoms on more than one occasion or are recognised as having asthma. Very few of the young people with this medical condition, carried their inhalers with them at all times. There were a variety of reasons that the young people expressed for not carrying their inhalers with them. These included: forgotten; run out/not replaced; doesn't fit in my pocket; not cool; I don't think I need it.

### **What are young people's reactions to the SCP?**

The majority of young people stated that, if the only format was a paper based one, they would not bother carrying it with them – they did not see this as a priority.

Some young people seemed interested in the idea of carrying something, which would support them in explaining to others what their condition was and help with managing it.

There were concerns about losing this information and what would happen? How would it be replaced? Would they have to pay?

### **Will they carry it?**

A small number of young people said they would carry it, if they remembered! However the majority stated that they did not see carrying a piece of paper as a priority and didn't always remember to carry their inhalers.

Worries about the paper based SCP being washed or getting lost was another concern. Some young people shared their experiences of money 'notes', being washed in jean and hoody pockets, so felt that this was likely to happen with a paper SCP.

### **What would encourage them to carry it?**

When discussing what would encourage young people to carry a SCP, they said

- If the only option was a paper-based version, then it would need to be discreet - credit card size was suggested on a number of occasions within a plastic pocket.
- If it looked interesting, with the use of colour and design appropriate to age.
- If there was an incentive to carry it! (for example discount for activities/shops)
- That it needed to be water and weather proof!

### **Paper format – suggestions for shape/size etc.**

98% of the young people asked stated they would not carry a paper based SCP. They expressed their views on the durability of paper/card – it getting wet; getting lost; getting damaged; being washed and generally just becoming 'worn'.

### **Ideas for different formats?**

Despite the information that has been gathered in London, young people living and using services within Kirklees, suggested an app on their phones that can be accessed from anywhere and will not intrude with their personal belongings and 'things to remember'. They commented that they do use their mobiles to support college and school work; access information about the costs of things, travel times, as well as for social activity and accessing fun apps.

The other suggestion was having a double sided plastic/vinyl type credit card with information on regarding their medical condition. This can be slipped in a wallet, bag, purse discreetly.

Some suggested that a coloured bracelet/band could be used on similar lines to a SOS, with information on. This could be linked with information that professionals could access on-line if needed.

### ***Children's reactions:***

15 children were asked their thoughts on the paper-based SCP. Seven of these children had asthma or bronchial related conditions. They were aged between 7 and 11 years with different ethnicities.

Children grasped the idea of carrying something with them on a regular basis to explain to adults what their condition was and how to support them with managing it. They related the SCP to a more formal environment such as school and the information could simply slot in to their book bag.

When asked about carrying the SCP with them when they were playing out, or meeting friends, most children said they wouldn't have anywhere to carry it; were slightly worried about losing this information; and didn't think it was practical; they would forget.

The majority of children said that they carried their inhalers to school in their book bags, but that their parents remembered to do this, not them. When they played out or visited friends' houses, either they didn't remember their inhalers, or didn't feel the need to bring them with them.

If it had to be paper based, the children suggested a concertina style leaflet which had a plastic pocket to keep it dry and clean or had a plastic top and bottom. They suggested the use of colour and an area on the front for them to add their own design, so it felt more personal to them.

Over half of the children did not have a mobile phone, so did not see any benefit to having an app, as they could not access it, but thought it was a good idea for when they were older and would have a phone.

### ***Parent / Carers reactions:***

#### **Do they think their child will carry one?**

Parents/carers were also involved in discussions on a paper-based SCP. Some of these parent/carers had children that had asthma or breathing related conditions (COPD). There were mixed views on the introduction of a Single Care Plan and some interesting suggestions.

This would be useful as there was often a lot of paperwork to complete or update if your child has a medical condition – school, out of school/holiday provision, uniformed groups, sports activities, dance activities, swimming lessons, outward bound activities, basically any other activity outside of school.

That if things changed with their child's condition, they would only have to update/amend one set of records and not have to do this for up to half a dozen different provisions.

They had concerns that their child would lose this information, which had confidential details on and were worried about data protection and identity theft for the future.

Some expressed their doubts that their child would forget to carry this with them when playing out with friends and asked how this SCP would differ with what is happening now when children play out with no SCP?

**Suggestions:**

A colour band is issued with a number on it for professionals to contact in order to access information on the medical condition, but were doubtful that this would actually happen.

Parents/carers thought that the use of an app on a mobile device would be more useful, robust and accessible than a paper based version for children aged 10-11 years of age.

There were a few suggestions on having a plastic card like the national insurance number card or debit card with this information, which could withstand the test of time on being sat on (in jeans), being washed, dried, left in damp clothes. They also recommended that more than one card be issued, as children and teens did lose things / were forgetful.

Parents shared frustrations on the practicalities of having something that was made of paper/card and how resilient and practical this would be. Some went on to share experiences of washing and tumble drying their teens credit cards, money, bits of paper, make-up and other items left in pockets of clothes.

## Feedback from Children and Young People in Calderdale

### Methodology

Young people in Calderdale were asked to respond to a short questionnaire. The questions were:

- What would make it 'cool' for you to carry your Single Care Plan with you? Would you like this designed by young people?
- What would it look like? (card, pendant, wristband, phone app., other)
- What would it be made of?
- What personal information would you want it to show?(name, phone number, number of emergency contacts, local hospital, g.p., medication and how to give it)

21 young people responded, their ages ranged from 11-19yrs. The young people came from a range of settings:

Youth Works – Town Centre Project

Youth Council

Cartwheel Youth Centre

Queens Road Youth Centre – Asian Girls Group

Brighthouse Youth Centre

Calder High School

### Summary of Responses

#### 1. What would make it cool for you to carry your single Care Plan? Would you like it designed by young people?

|                             |   |
|-----------------------------|---|
| Colourful                   | 7 |
| Small and simple            | 4 |
| Choice of different designs | 4 |
| Easy to read                | 1 |
| Easily accessible           | 2 |
| I phone app.                | 1 |
| U.V for use in night clubs  | 2 |
| Own design                  | 2 |
| Must be cool                | 2 |
| Easy to spot                | 1 |

#### 2. What would it look like?

|  |   |
|--|---|
| A plastic credit card style            | 8 |
| Necklace/dog tag-metal                 | 3 |
| Wristband – hollow with details inside | 2 |
| Pocketsize booklet                     | 1 |
| Rubber wristband                       | 5 |
| Not paper or card – too flimsy         | 3 |
| Back to a watch                        | 1 |

#### 3. What information would you want it to show?

|  |    |
|--|----|
| name                                   | 7  |
| age                                    | 1  |
| medical conditions (other than asthma) | 1  |
| emergency contacts                     | 12 |

|                                 |    |
|---------------------------------|----|
| medication – dosage and methods | 11 |
| GP                              | 1  |
| name of local hospital          | 2  |
| first aid needed                | 1  |
| ICE numbers                     | 1  |
| Organ donor?                    | 1  |
| Colour inhaler used             | 2  |
| 999 number                      | 4  |

## Feedback from Asthma UK

Asthma UK recommends that everyone with asthma has a written asthma action plan which they agree with their GP or Asthma Nurse. The efficacy of personal action plans in improving health outcomes, reducing hospital admissions and unnecessary deaths is very clear.

Asthma UK produces both a children's action plan **My Asthma** (for 6-12 year olds) and a version for older children and adults **Your Asthma**.

**My Asthma** is a pack consisting of:

- My Asthma Plan – personalised asthma action plan
- My Asthma Calendar and Stickers (symptom diary)
- My Asthma Parent Postcard (for parents to give to other carers, eg babysitters)
- My Asthma Guidance notes
- My Asthma Folder (to keep the resources in)

Asthma UK conducted an indepth evaluation of My Asthma using a combination of surveys and interviews, with healthcare professions, children and their carers. It aimed to find out if My Asthma was an effective self-management tool and if it had an impact on asthma outcomes. The results showed that My Asthma is a successful self-management tool for children but, despite it being engaging and easy to use, it is still not widely used. (Copy of evaluation report attached)

In relation to My Asthma, some key messages were:

### **From children:**

16 children answered questions about My Asthma.

- 53% found using the My Asthma Pack has led to an improvement in their asthma symptoms
- All children said that since using the pack they know what to do if their symptoms get worse.
- 60% of children said they had learned something new since using My Asthma. These include:
  - noticing when their asthma gets worse
  - knowing what their medicines are for
  - knowing what their triggers are
  - knowing how frequent their symptoms are: 'I cough every day'.
- When asked what they liked about My Asthma, children said that they liked the colours and the way it looks, and they liked using the stickers (in the symptom diary). They also liked being able to monitor their symptoms, and to be reminded to take their medicines.
  - "It's fun and looks cool on my wall and my friends like it too."
  - "Liked filling it in daily and doing the stickers, could see on a weekly basis how much coughing I'd done."
- No one said there was anything that they would change.

### **From parents:**

34 parents responded to the survey.

- 94% said that they would recommend the resource. When asked why they would recommend it, parents said that they found it very informative and a good way to engage their child:
  - "A good information tool."
  - "Very informative and user friendly to read and refer to."

- “A good tool in helping child understand their asthma.”
- “They are a brilliant learning tool for adults and children, a great way of interaction.”
- “It is really helpful for you and your child to understand their asthma.”
- “It is more helpful than the asthma nurse for children’s needs.”
- 68% said that their child’s attitude towards taking their medicines has improved since using My Asthma. Some parents described how their child’s self-management had improved:
  - “Used My Asthma resources from day one.”
  - “She now realises the importance of her medication.”
  - “She will ask for inhalers if she feels she needs them, realises when she needs to take them and why.”
  - “He never forgets to take it now.”
- When asked to rate the pack’s usefulness out of 10 (10 being very useful) the average response was 9.2. 45% thought that the calendar was the most useful part. 29% thought that the whole pack was very useful.

Over the past 5 years Asthma UK have engaged children, young people and their families in a range of consultation activities which have generated some key messages in relation to children and young people living with Asthma. A couple of those messages are particularly relevant to the discussion about SCP. Firstly, there is generally a low awareness and use of self-management plans by children and young people. However, young people feel strongly that they need more independence to control their condition and to show their parents that they can do this.