



connecting care for children

**EXPERIENCE MAPPING:  
A TOOL FOR SHARING PATIENT  
EXPERIENCE**

## Contents

|  |           |
|--|-----------|
| <b>Background</b> .....  | <b>3</b>  |
| What is Experience Mapping? .....  | <b>3</b>  |
| Why is Experience Mapping important to Children and Young People’s (CYP) Health and Wellbeing? ..... | <b>4</b>  |
| How does Experience Mapping offer a solution? .....  | <b>4</b>  |
| <b>How to do an Experience Map</b> .....   | <b>6</b>  |
| Preparation .....  | <b>6</b>  |
| Ten steps for effective Experience Mapping .....   | <b>7</b>  |
| Experience Mapping examples .....  | <b>9</b>  |
| <b>Frequently Asked Questions</b> .....  | <b>12</b> |
| <b>Thanks</b> .....  | <b>14</b> |
| <b>Authors</b> .....   | <b>14</b> |
| Contact information .....  | <b>14</b> |
| <b>References and further reading</b> .....  | <b>14</b> |
| References .....   | <b>14</b> |
| Further reading .....  | <b>14</b> |
| <b>Appendix:</b>   |           |
| <b>Parent/Guardian Consent Form</b> .....  | <b>15</b> |
| <b>Patient/Parent/Carer Information Sheet</b> .....  | <b>16</b> |

If you would like to use or edit anything in this guide please [get in touch](#) with us first.

## Background

Experience Mapping has been recognised as a really effective tool to capture and share patient experience. There's been less recognition of the benefits Experience Mapping offers to the health professionals that complete them – both as a powerful learning experience and to capture meaningful patient feedback.

For the patients who share their story as part of an Experience map, the benefits go beyond being part of an improvement project; even as a standalone activity, being listened to and having someone take the time to hear your story is a meaningful experience in itself.

### What is Experience Mapping?

Experience Mapping is an innovative approach, used to promote the patient perspective of care, to impact individual clinical practice through education and ultimately, to lead to improvements across the healthcare system.

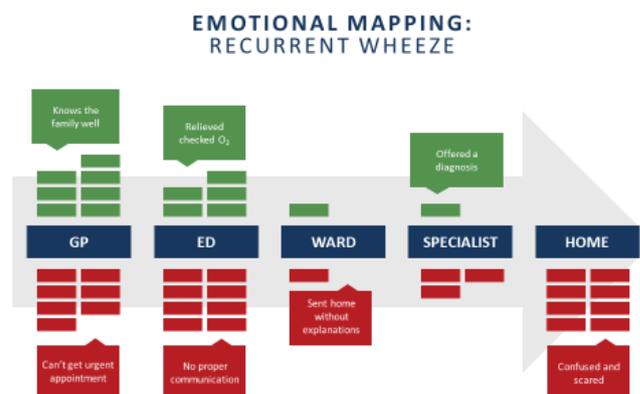
It can be used when patients come into contact with either:

- The healthcare service (e.g. admission to a hospital ward)

Or

- A particular healthcare pathway (e.g. children referred for a developmental assessment)

The health care professional undertaking the Experience map supports the patient or carer to tell the story of their own experiences, in their own voice. The positive and negative emotions and experiences are mapped along the journey.



**Figure 1:** a summary example of an Experience map

## Why is Experience Mapping important to Children and Young People's (CYP) Health and Wellbeing?

- The health and social needs of children and young people are increasing in complexity and the health care system can be difficult for families to navigate
- CYP care crosses many organisational boundaries
- The voice of CYP in healthcare is often forgotten
- Health professionals providing care for CYP and families, have limited opportunities to capture the lived experience of the patients they care for
- There is an ongoing CYP healthcare workforce crisis (1), investment in training and development of existing staff can support job satisfaction and staff retention
- In 2020 the RCPCH published *Paediatrician of the Future* which includes an expectation that paediatricians will be familiar with techniques to capture the patient perspective (2)

## How does Experience Mapping offer a solution?

Health system improvement often targets the Quadruple Aim (of Better Population Health; Improved Patient and Family Satisfaction; Improved Provider Satisfaction; and Reduced Costs) (3). Experience Mapping can improve child health across all these aims.

- **Better Population Health**

Experience maps:

- Are used as a tool in the design of healthcare pathways
- Improve understanding of the patient journey – the experiences and emotions that support earlier self-help and community care
- Help clinicians and managers understand the way the health and social care system is used by patients and families and use those insights to encourage early intervention

- **Improved Patient and Family Satisfaction**

Experience maps:

- Support patients to be listened to and heard
- Give children and young people a voice
- Help professionals address the lived experience and Experience impact of patients' journeys

- Demonstrate the importance of holistic care and where it can be improved
- Provide feedback to help services better meet patients' needs

- **Improved Provider Satisfaction**

Experience maps:

- Help to meet a health care provider's training and development needs
- Improve the professional's ability to emphasize with patients
- Create an opportunity for reflection on personal practice
- Improve understanding of health care delivered and received outside the organisation the provider is working in, supporting communication and relationship development across boundaries
- Offer the opportunity to receive and share meaningful feedback

- **Reduced Costs**

Experience maps:

- Help organisations design services that more-closely meet the needs of CYP and families, reducing unnecessary presentations and referrals
- Help organisations to support patients in self-care, increasing smaller, earlier (and less-costly) interventions
- Improve staff satisfaction, helping to reduce burn out and improve staff retention

## How to do an Experience Map

### Preparation

Take time to plan and prepare. There is not one way of doing an Experience map. The most important thing is to listen and use the Experience Mapping exercise to have an open, structured conversation.

This guide provides details with annotated examples for different types of Experience Mapping:

1. Exploring a patient's experience
2. Gathering feedback on a specific pathway
3. Understanding where patients go for information on a health topic

Prior to performing an Experience map, prepare information and resources in case patients need further support after your conversation. This can include where to take a complaint or where to get more information on a particular health issue.

### What you'll need:

- Pens (different colours)
- Paper

Optional: Different coloured post it notes (useful if mapping with a group)

### Time:

- 30 -45 mins

## Ten steps for effective Experience Mapping

1. Think about how to put the patient, and or parent, at ease. Introduce yourself and give some background about what you are doing
2. Make sure you are always honest and transparent in the way you work. Discuss confidentiality. Explain that the information will be recorded and stored anonymously.

If you are keeping a record of patient data or plan to publish the Experience maps get written consent from the patient, parent or carer (see appendix for a [consent form](#)).

**Tip:** This is a good opportunity to take contact details if you have an ongoing project and the patient or parent is interested in being involved

3. Ask the patient or parent to describe their journey to pull out the key steps of their pathway. If you have already plotted the different steps of a process, check that the steps you have make sense and if there is anything missing

**Tip:** You can use post it notes for this so that you can move the pathway around if the patient or parent remembers other things that happened once you get chatting

**Tip:** Try not to spend too long perfecting the process, you can adjust it as you go. The focus of your time should be on capturing the different emotions throughout the journey

4. Once you have laid out the pathway of care, go back to the beginning and ask the patient or parent 'how did you feel?' for each step

**Tip:** You may want a menu of faces or words that they can choose from but don't limit the feedback to one word; for each step try to get several emotions and reasons behind the emotions

**Tip:** Remember to ask about the bits in between the steps, you can pick up on details and ask more about what happened and how it made them feel

5. Write positive comments above the step and negative comments below

**Tip:** if you are interviewing a group, choose one colour post it note for positive emotions and one colour for negative

6. When you get to the end of the journey ask 'is there anything else?' Recap what you've got and check in that you've captured the main positive and negative moments accurately

7. Thank participants. If you think the patient or parent needs further support, signpost

them to useful resources and check they are ok. Pass on details for PALS if necessary or explain if you need to raise any concerns from what you have heard

8. Type up your Experience map in an easy-to-understand and visual way (see examples below)
9. Share the learning from your Experience map with the professionals involved in the healthcare service or pathway used and by the parent/carer or patient.

**Tip:** Pass on any feedback to the teams involved in your patients' care; it is often an opportunity to pass on detailed and reflective praise for teams

10. Reflect on what you have learnt from doing the Experience map, both about the patient journey/pathway but also about your interaction with the patient

**Tip:** Make a note of what you have learnt and anything that struck you from the exercise. Think about how this will change your future practice. Include your reflections in your presentations, so that learning can be shared and used to inspire others

Experience Mapping examples

Exploring a patient’s experience of the healthcare system: an Experience map with a mother on the ward

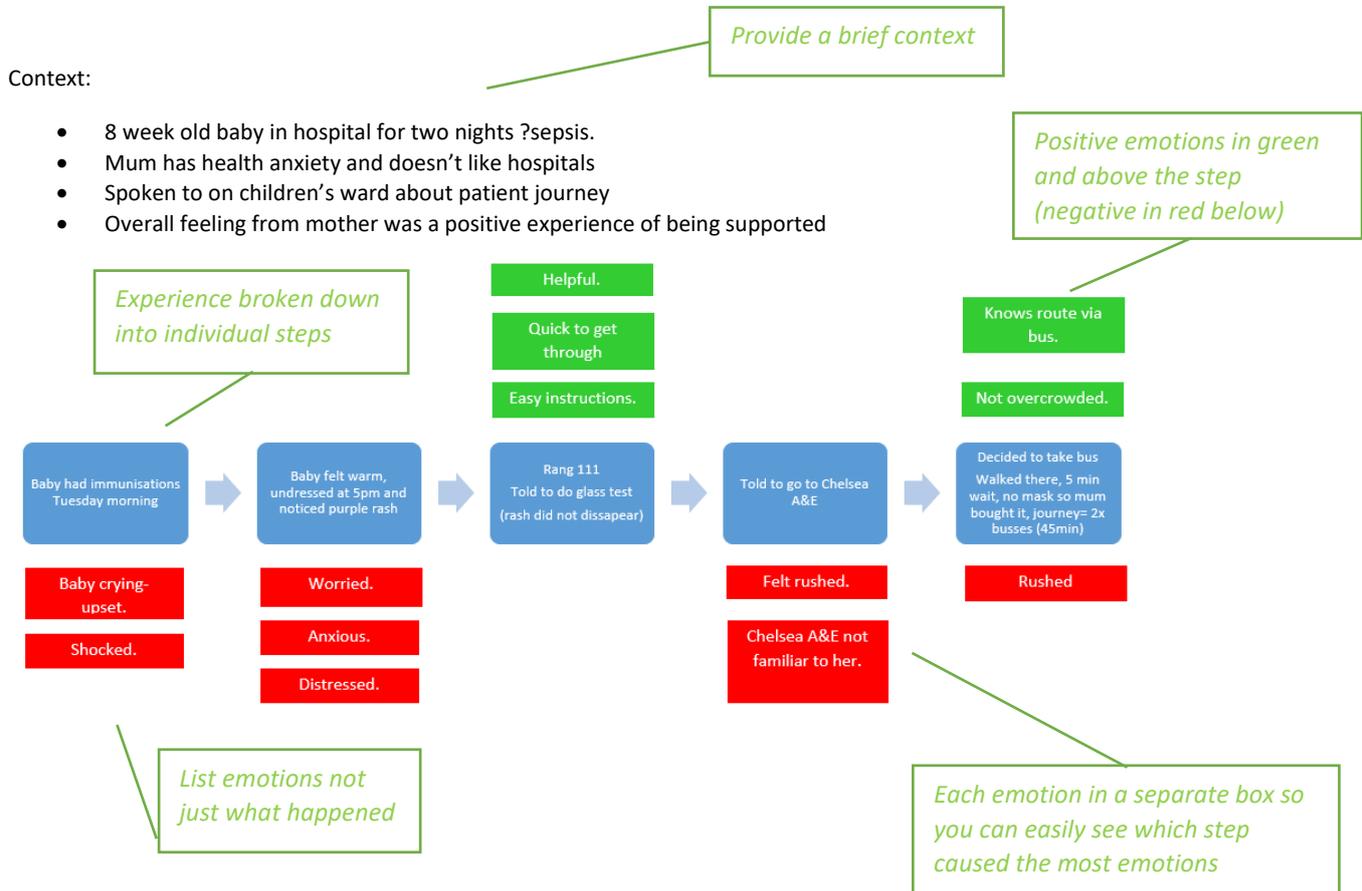
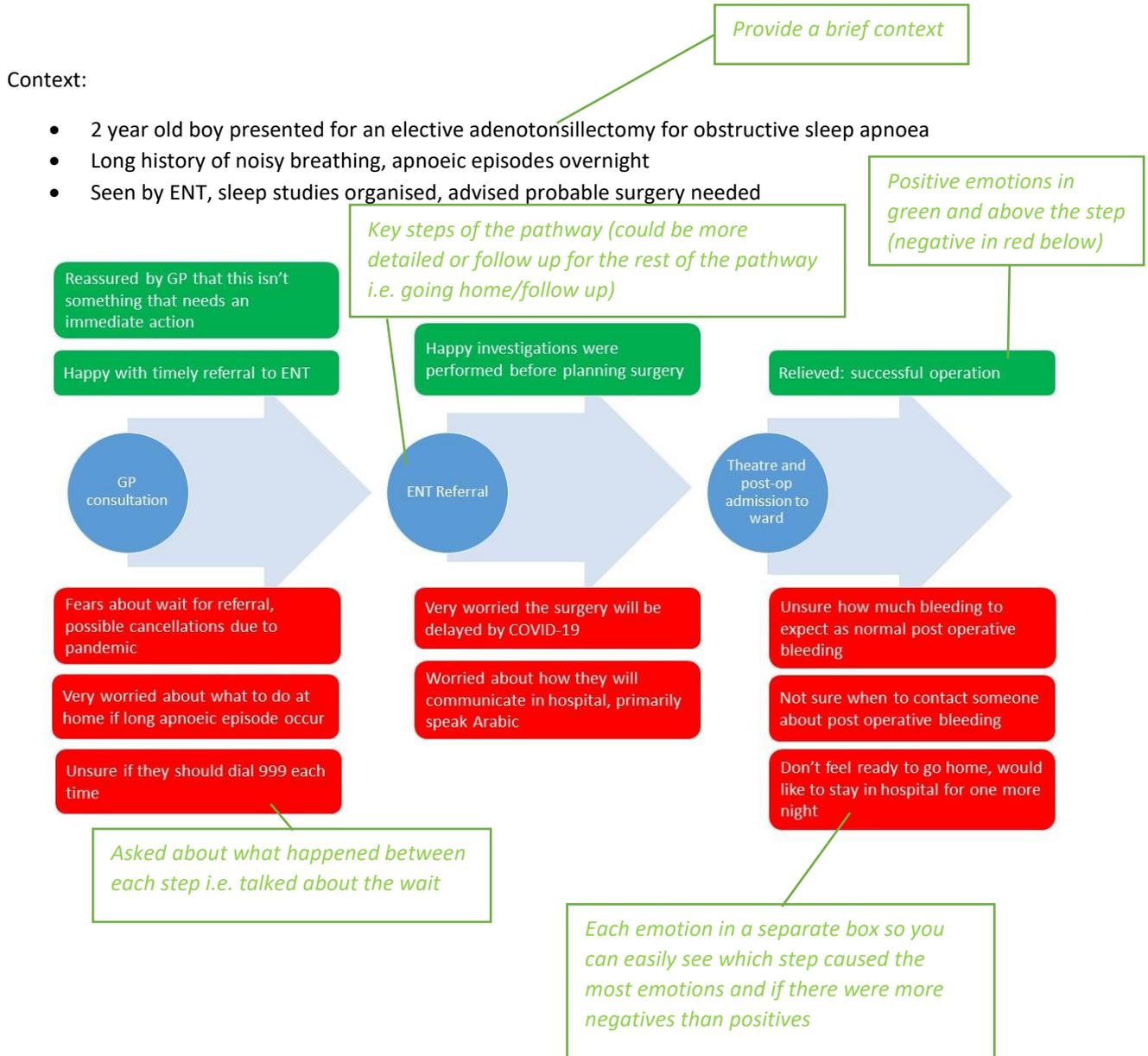


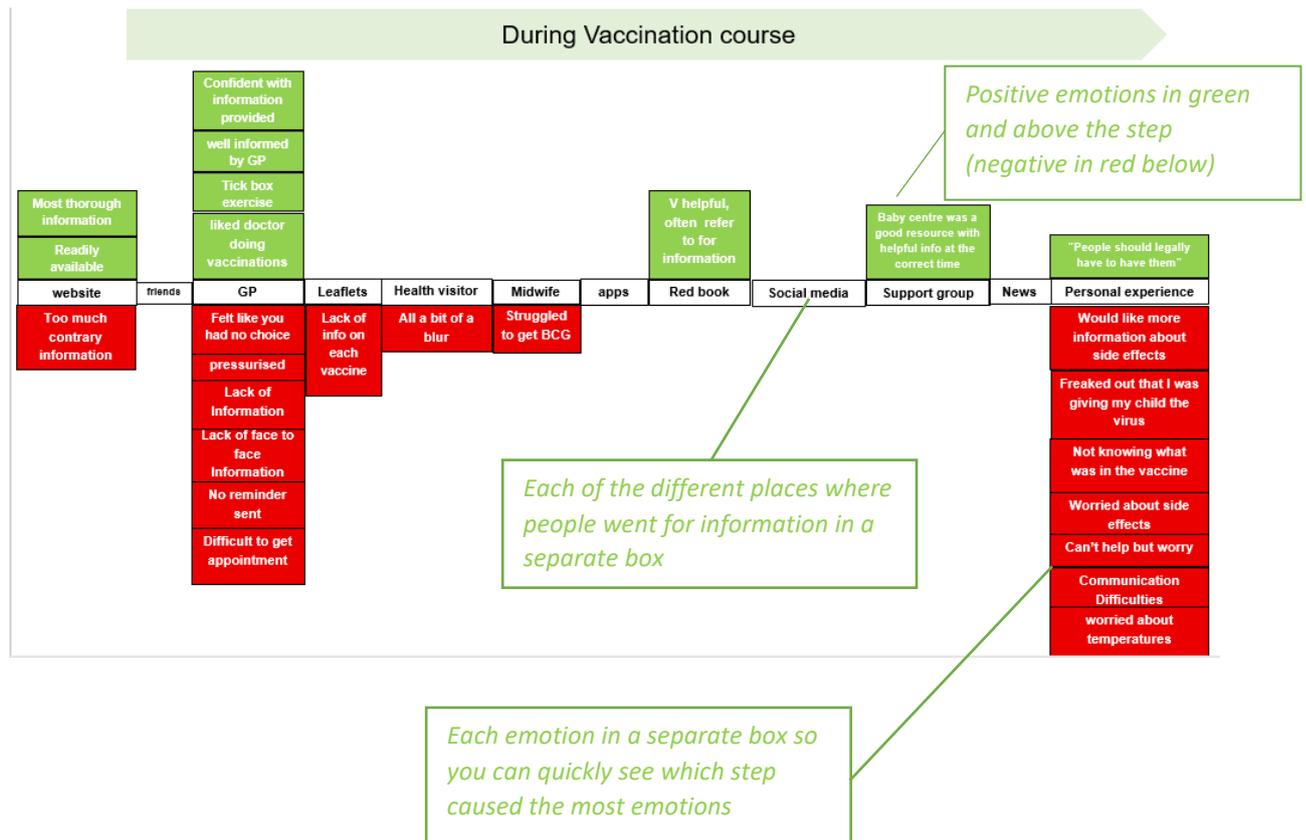
Figure 2. A good example of an Experience map that gathers feedback on a specific pathway, annotated with tips for displaying data

### Getting feedback on a specific pathway: an Experience map of parents of a two year old boy’s experience of the paediatric ENT elective surgical pathway



**Figure 3:** An example of an Experience map of a specific pathway, annotated with tips for displaying data

**Exploring where patients go for information on a specific health topic: an Experience map of the data obtained from a group of parents who were asked where they go for information on routine childhood vaccinations**



**Figure 4.** This Experience map describes the different places people went for healthcare information rather than a pathway, annotated with tips for displaying data

## Frequently Asked Questions

Experience Mapping is a great tool for understanding the patient perspective.

At times though, it can be tricky; below are some challenges and how you can overcome them.

### **Q: How can I break down the perceived hierarchy between myself and my patients when Experience Mapping?**

**A:** It can be difficult to lose the label of clinician when talking to patients, especially if you have previously been involved in that patient's care. When you approach families, emphasise that you are interested in capturing and sharing their experience; you want to broaden your understanding and aim to incorporate changes that improve patient care and/or the system. If there is an opportunity to be in a non-clinical, relaxed setting try to use that space.

### **Q: How do I remain focused on the conversation and not the paper in front of me?**

**A:** it's helpful to remember that Experience Mapping is a tool to facilitate a focused conversation. Refer to the map to follow the patient's journey but maintain a fluid conversation – think of the map as guideline.

### **Q: Should I remain neutral in the conversation?**

**A:** Be prepared to support the patient (or parent/guardian) who you are interviewing, as the process can generate deep Experience responses. You want to capture the patient's voice and their experience and not influence their responses. Non-verbal cues can be especially useful. Let them know you are listening with your body language, nod and maintain eye contact.

Be empathetic and use a conversational tone.

If you hear information that triggers emotions or upsets you, it is important to share this and seek support. Talk to your supervisor, line manager or freedom to speak up guardian.

You might want to share your experience and personal reflections with your wider professional workforce, at a team meeting or Grand round.

### **Q: How do I present the Experience map in an easy to read format?**

**A:** Ensure it's easy to follow the path and see the positives and negatives at first glance. Have individual boxes for each part of the journey and emotion.

Colouring the positive emotions green and the negative emotions red makes the maps immediately clear.

**Q: What consent do I need from patients?**

**A:** You do not need consent before having a conversation with patients about service improvement. Simply follow good professional practice.

Think about how you want to use the information you are getting. Most Experience maps collect views and feedback anonymously. If you do need to record/store personal information, follow the usual information governance protocols and make sure you get consent. If you would like to publish your Experience maps or put them on a website, it's best to get signed consent from families to use their information in that way.

We have included a template consent form to use for projects where identifiable patient quotes or information is used (Appendix 1). Make sure you know where and how to store the completed consent forms.

If in doubt, get advice – contact the data protection team

If you feel that the person you are talking to has a particularly powerful story and may be interested in sharing their story at a Schwartz Round or other meeting or in a video, ask for their contact details.

**Q: What next?**

**A:** If you are using Experience maps for a particular health topic/ pathway, get as many individuals as you can. Build up a body of maps and use one to inform the next and then to narrow down the issue. Think about how you can use these to influence change, whether this is in behaviour, the system, or the pathway itself.

You can also do this as a group activity with patients or parents. They often enjoy sharing their experiences with each other.

## Thanks

CC4C would like to thank Dr Dominique Allwood for her contribution in the design and development of the Experience Mapping tool which continues to support improvement in patient experience and health care provider training

## Authors

Dr Mando Watson, Phoebe Rutherford, Rianne Steele and Dr Arpana Soni

### Contact

Please contact us if you would like to discuss this guide: [imperial.cc4c@nhs.net](mailto:imperial.cc4c@nhs.net)

If you would like to use or edit anything in this guide please [get in touch](#) with us first.

## References and further reading

### References

- (1) Royal College of Paediatrics and Child Health, *2017 Workforce Census Overview*. 2019  
<https://www.rcpch.ac.uk/resources/workforce-census-2017-overview-report>
- (2) Royal College of Paediatrics and Child Health, *Paediatrician of the future: Delivering really good training*. October 2020  
<https://www.rcpch.ac.uk/sites/default/files/2020-10/rcpch-paediatrician-of-the-future-delivering-really-good-training.pdf>
- (3) Institute for Healthcare Improvement, *The Triple Aim or the Quadruple Aim? Four Points to Help Set Your Strategy*. November 2017  
<http://www.ihl.org/communities/blogs/the-triple-aim-or-the-quadruple-aim-four-points-to-help-set-your-strategy>

### Further reading

NHS Institute for Innovation and Improvement: The experience based design (EBD) approach: <https://improvement.nhs.uk/resources/the-experience-based-design-approach>

COVID-19 and preschool wheeze care: lessons learned. *Lancet Respir Med* Aug 2020. Heidi Makrinioti, Mando Watson, Andrew Bush, and Dougal Hargreaves:  
[https://www.thelancet.com/journals/lanres/article/PIIS2213-2600\(20\)30351-9/fulltext](https://www.thelancet.com/journals/lanres/article/PIIS2213-2600(20)30351-9/fulltext)

## Parent/Guardian Consent Form

**Project: 'Experience Mapping' sharing the experience of children, young people and their families**

Child's Name: .....

This project has been explained to me by: *(delete as appropriate)*

Prof/ Dr/ Mr/ Mrs/ Ms .....

*Add/delete/amend clauses as appropriate]*

**Please initial box**

|   |  |
|---|--|
| 1. I confirm that I have read and understand the Experience Mapping information sheet and have had the opportunity to ask questions which have been answered fully  |  |
| 2. I understand that my and/or my child's participation is voluntary, and I or my child are free to withdraw at any time, without giving any reason and without our medical care or legal rights being affected |  |
| 3. I understand that written notes will be made about my child's experience, but that this will remain fully anonymous and none of my child's personal identifiable data will be shared                         |  |
| 4. I understand that my child's comments will be fully anonymised and used to improve healthcare services for children and young people   |  |
| 5. I am happy for an anonymised account of my child's experience to be shared and published online  |  |
| 6. I agree to my child taking part in this project  |  |

\_\_\_\_\_

Name of parent / legal

\_\_\_\_\_

Signature

\_\_\_\_\_

Date

Guardian

\_\_\_\_\_

Name of Person taking consent

\_\_\_\_\_

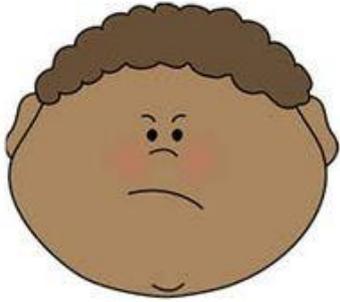
Signature

\_\_\_\_\_

Date

**Would you like to stay involved in? Please leave a contact email:**

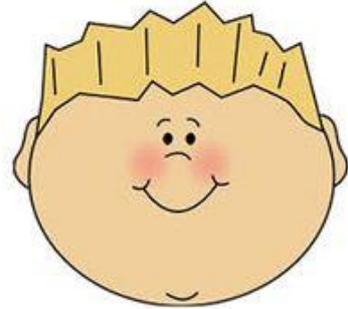
\_\_\_\_\_



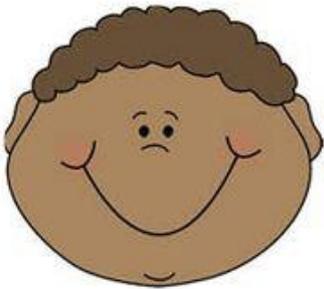
angry



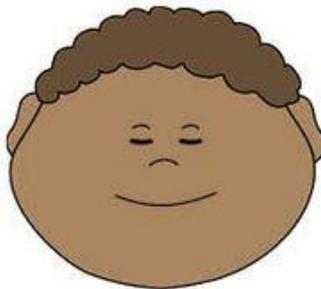
sad



happy



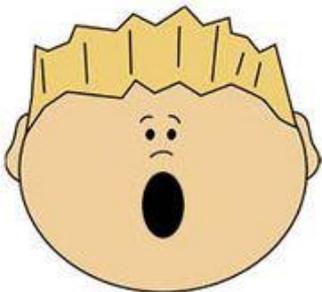
silly



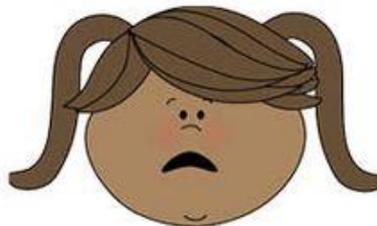
tired



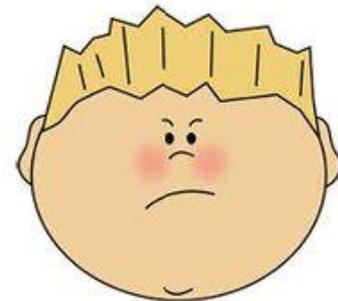
worried



surprised



scared



cranky

## Patient/Parent/Carer Information Sheet

**Project: 'Experience Mapping' sharing children, young peoples and their families experience of healthcare**

### **What is Experience Mapping?**

Experience Mapping is a tool used by healthcare professionals to capture and share patient experience of a healthcare service.

### **What does it involve?**

It involves a conversation between yourself and a healthcare professional and will take around 30 minutes.

The health care professional undertaking the Experience map will support you and/or your child to tell your story of your experiences, in your own voice.

The healthcare professional will take fully anonymous notes about the experience you describe.

### **Do I have to participate?**

Participation is voluntary, and you or your child are free to withdraw at any time, without giving any reason and without your medical care or legal rights being affected.

### **What happens afterwards?**

The anonymous information will be shared with the teams involved in your care, to help improve the services we offer.

**Many thanks for taking the time to read this information leaflet, if you have any further questions please ask the person who has given you this leaflet, see their contact detail below.**

**Contact name:** [\[insert contact name here\]](#)

**Contact email:** [\[insert contact email address here\]](#)