# Innovating for Improvement

**Sing and Say:** a web-based language stimulation project for children with craniosynostosis.

Oxford Craniofacial Unit





# About the project

# **Project title:**

Sing and Say: a web-based application of language stimulation resources for children with craniosynsotosis.

# Lead organisation:

Oxford Craniofacial Unit, Oxford University Hospitals NHS Foundation Trust

# **Project lead(s):**

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# Part 1: Abstract

This information will be used to give a brief summary of your project on our website, and may be revised for web copy. Please ensure that you do not exceed the word count as there is a strict word limit on the website.

Patients under the care of the Oxford Craniofacial Unit routinely undergo multi-disciplinary pre-operative assessments prior to undergoing transcranial surgery. These assessments inform patient's surgical, psychosocial and medical management and provide a developmental baseline. For many children, delays in emerging language development are identified. Children often require referral to local Speech and Language Therapy (SLT) services. However, due to variable local services, many children are unable to access much-needed therapy.

In response to the clinical need, the Oxford Craniofacial Unit SLT team created a bespoke suite of language stimulation videos, songs and resources for children with craniosynsotosis called: Sing and Say. Sing and Say allows the child's SLT to write a tailor-made language program for children with craniosynostosis based on their most recent language assessment. Each child receiving care at the Oxford Craniofacial Unit aged two years and younger will now have access to this resource as part of our standard package of care.

Results of baseline assessment indicate that 17% - 26% of children presented with delays in at least one domain of language development. This reinforces the high level of need for SLT intervention, particularly when the results are compared to the prevalence of language impairment in the general paediatric population – which is 6.5%. The production of this resource was ambitious taking longer than anticipated. The resultant innovation was worth the wait. It is now incorporated into standard care for children in the craniofacial unit with anticipated scale up and spread nationally and internationally over the next year.

Max words: 250

# Part 2: Progress and outcomes

This section is intended for you to summarise your outcomes and evidence for how these were achieved.

#### Sing and Say: The Intervention and Innovation

Previously, no language intervention resource existed for children with craniofacial anomalies taking into account their unique needs. A large body of literature exists about interventions for children with cleft lip and palate to address cleft-type speech characteristics (Bessell et al., 2013). However, no known language intervention existed for children with craniofacial anomalies. Children with craniosynostosis may be at an increased risk for attentional difficulties which makes engagement in traditional language intervention activities difficult. The prevalence of hearing impairment in this population also includes unique considerations for the production of the resource.

Pre-existing, marketed music and language interventions are generic in nature and fail to meet the specific needs of children with craniosynostosis including possible vision difficulties, limb anomalies associated with a syndrome, hearing impairment, attentional difficulties and difficulties with social communication (Shipster et al., 2003). Existing webbased applications do not include music written by a music therapist drawing on the relevant neurologic principles that govern using music to stimulate speech and language production in children (Thaut et al., 2001).

For Sing and Say, music therapists and speech and language therapists collaborated to produce a resource to encourage communication, joint attention and interaction skills. The novel multi-pronged approach of music, technology and specifically-designed language activities to encourage children and parents is aimed at captivating families and encouraging participation in a purposeful language intervention in a method that families can access. It is intended to be used as a therapy adjunct for children who are accessing speech and language therapy locally, or as a stop-gap measure while children wait for local services. The specialist speech and language therapist can see the results of the child's strengths and weaknesses identified on assessment, to identify areas of the Sing and Say suite of resources they can use at home to encourage their child's communication.

Initially, the plan for this project was to be 'paper-free' with all resources to be based online. However, after discussion with the team and reflection, we decided that we would make a book to 'gift' families with all of the details of the website and the basics of language development at the point when we discuss the need to refer their child to local services. It was felt that the provision of something tangible that would direct families to a web-based resource would be most beneficial. An additional aim of this project was to test the feasibility and desirability of an online resource.

# Impact on Quality

The efficacy of the intervention will be measured by comparing children's language outcomes at the point of initial assessment and post-intervention. Baseline pre-operative language data has been gathered on 58 children. Specifically, children's language was measured as follows:

# Before their operation:

- Communication and Symbolic Behavior Scales Developmental Profile (CSBS-DP);
- Baileys Developmental Language Scales Third Edition;
- Hearing assessment

After their operation:

- CSBS-DP
- Parent feedback about the use of Sing and Say.

# Additional parent feedback:

An adjustment to the outcome measures was made over the course of the project. We introduced the collection of parent feedback about the videos prior to the conclusion of the intervention period. Prior to their MDT appointment, parents were shown the video by the Speech and Language Therapy Assistant and then given a chance to participate in a quick survey to provide their views on the usefulness of these videos.

#### Baseline Language Outcomes

During the set-up phase comprehensive baseline language data were collected from 58 children. The locations of the children are highlighted on the below heat map. This image highlights the variability in the local health authorities children return to for Speech and Language Therapy if required.



Image 1. Heat map of the home location of children in the baseline language assessment group (n=58).

Children in this baseline assessment group were aged 6 months -2 years of age. As language is a developmental skill, the subtle language difficulties that some children with craniosynostosis may develop may not present on early assessment during this age group.

Sing and Say is designed to be used with children under two years of age, hence if delay emerges at a child's post-operative or 18 month year old assessment, they are still within the target range for the Sing and Say suite of resources.

Results of assessment (Table 1) indicate that 17% of children (n=10/58) presented with delayed early social skills; 22% of children (n=13/58) presented with delayed speech development; 26% (n=15/58) presented with delayed symbolic play development. Resources to target these key areas are available on the Sing and Say website.



Table 1. Domains of Language Delay in the Baseline population vs the GeneralPopulation

This reinforces the high level of need for SLT intervention, particularly when the results of language assessment are compared to the prevalence of language impairment in the general paediatric population – which is 6.5% (Tomblin et al., 1996).

# Feedback from Parents:

# Shooting Star Video

Feedback from parents of children with craniosynostosis about their perceptions of the Shooting Star video was secured during their attendance at multi-disciplinary clinic appointments. Parents were asked a series of questions and given an opportunity to provide free form feedback.

This was such a lovely thing to do for all children involved I'm so very proud of all the children that took part and the wonderful staff for giving their time up to make this happen thankyou everyone [Parent]

Great positive	It's nice to see the
video with a	children looking so
hopeful message	happy
[Parent]	[Parent]
The following feedback was provided by parents:	

How of cranio	ften do you synostosis	i see in pł	images of ch notos and vic	ildre leos	n with in the general ı	media?	Response Percent	Response Total
1	Never						41.2%	7
2	Rarely						52.9%	9
3	Sometimes						5.9%	1
4	Most of the Ti	me					0.0%	0
5	All the Time						0.0%	0
Analysis	Mean:	1.65	Std. Deviation:	0.59	Satisfaction Rate:	16.18	answered	17
	Variance:	0.35	Std. Error:	0.14				

Ho of	ow imp childr	oortant do en with c	o you ranio	think it is for synostosis?	' your	child to see im	ages	Response Percent	Response Total
1	Not at	t all Importa	nt					5.9%	1
2	Slight	ly Important	t					0.0%	0
3	Impor	tant						29.4%	5
4	Fairly	Important						17.6%	3
5	Very I	mportant						47.1%	8
An	alysis	Mean:	4	Std. Deviation:	1.14	Satisfaction Rate:	75	answered	17
		Variance:	1.29	Std. Error:	0.28				

How	/ do ː	you feel a	about	the	images i	n: 'Sh	ooting Star?'		Response Percent	Response Total
1	Very	y Unhappy							0.0%	0
2	Unh	арру							0.0%	0
3	Indi	fferent							11.8%	2
4	Нар	ру							29.4%	5
5	Very	/ Нарру							58.8%	10
Ana	lysis	Mean:	4.47	Std.	Deviation:	0.7	Satisfaction Rate:	86.76	answered	17
		Variance:	0.48	Std.	Error:	0.17				

#### Language Stimulation Videos (parents of children under 3)

Feedback has been obtained to date from 3 parents of children with craniosynostosis aged 6-9 months of age. These children fall within the target range for Sing and Say and we were particularly interested in their feedback. Parents of the first three children aged under three attending the multi-disciplinary clinic were approached to participate in this survey. Parents were asked to indicate their responses to five questions on a 5 point scale. Results are shown below and are expressed as averages.

Plea follo easy	se s wing / to u	tate how g stateme use.	stron ent: T	igly he S	you agre Sing and S	e/disa Say la	agree with anguage v	n the videos	are	Response Percent	Response Total
1	Stro	ngly Disag	ree							0.0%	0
2	Disa	agree								0.0%	0
3	Indi	fferent								0.0%	0
4	Agre	ee								33.3%	1
5	Stro	ngly Agree								66.7%	2
Anal	ysis	Mean:	4.67	Std.	Deviation:	0.47	Satisfaction	n Rate:	91.67	answered	3
		Variance:	0.22	Std.	Error:	0.27					

Plea follo clea	se s wing r and	tate how g stateme d easy to	stron ent: T unde	gly he S rsta	you agree ing and \$ nd.	e/disa Say la	agree with the Inguage video	s are	Response Percent	Response Total
1	Stro	ngly Disagi	ree						0.0%	0
2	Disa	agree							0.0%	0
3	Indi	fferent							0.0%	0
4	Agre	ee							33.3%	1
5	Stro	ngly Agree							66.7%	2
Anal	ysis	Mean:	4.67	Std.	Deviation:	0.47	Satisfaction Rate	: 91.67	answered	3
		Variance:	0.22	Std.	Error:	0.27				

Plea follo clea	se s wing r and	tate how g stateme d easy to	stror ent: T unde	ngly he S ersta	you agre Sing and S nd.	e/disa Say la	agree with the Inguage videos	are	Response Percent	Response Total
1	Stro	ongly Disag	ree						0.0%	0
2	Disa	agree							0.0%	0
3	Indi	fferent							0.0%	0
4	Agr	ee							33.3%	1
5	Stro	ongly Agree							66.7%	2
Anal	ysis	Mean:	4.67	Std.	Deviation:	0.47	Satisfaction Rate:	91.67	answered	3
		Variance:	0.22	Std.	Error:	0.27				

# Language Stimulation Videos (parents of children older than 3).

Feedback about the language stimulation videos was obtained from 10 parents of children with craniosynostosis older than 3 years of age (Age range of children 5 - 16 years of age). Parents provided responses on a five point scale indicating answers to the following (question one, question two, question three). Averages of the responses are provided in the table below:

Ple fol eas	ease s lowing sy to u	tate how g stateme use.	stron ent: T	gly you agre he Sing and	ee/disa Say la	agree with the Inguage videos	are	Response Percent	Response Total
1	Stron	gly Disagre	е					0.0%	0
2	Disag	ree						0.0%	0
3	Indiffe	erent						0.0%	0
4	Agree	)						20.0%	2
5	Stron	gly Agree						80.0%	8
An	alysis	Mean:	4.8	Std. Deviation:	0.4	Satisfaction Rate:	95	answered	10
		Variance:	0.16	Std. Error:	0.13				

Ple fol cle	ease s Iowing ar and	tate how g stateme d easy to	str ent: un	ongly y The Sinderstan	ou ag ng an d.	ree d S	e/disagree with ay language vi	the deos are	Response Percent	Response Total
1	Stron	gly Disagre	е						0.0%	0
2	Disag	ree							0.0%	0
3	Indiffe	erent							0.0%	0
4	Agree	)							0.0%	0
5	Stron	gly Agree							100.0%	10
An	alysis	Mean:	5	Std. Dev	iation:	0	Satisfaction Rate:	100	answered	10
		Variance:	0	Std. Erro	r:	0				

Ple sta rar	ease s atemei nge, I v	ay how n nt: If thes would ha	nuch e vide ve us	yoı eos ed	i agree/dis were targ them.	sagre jeted	e with this at my child's aç	je	Response Percent	Response Total
1	Strong	gly Disagre	е						0.0%	0
2	Disag	ree							0.0%	0
3	Indiffe	erent							10.0%	1
4	Agree	9							40.0%	4
5	Stron	gly Agree							50.0%	5
An	alysis	Mean:	4.4	Sto	I. Deviation:	0.66	Satisfaction Rate:	85	answered	10
		Variance:	0.44	Sto	l. Error:	0.21				

When asked why parents thought it was important for children with craniosynostosis to see images of themselves depicted on video, common themes of 'encouraging awareness', 'reducing stigma' and 'belonging' emerged. The range of the parents' responses are depicted in the word cloud below:



# Feedback from Staff

Additional responses to the intervention and the extent of national and global impact of this project are outlined in the Sustainability and Spread section of this report. Preliminary feedback has also been obtained from the Oxford Craniofacial Unit MDT. Staff have shared: their excitement about the release of Sing and Say. One Speech and Language Therapist

shared her thoughts on what it means for her clinical practice:

It was so disheartening to identify that a child has speech and language needs, and know that when you refer them to local speech and language therapy they will have a long wait for much-needed therapy. Some children wait up to a year for a one-off appointment! Sing and Say now gives us an opportunity to provide parents with access to ideas they can implement immediately in the home environment while they wait for local services' [Speech and Language Therapist]

# Another team member stated:

"Often, for young people with ongoing medical needs, there is a huge demand on the time parents and carers are able to spend with them. Sing and Say is an excellent tool. It provides parents and carers with the opportunity for positive interaction with their child – an interaction which isn't dictated by the need to provide care for their medical condition, but instead is about having fun, and promoting language and communication in an engaging way." [Clinical Psychologist]

# Summary

The results of the baseline assessment reinforce the clinical need for Sing and Say. The initial response to the Sing and Say videos has been heartening and we look forward to continuing to evaluate the implementation phase of this project in due course.

Max words: 1,000

# Part 3: Cost impact

This section is intended for you to review the cost impact of your project – giving an indication of whether the intervention is cost saving, cost neutral or requires ongoing investment.

Since 1998, the provision of craniofacial surgery in the UK has been commissioned on a national level by the National Specialist Commissioning Team (NCST) which is part of the Department of Health and is responsible for funding, managing and developing 'specialist services.' There are four supraregionally funded designated craniofacial centres in the UK: Oxford Craniofacial Unit, Great Ormond Street Craniofacial Unit, Alder Hey Children's Hospital Craniofacial Unit and the Birmingham Children's Hospital Craniofacial Unit. Each Unit comprises a multi-disciplinary team. As part of this team, the Oxford Craniofacial Unit Speech and Language Therapists provide expert, specialised assessment alongside a child's multi-disciplinary clinic appointment or prior to undergoing transcranial surgery.



After their assessment, and if clinical need is identified, children are referred for local Speech and Language Therapy (SLT) support. However, the commissioning landscape for local services in the UK has changed, making access to local SLT complex. The *Health and Social Care Act* (2012) established clinical commissioning groups (CCGs) as the primary commissioners of the majority of health services, including speech and language therapy. Resulting in a system of fractured services and unequal access to SLT: best-characterised as a postcode lottery (ICAN, 2018). Many parents report that local SLT is difficult to access (Care Quality Commission and Ofsted, 2017).

The long-term implications for being unable to access appropriate early SLT intervention are profound. It is estimated that 75% of children with persistent communication difficulties at pre-school age are likely to be in need of special education support (Snowling et al., 2001). Nationally, local authorities were allocated £130 million of funding for children with special education needs for 2017/8 (Education and Skills Funding Agency, 2017), demonstrating that the cost to the country of this children's education alone is substantial.

Research indicates that with effective, appropriate early intervention, children can make positive gains with their speech and language development (Ward, 2009). The long-term economic impact of communication impairment continues into the workplace. Communication skills are highly-valued by employers, however difficulty recruiting staff with sufficient skills has been reported (ICAN, 2016). Communication difficulties at work can impact on problem solving, effective practice and decision-making (Littleton & Mercer, 2013). Loss of production through the lack of soft skills, including communication, has been estimated at £8.4 billion a year by 2020 (McDonald, 2015).



The Sing and Say project is intended to be actuarial in nature. The implementation of this project did not change the costs of Speech and Language Therapy service provision in the Oxford Craniofacial Unit. The costs for setting up the project were remunerated by funding received under the auspices of the Innovating for Improvement grant. However, the failure to address speech and language needs has broader, long-term implications for children who access our service. The correlation between children with communication impairment and low attainment, behavioural and emotional difficulties, mental health issues, poor employment or training prospects and youth crime is well-established (Snow et al., 2004; 2008; 2009, 2011, 2012, 2016). This project is cost neutral, however the investment of providing appropriate early intervention for children with craniofacial conditions in the UK will have long-term fiscal, social and emotional benefits. It is our hope that Sing and Say will reduce the need for SLT appointments in the future.

Max words: 500

# Part 4: Learning from your project

This section is for you to reflect on your learning from implementing your project and identify important lessons for other change makers.

Our project is still ongoing. We have almost completed the intervention and we have collected baseline data. We have actively commenced the final stage of the project which is to collect patient feedback and measure the impact of the intervention. We are very grateful for the support of the wider Oxford Craniofacial Unit multi-disciplinary team and our SLT colleagues in the four designated craniofacial units for their support and enthusiasm for Sing and Say. The contribution and commitment of the web-development team at the Oxford University Hospitals NHS Foundation Trust also assisted us in moving the project forward in the final stages of completing the intervention.



#### Creating the Intervention

The biggest difficulties were the obstacles we encountered whilst creating the intervention package. All content was written very easily and completed on schedule. However, we seriously underestimated the time it would take for official approval at each stage of the project, and regularly came to a grinding halt while we waited to commence the next stage of the project. If we were to undertake this project again, we would have invested more time strategically meeting with Trust Finance and patient information officers to ensure they fully understood the scope of the project and the importance of supporting adherence to a timeline. The Finance team were supportive, however the pre-existing policies and procedures were not conducive to our timeline. This is because the approval processes at each stage took up to three months at times. All too often we found that the creative scope of our project fell outside of the realms of existing procedures. This led to difficulties with our external creative suppliers and internal finance team.

#### New Directions: Expansion of the original intervention

A pivotal point for the direction of the project arose when discussing the language stimulation videos with the video production team. When in discussion with the producer, the idea to use child actors was floated. I immediately countered this with the fact that I felt very strongly that children with craniosynostosis are not regularly featured on film and that it would be important for our patients to see themselves portrayed positively in this way. This lead to discussions with the team about how we could use this project to positively present children with craniosynostosis on film, create a way to engage with the craniofacial community and promote the use of Sing and Say. Thus the music video: 'Shooting Star' was born.



#### Music

Engaging with the arts in this project has been a pleasure. The flow-on effects of producing tailor-made music for children with craniosynostosis soon became clear. Our Registered Music Therapist really took the time to understand the needs of the children in this project. One of the children who participated in filming the video returned home that night and as they were going to bed said: *'I'm not a rockstar anymore am I Mum?'* We loved it that for one afternoon these children felt like rockstars! The same child attended the hospital for a preplanned procedure the following week and our team organised the Music Therapist to attend their bedside and play: 'Shooting Star'. Another child who performed in the video shared with me that they would like to try out for his school musical after performing in the video!



# Parent and Patient Feedback

The most surprising feedback that I received was from a parent during the filming party for 'Shooting Star'. The intent of the video was to provide a forum for children to see other children with craniosynostosis depicted positively on film. However, one parent shared what 'Shooting Star' would have meant for her:

'If I had seen this video when N was first diagnosed, it would have meant the world to me. When you first have a baby with craniosynostosis, you worry about how they are going to grow up. If I could have seen a video like this of happy, healthy children, it would have been so important to me.' [Parent]



# Engagement of the Wider Team

Production of the video resources on this scale would not have been possible without the support of the wider Oxford Craniofacial Unit team who volunteered their time to support the filming party for Sing and Say, with genetics counsellors, specialist nurses, research assistants and speech and language therapists supporting children and families on the day. One staff member shared with me that it was: *'such a special day'*.



# Engaging with Patients and Families: Social Media

One of the most important lessons we learned was the value of using social media to engage directly when engaging families. We used pre-existing patient support groups on Facebook to great effect to generate interest in the project and secure preliminary feedback. It was also via the Facebook group feedback that we learned how much the 'Shooting Star' project has resonated with the families (see below).

What an aweso unit. All childre craniosynostos	me video made by Ox en featured have been is	ford craniofacial diagnosed with
How many likes	s and shares can we ge	et these talented
	YOUTUBE.COM Children with crani in a music video: 'S Made by Oxford Cranic	osynostosis star hooting Star' bfacial Unit, this o
🖒 Like	Comment	🖒 Share
00 83		
38 shares		

We also learned that many families nation-wide had wanted to participate but were unable to due to the distance to travel to Oxford. When opportunity to participate in the Sing and Say filming party was shared on Facebook, these were some of the comments from families:



As a result of this feedback, we are currently investigating a way to enable all children to participate in a music video via sending their videos in for a 'carpool karaoke' format and filming in Liverpool, London and Birmingham (the locations of the other specialist units).

#### Social Media

The potential for the global impact of this project did not become apparent until Sing and Say was noted on social media by colleagues in Australia and America who subsequently contacted the Oxford Unit about whether they could use the resource. The answer was: 'Of *course*!'

As evidence of the level of patient engagement, within a few days of sharing the Shooting Star video, on the OUH Trust YouTube channel it had over 600 views (see below). Given the rarity of craniosynostosis (one in 1400-2100 children - Lajeunie, Le Merrer, Bomaiti-Pelllie et al, 1995; Cornelissen, den Ottelander, Rizopoulous et al, 2016), this demonstrates that this video really struck a chord with the craniofacial community.



As a team we are so delighted to see the patients that we work with depicted so positively on camera. We are proud of a resource that is freely-available and will facilitate children's speech and language development. We take away many lessons from this project and look forward to measuring the impact of the Sing and Say intervention and continuing to gather feedback from children and parents. We hope to expand this intervention to children in other age groups older than 2 years of age in the future.



Max words: 1,000

#### Part 5: Sustainability and spread

This section is intended for you to communicate your plans for sustainability within your organisation and spread beyond your project team.

#### Sustainability in the Oxford Craniofacial Unit

Long-term sustainability of the Sing and Say intervention will be achieved by incorporating the use of the app into our regular advice clinics as a meaningful and functional resource for families. This project has a once-only set up cost and the incorporation of Sing and Say into our regular clinical practice will not incur any additional costs.

When children attend for pre-operative Speech and Language Therapy assessments or mutli-disciplinary craniofacial clinic appointments, their speech and language skills are routinely assessed and screened. Upon identification of need, parents will now be given access to Sing and Say and a tailor-made speech and language therapy program of Sing and Say activities based on their assessment. Referral to local Speech and Language Therapy services will also be made.

Long-term measurement of the intervention will be incorporated into our longitudinal developmental assessment protocol. We regularly assess all children with craniosynostosis pre-operatively, at 18 months, 3 years, 6 and 10 years of age.

#### Scale-up and Spread

Sing and Say is now available to the Speech and Language Therapists in all four NHSdesignated Highly-Specialist Craniofacial Units (Alder Hey, Birmingham, Oxford and GOSH). We have worked with our colleagues in the four units to encourage buy-in to this project and they have enthusiastically shown the preliminary videos to families in their unit to gather feedback. We look forward to hearing feedback from their units about the use of Sing and Say and working with our colleagues to ensure that it is incorporated into their 18 month assessment and early communication advice protocols and pathways.



# **Publications**

A full-colour double-page spread of the Sing and Say project 'Shooting Star' filming party was featured in the Headlines Craniofacial newsletter (see below).



#### **UK Conference Presentations**

We were also invited to present on the project at Headlines Craniofacial Conference in 2017 at Kings College London. We were invited to provide an update on the project at the Headlines Craniofacial Conference in May, 2018 at Sheffield Hallam University (which was rescheduled to June, 2018 due to snow).

Headlines Craniofacial Support	•••
We're looking forward to the Headlines Conference Specialist Speech and Language Therapist, John R provide an update on the 'Sing and Say' project - a stimulation app for children with Craniosynostosis.	018. Sarah Kilcoyne, dcliffe Hospital, will eb based language
Find out more about our packed programme and div	rse speakers at:
http://www.headlines.org.uk/headlines-conference-2	18.asp
Headlines Conference 2018 - Saturday 10.30 – 17.00	March 2018
Headlines is a charitable organisation based in the UK wh and help to all those affected by Craniosynostosis (both sy syndromic) and associated conditions.	h aims to provide support dromic and non-
HEADLINES.ORG.UK	

# Global Impact

After sharing the Sing and Say website and videos on social media, the Oxford team have been contacted by Craniofacial Units in Australia and America who have expressed an interest in using Sing and Say in their own units. The European phase of the scale and spread phase of this project will commence in October, 2018 when this project will be presented at the European Society of Craniofacial Surgery in Athens. The wider international phase will be implemented in September, 2019 when we will present this project at International Society of Craniofacial Surgery. From the beginning of this project, we thought about how we could engage families for whom English is an additional language and craniofacial units from non-English speaking countries. Built into the videos is the ability for the subtitles to be automatically translated into any one of hundreds of languages (see below) from Afrikaans to Zulu, meaning any parent that can read can work with their child to sing and say!



Impact Outside of the Craniofacial Community

Difficulties in accessing speech and language therapy is not limited to the children with craniosynostosis. This is a nation-wide problem. We aim to connect with the Royal College of Speech and Language Therapists to advertise this as an adjunct therapy resource for speech and language therapists while they have children on their waiting list. Other specialist services within Oxford University Hospitals NHS Foundation Trust have also expressed an interest in using Sing and Say.



# Future Directions

We advertised the Sing and Say 'Shooting Star' filming party via the Headlines craniofacial support website and in the Oxford Craniofacial Unit. The interest from families was overwhelming, however due to the distance, many families in the UK were unable to attend. We are investigating alternative funding options to 'take the show on the road' and conduct filming parties in Birmingham, Alder Hey and London to enable more children and families to participate.

The response to the 'Shooting Star' song has been very positive and we have plans to release it as a 'Christmas Single' together with a: '12 days of craniofacial Christmas' to raise awareness of the Sing and Say intervention.

We will also put a call out to families of children with craniosynostosis to make a 'carpool karaoke' version of the *'l love you'* song <u>http://www.ouh.nhs.uk/singandsay/songs/default.aspx</u> for children under five and older children will have a chance to participate in a version of '*Shooting Star*' when we present at the Headlines Conference in Sheffield in June, 2018.



#### Intervention Impact

The next milestones include measuring the intervention and parental response to the intervention. We have actively commenced the final phase of this project.

Our project team are very proud of Sing and Say and look forward to sharing this project with our patients and children throughout the UK and the world.

Max words: 800

# Appendix 1: Resources and appendices

The Sing and Say website contains all of the original songs, videos and information for families created as part of this intervention package. Thanks to the generous grant from the Health Foundation, these are all now freely available to any child in the UK and around the world who would benefit from these resources. Resources are being added on a weekly basis. We welcome you to review the content of the website, listen to the songs and turn up the volume – LOUD!

#### www.ouh.nhs.uk/singandsay

You may be interested in navigating to the following highlights:

# **Shooting Star Video**

http://www.ouh.nhs.uk/singandsay/shooting-star/default.aspx

# Language Stimulation Videos

http://www.ouh.nhs.uk/singandsay/videos/default.aspx

# **Original Songs for Language Learning**

http://www.ouh.nhs.uk/singandsay/songs/default.aspx

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