



University of  
St Andrews

# Participant Information

PIS\_MG&EH\_MusicTherapy\_2023v1.0

## Parents' Perspectives on Music Therapy for Children with Down Syndrome

Mona Giff and Dr Eve Holden

### What is the study about?

We invite you to participate in a research study about how Music Therapy might impact parent-child interactions and relationships in families of children with Down Syndrome. We are interested in your perspectives of being a parent to someone with Down Syndrome who has participated in Music Therapy.

### Why have I been invited to take part?

You have been invited to take part because you responded to one of our adverts looking for participants. We are looking for people who are parents of someone with Down Syndrome who attended Music Therapy. We are looking for parents from the UK who are an adult (16+ in Scotland, or 18+ in the rest of UK) and who are fluent in English. If you do not meet these criteria, please do not complete this survey.

### Do I have to take part?

This information sheet has been written to help you decide if you would like to take part. It is up to you and you alone whether you wish to take part. If you do decide to take part, you will be free to withdraw at any time without providing a reason and with no negative consequences.

### What would I be required to do?

If you choose to complete this study, you will be asked to complete a survey estimated to take 30-40 minutes. This will include several different types of questions (open-ended, multiple choice) asking about your child's general experience of Music Therapy, and how it might have impacted your interactions and relationship with your child. There will also be attention check questions which will check whether you have been paying attention every 10 minutes or so. These will not impact whether you get reimbursed.

### Are there any risks associated with taking part?

We appreciate that some people will consider the questions in this study to be sensitive, as it is enquiring about the nature of your relationship with your child with Down Syndrome, as well as any potential hardship. If you suspect that answering questions on this topic will cause you distress, we recommend you do not participate.

Due to providing your email address, there is a risk of identifying you from the information you provide. We only ask for your email to allow reimbursement for participation. You are not required to share your email address if you do not wish to be reimbursed. We will not make any attempt to identify you or your child from this or from your survey responses. We will delete your email address after you are reimbursed for participation. We do not directly ask any other questions which could be used to identify you, but if any identifiers are offered up in answers to other questions (e.g. names), these will also be deleted.

### Are there any benefits associated with taking part?

Music Therapy has helped many individuals in the past, not just those with learning disabilities. However, in the field of Down Syndrome and Music Therapy, there is still much work to be done. By

understanding the potential link between Music Therapy and Down Syndrome, we can add to the sparse literature, as well as potentially highlight its importance. In doing so, this could be used as evidence by others to allow for more resources to be allocated to Music Therapy, allowing for more people to benefit from sessions.

You will be compensated for your time completing this survey with a £5.00 amazon voucher (estimated to take 30-40 minutes).

### **Informed consent**

It is important that you can give your informed consent before taking part in this study. You will have the opportunity to ask questions about the research before you provide your consent. If you have any questions that you would like answering in relation to the research before deciding to take part, please email my supervisor, Dr Eve Holden at eh54@st-andrews.ac.uk.

### **What information about me or recordings of me ('my data') will you be collecting?**

Questions in the survey will cover demographics and background information as well as your child's experience of Music Therapy and how your relationship with them may have changed after attending the sessions. Additional attention-check questions will be included occasionally throughout the survey. The data will be collected via an online questionnaire software called Qualtrics.

If an identifier is accidentally offered (e.g. names), this will be anonymised, by removing the details. Questions in the survey will fit within 5 topics: general information, music enjoyment of the children, structure of Music Therapy sessions, changes noticed after attending sessions, and interaction dynamics between you and your child.

#### Demographic and background questions:

We will ask for demographic information so that we can better understand the context of participant reports of their and their children's experience. These include questions about your child's age, how verbal your child is and the time period your child attended Music Therapy sessions.

#### Questions on Music Therapy and interactions with your child:

We will ask for information about the Music Therapy sessions. These include questions about the structure of sessions, whether your child enjoyed the sessions and your child's general enjoyment of music.

We will ask for information about you and your child's relationship. These will include questions about day-to-day life with your child and any areas of hardship in your relationship.

Finally, we will ask for your email address. This will only be used to organise your compensation, and not for any other purposes.

When your data is collected, it will be considered 'personal'.

- Personal data means information relating to people who can be identified directly from the information in question, or who can be indirectly identified from that information in combination with other information.

Providing your email address is what classifies the data as personal. You are not required to share your email address if you are not interested in being rewarded. Other information we directly request could not be used to identify you or your child, unless it is provided in free-write questions.

**How will my data be stored and who will have access to it?**

Data will be downloaded from Qualtrics (the survey platform used) to be stored in a OneDrive folder, on password-protected computers and hard drives only accessible to Mona Giff and Eve Holden. Once downloaded, the data will be deleted from Qualtrics. Email addresses will be deleted once participants are reimbursed (estimated within ~4 weeks of participation) and will not be used for any other purpose. The departmental administrator responsible for processing emails for reimbursement will only be given a list of emails and will not have access to participant responses. Any other identifiable data that is offered up in free-write response questions will be edited such that no one, including the researchers, could use any reasonably available means to identify you or your child from the data.

**How will my data be used and in what form will it be shared further?**

Your research data will be analysed as part of the research study. It will be written up as part of my final year dissertation. Data may also be shared in a research publication and/or alongside a research publication through deposition in a public research data sharing platform, such as the Open Science Foundation, or a UK data service. This may include quotes/excerpts taken from participant responses as examples for themes extracted. Only quotes/excerpts from free-write answers would be shared i.e. full written responses would not be shared publicly. These would not be identifiable as yours as any identifiable information will be removed and made anonymous. Anonymous versions of the data may be shared with future researchers to prevent unnecessary collection of new data. In retaining the data beyond this specific project, unnecessary additional data collection or imposition on the time and resources of participants is avoided.

**When will my data be destroyed?**

An anonymised version of your data will be kept by my supervisor indefinitely for use in future studies. The data will be reviewed every 5 years for deletion.

**Will my participation be confidential?**

Yes, your participation will be confidential. Only Ms Mona Giff and her supervisor Dr Eve Holden will have access to the email addresses and participant responses. The administrator responsible for organising reimbursement will only be given the list of email addresses and will not have access to your responses. Email addresses will then be deleted.

**Use of your personal data for research and your data protection rights**

The University of St Andrews (the 'Data Controller') is bound by the UK 2018 Data Protection Act and the General Data Protection Regulation (GDPR), which require a lawful basis for all processing of personal data (in this case it is the 'performance of a task carried out in the public interest' – namely, for research purposes) and an additional lawful basis for processing personal data containing special characteristics (in this case it is 'public interest research'). You have a range of rights under data protection legislation. For more information on data protection legislation and your rights visit <https://www.st-andrews.ac.uk/terms/data-protection/rights/>. For any queries, email [dataprot@st-andrews.ac.uk](mailto:dataprot@st-andrews.ac.uk).

**Withdrawing your data**

You can withdraw your data before email addresses are processed for reimbursement (estimated within ~4 weeks of data collection). Email addresses will then be deleted, and your data anonymised. Once data is anonymised, you will not be able to withdraw it, because we will not know which data is yours.

### **Ethics review**

This research proposal has been scrutinised and subsequently granted ethical approval by the University of St Andrews Teaching and Research Ethics Committee.

### **What should I do if I have concerns about this study?**

In the first instance, you are encouraged to raise your concerns with my supervisor. However, if you do not feel comfortable doing so, then you should contact the School Ethics Contact (contact details below). A full outline of the procedures governed by the University Teaching and Research Ethics Committee is available at <https://www.st-andrews.ac.uk/research/integrity-ethics/humans/ethical-guidance/complaints/>.

### **Contact details**

**Researcher:** Mona Giff

**Supervisor:** Dr Eve Holden contactable at: Eh54@st-andrews.ac.uk

**School ethics contact:** psyethics@st-andrews.ac.uk

### **Support resources and information:**

*In case the topics of this survey cause you any distress, please see the following suggested source of support.*

#### **Family Lives**

A free, confidential phone, live chat, and web service for people the UK in need of emotional support, information, advice and guidance on any aspect of parenting and family life.

Website: <http://www.familylives.org.uk/>

Phone number: +44 0808 800 2222 (and +44 08000 28 22 33 for callers from Scotland)

#### **Mind UK**

A charity providing advice and support to empower anyone experiencing a mental health problem.

Website: <http://www.mind.org.uk/>

Phone number: 0300 123 3393

#### **Samaritans UK**

A charity aimed at providing emotional support to anyone in emotional distress or struggling to cope. Open 24 hours a day

Website: <http://www.samaritans.org/>

Phone number: 116 123

### **Down Syndrome specific resources:**

- Positive About Down Syndrome (A website by parents for parents and parents to be): <https://positiveaboutdownsyndrome.co.uk>
- Website to find support near you: [https://www.google.com/maps/d/u/0/viewer?mid=1u\\_MuZqBnP2QMm4fNTqoiYMP5NbZwDzGz&ll=54.056646221234516%2C0.5047970148907552&z=7](https://www.google.com/maps/d/u/0/viewer?mid=1u_MuZqBnP2QMm4fNTqoiYMP5NbZwDzGz&ll=54.056646221234516%2C0.5047970148907552&z=7)
- Down's Syndrome charity in Scotland which offers resources to parents of people with Down Syndrome: <https://www.dsscotland.org.uk/>
- Down's Syndrome Development Trust, provides resources to parents and activities for people with Down's Syndrome: [Resources - Down Syndrome Development Research](#)