

## **1. Introduction**

This Privacy Statement describes how the Dutch expertise network for autism in young children ('Autisme Jonge Kind'), a non-profit organisation (hereafter referred to as "AJK", "we", "us" or "our") processes personal data when you make use of the BEAR app. This Privacy Statement explains how the BEAR app uses the personal data that is collected and what rights you have. The Privacy Statement applies to those who make use of the BEAR app, namely the parent(s)/caregiver(s) (hereafter "parents") and child that participate in the BEAR intervention.

You have accessed this BEAR app through the BEAR counsellor. This BEAR counsellor has entered certain personal data in the BEAR app on your behalf.

AJK ensures any personal data you share remains confidential. We carefully process and secure your data. In doing so, we adhere to the [NEN 7510 standard](#) for Information Security in Healthcare and the requirements set by the General Data Protection Regulation (GDPR).

## **2. Who is responsible for processing personal data?**

AJK is responsible for the management and processing of your personal data via the BEAR App (as the data controller). AJK is based in De Bilt (KVK number 90714571). For any questions related to this Privacy Statement, please send an email to: [info@beer-online.nl](mailto:info@beer-online.nl).

## **3. What is the BEAR app?**

The BEAR app is a resource for the BEAR intervention (Blended E-health for children at eArly Risk). The BEAR intervention is a playful and low-threshold form of support for parents of young children whose development in the areas of play, interaction, communicating or exhibiting flexible behaviour is less straightforward.

The BEAR app, belonging to the BEAR intervention, is a smartphone application that enables parents to:

- Read general information on child development in several chapters. This includes examples, tips and exercises;
- Communicate safely with the BEAR counsellor: parents can attach topics for discussion and note down reactions to exercises, BEAR counsellors can attach reports of appointments and videos can be shared;
- Save basic data (such as the child's name, address and date of birth) for the services provided by the BEAR counsellor;
- Complete and save the CoSoS/ESAT;
- Keep track of appointments.

## **4. The BEAR App and (scientific) research**

One of AJK's objectives is to conduct scientific research and translate its outcomes into useful products for clinical practice. The BEAR intervention and the BEAR app are a result of this. Scientific research into the experiences of parents and healthcare providers also remains necessary in the future. For example, to further improve tailoring care to the needs of users. For any potential participation in scientific research, you will be informed separately by your BEAR counsellor. If you give your BEAR counsellor permission to share your contact details with the researchers, you may be contacted by them afterwards.

In addition, AJK would like to gain insight into where in the country the BEAR app is being used. To do this, AJK uses the four digits of your postal code (so no letters) and stores these separately, without any other personal data.

## 5. Collection and use of personal data

The BEAR app collects personal data at various moments, namely:

1. When creating an account. This is the moment where your BEAR counsellor enters your personal data into an online system to give you access to your personal app account. A link is then created between your app account and that of your BEAR counsellor (see Table 1).
2. During the BEAR intervention. You decide for yourself whether you want to share this data. This includes:
  - data that you and the BEAR counsellor enter into the app (see Table 2);
  - data that AJK collects automatically when you use the app (see also Table 2).

The BEAR app can also collect health data of young children. This personal data may only be processed by AJK after you (the parent) have given permission for this on the login screen.

The following clarifies exactly what personal data is involved, for what purpose it is processed and relying on which legal basis.

**Table 1.** Personal data collected when creating an account (by the BEAR counsellor)

Type of data	Purpose
Child's first and last name	<ul style="list-style-type: none"><li>- Account creation<sup>1</sup></li><li>- Account identification<sup>1</sup></li></ul>
Child's date of birth	<ul style="list-style-type: none"><li>- Account creation<sup>1</sup></li><li>- Account identification<sup>1</sup></li></ul>
Name parent 1	<ul style="list-style-type: none"><li>- For identification purposes by the BEAR counsellor during intervention<sup>1</sup></li></ul>
Name parent 2	<ul style="list-style-type: none"><li>- For identification purposes by the BEAR counsellor during intervention<sup>1</sup></li></ul>
Email address parent(s)	<ul style="list-style-type: none"><li>- Creating child's account<sup>1</sup></li><li>- Sending BEAR app updates<sup>2</sup></li><li>- Sending a newsletter<sup>3</sup></li></ul>
Address (street and house number)	<ul style="list-style-type: none"><li>- Important for the services provided by the BEAR counsellor during intervention (so they know where to come visit)<sup>1</sup></li></ul>
Address (postal code)	<ul style="list-style-type: none"><li>- Important for the services provided by the BEAR counsellor during intervention (so they know where to come visit)<sup>1</sup></li><li>- To monitor in which regions in the Netherlands the BEAR intervention is used<sup>2</sup></li></ul>
Address (city)	<ul style="list-style-type: none"><li>- Important for the services provided by the BEAR counsellor during intervention (so they know where to come visit)<sup>1</sup></li></ul>
Phone number	<ul style="list-style-type: none"><li>- Important for the services provided by the BEAR counsellor during intervention (so they can reach you)<sup>1</sup></li></ul>

**Legal basis:**

<sup>1</sup> Necessary for the performance of a contract (Art. 6 (1) (b) GDPR)

<sup>2</sup> Necessary for the purposes of the legitimate interests pursued by AJK to better tailor our care (art. 6 (1) (f) GDPR)

<sup>3</sup> Based on consent (Art. 6 (1) (a) GDPR)

**Table 2.** Personal data collected during the duration of the BEAR intervention

Type of data	Purpose
ESAT questionnaire	- Helps for starting the BEAR intervention <sup>1</sup>
Notes on Exercises	- To enable content exchange with BEAR counsellor <sup>1</sup>
Appointments (including discussing input field, report and video)	- A resource to keep track of appointments <sup>1</sup> - To enable content exchange with BEAR counsellor <sup>1</sup>
Information about your use of the app (for example: when you log in, which parts of the app you visit)	- To monitor how the app is used and whether it is technically functioning well <sup>2</sup>
Settings	- To personalise the functionality of the app and set preferences regarding language and notifications <sup>3</sup>
Unique device IDs	- For app security <sup>2</sup>

**Legal basis:**

<sup>1</sup> Based on consent (Art. 6 (1) (a) GDPR)

<sup>2</sup> Necessary for the purposes of the legitimate interests pursued by AJK to better tailor our care (art. 6 (1) (f) GDPR)

<sup>3</sup> Necessary for the performance of a contract (Art. 6 (1) (b) GDPR)

## **6. Sharing with third parties**

We can share your personal data with third parties for the purposes described in this statement. We will only share your personal data with others for legitimate purposes and after we have taken steps to ensure that your personal data is processed in a manner consistent with this Privacy Statement. These third parties include:

- *The BEAR counsellor:* The BEAR app has the functionality that parents can exchange substantive information with the BEAR counsellor via notes/annotations.
- *Our affiliated organisations:* AJK collaborates with academic centres (e.g. Karakter child and adolescent psychiatry and Accare child and adolescent psychiatry and the Nederlands Centrum voor Jeugdgezondheidszorg) for the purpose of scientific research. You could be asked by the BEAR counsellor for possible participation in scientific research. We will ask your permission separately for the use of data for this purpose.
- *Our service providers:* Your personal data can be passed on to our service providers who provide services on our behalf. They provide services such as cloud hosting and application maintenance. Our service providers are subject to contractual obligations to protect your personal data and to process personal data only as instructed.
- *Other third parties when this is necessary in accordance with legal obligations:* We can share your personal data with third parties to comply with court orders, other legal obligations, to enforce or apply our terms of use and other agreements, and to protect the rights, property or safety of AJK and affiliated organisations.

## **7. Security**

The password you provide when registering with the BEAR app is encrypted to guarantee protection against unauthorised access to your personal data. The BEAR app and the processors and sub-processors engaged by AJK invest in high-quality security and do their utmost to protect the privacy of users.

## **8. Where we store your personal data**

Your data is processed by professional data storage providers in the Netherlands and the US. A data processing agreement has been concluded with them. Most processors and sub-processors are located in the European Economic Area (EEA). For (sub)processors who process personal data *and* are located outside of the EEA, we ensure that we comply with chapter V of the GDPR by relying on adequacy decisions or EU Model Clauses (SCCs) together with the necessary international transfer assessments.

## **9. Retention of personal data**

We retain your personal data for as long as your account is active. Your account will automatically become inactive two years after completion of the BEAR intervention. After your account has become inactive, all data will be permanently deleted with the next deletion cycle. This is different if you have given permission to retain the personal data for a longer period for the purpose of scientific research or a longer retention period is necessary to comply with our legal obligations or to resolve any disputes.

If you consent to the use of your data for further research, we will also retain your contact details for longer.

You can also delete your account yourself at any time (so within the two years) via the 'delete account' button. Your account will then be deleted in line with our retention periods as described above.

## **10. Changes**

If we make changes to this Privacy Statement, we will publish the changes on this page and inform you via a notice (see no. 11 below). We also encourage you to regularly visit [www.autismejongekind.nl](http://www.autismejongekind.nl) for the latest version of this Privacy Statement. If you are of the opinion that we do not comply with the contents of this Privacy Statement, please let us know at [info@beer-online.nl](mailto:info@beer-online.nl). We will then try to solve the problem as soon as possible.

## **11. Notices**

Any notice sent to you by AJK and relating to the BEAR app based on this statement can be sent to you via email. This will be sent to the email address that you have provided when your account was created and such a notice will be deemed to have been given once sent.

## 12. Your rights

Right of access	You have the right to access the personal data we process, subject to exceptions. Upon request, we can also provide you with a copy of the personal data.
Right to rectification	You have the right to request that AJK corrects, amends or supplements your personal data if we have incorrect or incomplete data about you. You can also correct, amend or supplement your personal data yourself in the BEAR app.
Right to withdraw consent	You have the right to withdraw your consent previously given to the processing of certain personal data at any time by sending a message via the contact form in the BEAR app.
Right to erasure	You have the right to request deletion of all irrelevant personal data we have collected about you when (i) the data is no longer necessary in relation to the purposes for which they were collected; (ii) you withdraw your consent; (iii) you object to the processing and there is no overriding legitimate grounds for the processing; (iv) we have processed your data unlawfully.
Right to restriction of processing	You have the right to restrict our use of your personal data if (i) you contest the accuracy of the personal data; (ii) the use is unlawful but you do not want us to delete the data; (iii) we no longer need the personal data for the relevant purposes, but require it for the establishment, exercise or defence of legal claims; or (iv) you object to data use on the basis of our legitimate grounds pending verification of whether AJK does indeed have compelling interests to continue the relevant data use.
Right to data portability	Under certain circumstances, you have the right to obtain personal data (in a structured, commonly used and machine-readable format) that you have provided to us and reuse it elsewhere or ask us to transmit it to a third party of your choice.
Right to object	Insofar as we depend on our legitimate grounds to use your personal data, you have the right to object to such use. We must then stop such processing unless we can demonstrate compelling legitimate grounds for the use that violates your interests, rights and freedoms, or when we need to process the data for the establishment, exercise or defence of legal claims.
Right to lodge a complaint	You have the right to lodge a complaint with the Dutch Data Protection Authority (DPA, or 'Autoriteit Persoonsgegevens'), if you are of the opinion that the BEAR app or another involved party is handling your data improperly or is otherwise not complying with applicable legal requirements. More information can be found on the DPA's website: <a href="https://www.autoriteitpersoonsgegevens.nl/en">https://www.autoriteitpersoonsgegevens.nl/en</a> .