

Downloading 24-month data



Overview

The DOLFIN protocol states that “Primary outcome (PARCA-R) and secondary outcome neurodevelopmental data will be shared with the local neonatologist or paediatrician, or GP for participants no longer under hospital follow-up; information about norms will be provided to aid local clinician interpretation.”

All parents whose infants are enrolled in DOLFIN consented to this at initial recruitment.

These data refer to:

- The Parent Report of Children’s Abilities-Revised (PARCA-R)
- The Ages and Stages Questionnaire-3 (ASQ-3) (more information at <https://agesandstages.com/productspricing/asq3>)
- The Strengths and Difficulties Questionnaire (SDQ) (more information at <https://www.sdqinfo.org/py/sdqinfo/c0.py>)

We hope that sharing this information will be clinically useful at sites and may prevent parents needing to complete one or more measures again. It is the PI’s responsibility to ensure that this information, provided by parents in the 24-month follow-up questionnaire, reaches the clinician responsible for the infant’s ongoing care.

Method

When a parent completes their infant’s 24-month follow-up questionnaire, the site staff will receive an email flagging this. This email will have a guide to scoring the PARCA-R questionnaire attached. This is for information only; no scoring at site is required unless you personally plan to use the results in your service. It will also include the links to the ASQ-3 and SDQ given above.

When you receive this email, go to the infant’s Participant Details page on OpenClinica.

Downloading 24-month data



Enter Participant ID: View

Alerts & Messages ▶ **Participant TST_DF_11584**

Quick Access ▶
My Queries
Recent
TST_DF_11584
TST_DF_10216
Instructions ▶

Info ▶

Icon Key ▶

Statuses

- Not Started
- Not Scheduled
- Scheduled
- Data Entry Started
- Stopped
- Skipped
- Completed
- Signed
- Locked
- Archived
- Removed

Actions

- View
- Edit
- Clear

General Information

Edit

Participant ID	TST_DF_11584	Status	Available
Study Name	DOLFIN TEST 01	Site Name	Royal Victoria Infirmary, Newcastle

Visits

1 visit added

Sort by Date

Parent-provided 24-month data (clock icon) | **Parent-provided 24-month data** (download icon)

28-Oct-2024

Parent 24 Month Questionnaire (green check) | **Parent 24 Month Questionnaire** (green check)

05-Oct-2022 | 05-Oct-22 by...

Parent 18 Month Questionnaire (green check) | **Parent 18 Month Questionnaire** (green check)

05-Oct-2022 | 05-Oct-22 by...

Parent 12 Month Questionnaire (green check) | **Parent 12 Month Questionnaire** (green check)

05-Oct-2022

This is the form for downloading the neurodevelopmental data for sharing

This is the completed 24-month questionnaire. **Do not download this!**

Remember:

- Make sure that the **Parent 24 Month Questionnaire** is completed (the check mark icon on the form is green). Do not carry out this process if the icon is orange (🚫)
- The **Parent-provided 24-month data** CRF should already be scheduled (shown with the 🕒 icon)
- If the **Parent-provided 24-month data** CRF is not scheduled / visible, return to the infant's record the next day (there may be a delay in syncing between our systems). If it is still not visible, contact the DOLFIN Coordinating Centre
- **Do NOT download the Parent 24 Month Questionnaire itself. The questionnaire contains several sections and the parent did not give consent for all of these to be shared**

Click on the **Parent-provided 24-month data** CRF file:

Downloading 24-month data



Sort by Date

Parent-provided 24-month data
28-Oct-2024

Parent-provided 24-month data

Parent 24 Month Questionnaire
05-Oct-2022

Parent 24 Month Questionnaire
05-Oct-22 by...

Edit Parent-provided 24-month data

This will open the CRF:

All changes saved.

TST_DF_11584: Parent-provided 24-month data (for clinician)

Data from DOLFIN 24-month questionnaire completed by parent:
Child's physical development
Parent Report of Children's Abilities-Revised (PARCA-R)
Strengths and Difficulties Questionnaire®
Ages and Stages Questionnaires®-3

Instructions
Please download the data within this questionnaire and add a copy to the infant's medical notes. Do **NOT** download this data until the DOLFIN 24-month Parent Questionnaire has been completed. That data will be automatically imported into this questionnaire.
Consent has been provided by the parent for the sharing of this data with the clinician responsible for the infant's ongoing care, or GP if they are no longer under specialist review. It is the PI's responsibility to ensure that this information reaches the clinician responsible for the infant's ongoing care.
Please refer to the relevant guidance sheet for details of how to download this data.

This form was completed by the child's:
 Mother
 Father
 Another person with parental responsibility

Date form completed:
2024-01-03

All changes saved.

Close Next →

Return to Beginning Go to End →

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Downloading 24-month data



Click on the Print icon in the top-right corner:



ata (for clinician)

The following pop-up window should appear:

Options

To prepare an optimized print, please select the options below

Show History

show

Paper Size

A4 Letter

Paper Orientation

Portrait Landscape

Remember to set these same print settings in the browser's print menu afterwards!

1. Uncheck the "Show History" box

2. Click "Prepare"

Downloading 24-month data



Print / save to PDF as per your computer and browser's settings:

TST_DF_11584: Parent-provided 24-month data (for clinician)

Data from DOLFIN 24-month questionnaire completed by parent:

Child's physical development
Parent Report of Children's Abilities-Revised (PARCA-R)
Strengths and Difficulties Questionnaire©
Ages and Stages Questionnaires®-3

Instructions

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Please refer to the relevant guidance sheet for details of how to download this data.

This form was completed by the child's:	Date form completed:
<input checked="" type="radio"/> Mother <input type="radio"/> Father <input type="radio"/> Another person with parental responsibility	2024-01-03

Your child's health and physical development

The following questions ask about your child's health and physical development. *Please answer all of the questions as best you can. You may feel that some of these questions do not apply to your child, but it is important to answer them all so we can find out about your child's general health and development.*

1. In general, how is your child's health compared with other children of the same age?

Excellent
 Good
 Fair
 Poor

1 of 11 | 28/10/2024, 11:14

Print 11 sheets of paper

Destination: Save to PDF

Orientation: Portrait Landscape

Pages: All

Color mode: Color

More settings: More settings

[Print using the system dialog...](#)

Save Cancel

This page may look different depending on your device and browser

GUIDANCE SHEET 15

Once you have downloaded the PDF:

- Save a copy to the infant's medical notes
- Securely send a copy to the clinician responsible for the infant's ongoing care (or their GP if they are no longer under specialist review) along with the guide to scoring the PARCA-R and the links to further information on the ASQ-3 and SDQ

Once you have completed this process, the CRF will show as Data Entry Started on the infant's Participant Details page:

Parent-provided 24-month data 28-Oct-2024

Parent-provided 24-month data 28-Oct-24 by mhurd (1)

You do not need to take any further action. The CRF will not be included on the report of missing or partially completed CRFs at your site.